Executive Functioning and Service Use Among Individuals with Fetal Alcohol Spectrum Disorder

By

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

Doctor of Philosophy

in

SCHOOL AND CLINICAL CHILD PSYCHOLOGY

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Abstract

In this manuscript-based thesis, I investigated the development of executive functioning (EF) in individuals with FASD, the types and intensity of services individuals with FASD and their caregivers access, and the associations between early EF, adaptive functioning, mental health, and later outcomes among individuals with FASD. Following a review of the relevant literature, two studies are presented. In Study 1, *Longitudinal Development of EF Among Individuals with FASD,* I investigated the developmental trajectory of EF among 16 individuals with FASD from adolescence (M_{age} = 13.1 years) into young adulthood (M_{age} = 19.4 years). EF was measured using both performance-based tasks (NEPSY and D-KEFS) and behavioural reports (BRIEF caregiver form). Associations between early EF skills and later outcomes were also investigated. Later outcomes included a measure of adaptive functioning (ABAS-II) and indicators of mental health (BASC-2). EF skills among this group are generally impaired and stable throughout this developmental period, with mean scores well below the normative average on the majority of measures. Only metacognitive skills, as measured via behavioural reports, increased significantly in severity during young adulthood. Notably, pockets of normative strength were indicated on a performance-based task of switching at both time points, and on a performance-based task of inhibition during young adulthood only. When intraindividual variation was examined, a large portion of the sample evidenced significant change in performance, with 30% experiencing change on the BRIEF and 45% experiencing change on at least one performance-based task. Finally, multiple significant correlations were found between early EF skills and later outcomes, particularly, adaptive functioning. Areas of EF also predicted later adaptive skills. Results highlight important areas of personal strength for this population while also emphasizing the importance of considering the heterogeneity of this disorder.

Findings also shed light on important relationships between early EF skills and later functioning. Suggestions for future research and clinical implications are discussed.

In study two, *Supporting Individuals with FASD: Trends in Service Use*, I investigated service use trends among the same sample at the same time points. Service use was measured across five domains: medical services, mental health services, social services, educational services, and caregiver services. I then explored the relationships between early EF, mental health, and adaptive functioning and later trends in service use. All services were accessed throughout both adolescence and young adulthood for this population, with education services accessed most frequently at both time points. The frequency of service used remained stable for all services except caregiver services, which increased significantly during young adulthood. Multiple significant associations were also found between early EF, adaptive skills, and mental health functioning and later service use. Findings highlight the importance of early functioning and the relationships with later supports. Suggestions for future research and clinical implications are discussed.

Keywords: Fetal Alcohol Spectrum Disorder, developmental disability, executive functioning, mental health, adaptive functioning, strengths-based, clinical implications

Preface

This thesis is an original work by Allison Lavinia McNeil. The research project affiliated with this thesis received research ethics approval from the University of Alberta Research Ethics Board. Study 1: “Outcomes of Individuals with FASD”, Pro00016902, 9 September 2010. “Study 2: “Longitudinal Assessment of Individuals with PAE and FASD,” Pro00057460, 29 January 2016.

Dedication

For my daughters, Aoife and Bridget. It’s never too late to chase your dreams.

Acknowledgements

First and foremost, thank you to my PhD supervisors, Dr. Jacquie Pei and Dr. Carmen Rasmussen, who helped me tremendously throughout this journey. Dr. Pei, you were so very encouraging years ago when I was living in Whitehorse, contemplating a return to school. Without your guidance and never-ending enthusiasm, I would not be where I am today. Your patience, guidance, and most importantly, your belief in me, has had a monumental impact; thank you. I also want to thank Dr. Robin McGee, my master's supervisor, who I have looked up to since starting my journey as a psychologist. You never cease to amaze me. Additional thanks to Dr. Christina Rinaldi for serving on my supervisory committee and for providing me with thought-provoking feedback and challenging me to "think big". I would also like to thank Dr. Phillip Sevigny (examining committee) and Dr. Jason Brown (external examiner), for contributing their time and expertise.

Thank you to the participants who volunteered to come back and participate in this research. Your time and effort are greatly appreciated. Thank you for giving me a glimpse into your lives and thank you for trusting me enough to share your experiences. To the youth I tested, thank you for persevering through hours of testing, putting up with my corny jokes, and trying your best. You amaze me.

To my family in Nova Scotia, who watched my new baby so that I could write. To my husband who picked up the slack and rode the waves of me juggling a baby, work, and school. To my friends and colleagues who provided never ending encouragement and told me to keep going. I can never, ever, thank you enough.

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Chapter 1: Introduction

Fetal Alcohol Spectrum Disorder (FASD) is a common neurodevelopmental disability resulting from prenatal alcohol exposure (PAE). PAE can result in a broad range of impacts on the body and brain and individuals impacted are diverse with respect to their physical, cognitive, behavioural, and social-emotional functioning (Mattson et al., 2019). The estimated prevalence of Canadian children with FASD is between 2% and 3% according to a recent population-based study (Popova et al., 2018) and over 30% in some special populations such as a youth detention centre in Australia and a correctional facility in Northern Canada (Bower et al., 2018; McLachlan et al., 2019). Conservative North American estimates range from 3% to 5% of the population, resulting in an economic impact of between $1.8 and 9.7 billion annually across sectors in Canada (May et al., 2018; Popova et al., 2016, 2019; Thanh & Jonsson, 2015).

The past few decades have witnessed substantial efforts by researchers to conceptualize and define the array of neurobehavioural challenges and developmental outcomes experienced by this population. FASD is a heterogeneous disability and individuals with FASD experience an array of mild to severe challenges across many domains of functioning, including cognitive ability, academic achievement, learning, memory, attention, executive functioning (EF), affect regulation, and adaptive functioning (Ali et al., 2018; Cook et al., 2016; Mattson et al., 2019, McLachlan et al., 2020). These individuals also frequently face hardships in their daily lives with respect to securing housing and employment, graduating, becoming involved in the legal system (e.g., criminal offending, victimization, incarceration), and abstaining from substances (Clark et al., 2004; Lynch et al., 2015; McLachlan et al., 2020; Rangmar et al., 2015; Streissguth et al., 2004). These adverse outcomes generally intensify and accumulate with age and are believed to be the result of the complex and multifaceted interactions between the individual, their relationships, and the environment (Burnside & Fuchs, 2013; Clark et al., 2004; Kambeitz et al., 2019; McLachlan et al., 2020; Streissguth et al., 2004).

Historically, FASD has been described and viewed through a deficit-focused lens, highlighting the negative and problematic issues that can accompany this disorder. This deficit-focused perspective to understanding individuals with FASD is overly narrow, focuses only on need, and has added to the stigmatization of this group; it ignores the positive characteristics, strengths, and rich diversity of this population (Flannigan et al., 2021; Olson & Sparrow, 2021; Skorka et al., 2020). Conversely, a deficit-focused view has also fueled advocacy for services and supports and for a better understanding of individual strengths, areas of growth, and the needs of caregivers and family members (Flannigan et al., 2021). Although this shift to understanding disability from a holistic perspective has been adopted by a number of researchers in the field of neurodevelopmental disabilities (Shogren et al., 2006), its uptake has been slow in the field of FASD (Flannigan et al., 2021).

Adopting a strengths-based approach to understanding FASD is important, and its benefits are broad. At the individual level, a strengths-based approach promotes a sense of competence and increases well-being and resilience (Carter et al., 2015; Grove et al., 2018, Riosa et al., 2017). It also supports family members and caregivers by promoting an optimistic outlook thus decreasing the worry, stress, and anxiety that often plagues this group of individuals (Lee et al., 2020; Shochet et al., 2019). Finally, it extends to other environments and future outcomes through supporting academic achievement, critical life transitions, and overall quality of life (Carter et al., 2015; Grove et al., 2018). A better understanding of strengths among individuals with FASD additionally impacts intervention through the inclusion of fostering strengths and a focus on healthy outcomes (Flannigan et al., 2020; Flannigan et al., 2021).

This dissertation takes a strengths-based view of FASD. While it does identify areas of need in this population, it does not do so in isolation. Rather, challenges are considered contextually and viewed as an opportunity to focus intervention with the goal of improved future outcomes. In addition, identified areas of growth are embedded in a developmental taxonomy and examined in terms of their potential to impact healthy future functioning. Broadly, this research was designed while considering two overarching questions: *What does development among individuals with FASD look like over time?* And *what can be done now, that will support healthy outcomes for individuals with FASD?*

In addition to taking a strengths-based approach, this research was developed with the goal of supporting evidence-informed clinical practice. Recommendations for future clinical practice are included in the hopes that practitioners in the field will have a better idea of when and how to support individuals with FASD. Finally, the clinical recommendations that stem from this research were developed to aid in mitigating the adverse outcomes often experienced by these individuals.

Purpose and Outline of Dissertation

This manuscript-based dissertation consists of a literature review followed by two lines of inquiry. In the first study I examine the longitudinal development of EF among individuals with FASD during the critical transition between adolescence and young adulthood. In the second study I examine service use trends accessed by individuals with FASD and their caregivers longitudinally, during the same period. Within these two studies, relationships between early functioning and later outcomes are explored. Combined, the literature review and the two studies presented in this dissertation are unified by two main ideas. First, that using a strengths-based research approach is critical in supporting individuals with FASD, particularly for clinicians who work with this population. Second, taken from ecological theory (Bronfenbrenner, 1979), that individual development is complex and is impacted by the many relationships and environments that interact with individuals.

Central to this dissertation is an understanding of the concept and development of EF. Thus, Paper 1 (*Theories and Development of Executive Functioning: A Literature Review*) is a literature review outlining the current challenges in the field when attempting to delineate the development of EF. First, I review current theories of EF, then I outline the development of three main foundational EF skills (working memory, inhibition, and shifting) using a developmental lens. Implications for future directions and clinical practice are provided.

Paper 2 (*Longitudinal Development of Executive Functioning Among Individuals with Fetal Alcohol Spectrum Disorder*) entails a closer examination of EF within a unique population. Using a longitudinal design, I examine the development of EF among individuals with FASD between adolescence and young adulthood, using performance-based measures and behavioural measures (i.e., parent/caregiver questionnaires). I then examine the associations and predictive relationships between EF skills in adolescence and later functional outcomes in young adulthood including adaptive functioning and indicators of mental health among the same group of individuals. The following research questions were explored: 1) How does EF develop from adolescence into young adulthood among individuals with FASD? 2) Are EF skills during adolescence associated with mental health and adaptive functioning during young adulthood among individuals with FASD? Again, clinical implications are outlined. Briefly, I found areas of both strength and need within the domain of EF and possible differences in its developmental trajectory during this period. I also found that EF both predicts and is significantly associated with areas of later healthy functioning.

Paper 3 (*Supporting Individuals with Fetal Alcohol Spectrum Disorder: Trends in Service Use*) complements Paper 2 by investigating the trends in service use among the same individuals with FASD and their caregivers. It also examines the associations between service use during adolescence and later healthy functioning. Specifically, I again used a longitudinal design and examined service use intensity including the use of medical, social, educational, mental health, and caregiver services among the same group of individuals with FASD and their caregivers during adolescence and again during young adulthood. I then examined the relationships between EF, adaptive functioning, and indicators of mental health during adolescence, and later service use intensity across the same areas of service. The following research questions were explored: 1) What does service use look like among individuals with FASD and their caregivers? 2) Does service use intensity among individuals with FASD and their caregivers change from adolescence to young adulthood? 3) Is there an association between brain-based functions during adolescence (i.e., executive functioning, indicators of mental health, adaptive functioning) and later service use during young adulthood? Briefly, I found that a broad array of services was accessed throughout this critical period by both individuals with FASD and their caregivers. Service use intensity remained stable for all services with the exception of caregiver services which increased during young adulthood. Multiple significant associations between early areas of functioning (i.e., EF, indicators of mental health, adaptive functioning) and later service utilization were indicated. Finally, clinical implications were suggested.

Contributions to the Literature

Paper 2 (*Longitudinal Development of Executive Functioning Among Individuals with Fetal Alcohol Spectrum Disorder*) addresses two gaps in the field of FASD. A significant area of challenge for individuals impacted by PAE is deficits in EF (Mattson et al., 2019; Rasmussen &

Bisanz, 2009; Rasmussen et al., 2013). However, little is known about how EF develops longitudinally in this population. Cross-sectional studies of children with EF indicate that adolescents with FASD appear to show greater impairment (compared to the norm) on measures of EF than their younger counterparts (Rasmussen & Bisanz, 2009; Rasmussen et al., 2007; Tamana et al., 2014). However, because age comparisons through longitudinal design have not been made, the actual trajectory of EF development among this population is assumed and not known. Paper 2 addresses this gap by examining EF development longitudinally among a group of individuals with FASD. A better understanding of how EF develops in this population is critical as it is currently unknown whether EF is delayed, a stable cognitive deficit, or if it follows an altered trajectory than what is observed in typically developing individuals. This information is particularly important during the transition into adulthood, when expectations increase, and independent functioning is critical. In addition, it is a time when individuals age-out of systems and are faced with decreasing supports and challenges in accessing FASD-informed services, thus detailed information about how their skills develop will support intervention efforts.

In addition to examining the developmental trajectory of EF, Paper 2 explores the predictive relationship between early EF skills and later outcomes. It is currently understood that EF plays an important role in a vast array of skills and that it is a critical component of healthy functioning through one’s ability to self-regulate and engage in goal-directed behaviour (Miyake & Friedman, 2012). Specifically, EF skills robustly predict important living skills and factors associated with mental health including physical health, substance abuse, budgeting ability, and criminal offending outcomes later in life, even after controlling for IQ, gender, and social class (Moffitt et al., 2011). During adulthood, EF predicts marriage satisfaction, career satisfaction, and mental and physical health, further emphasizing its role in healthy functioning (Dunn, 2010; Eakin et al., 2004; Prince et al., 2007). The current study will help to determine important predictive relationships between EF and later mental health and independent living skills among individuals with FASD.

Paper 3 (*Supporting Individuals with Fetal Alcohol Spectrum Disorder: Trends in Service Use*) also contributes important novel information to the field of FASD. As previously mentioned, FASD incurs a significant financial footprint on society because the needs of these individuals transcend a number of major systems (e.g., medical, social services, education, legal). Perhaps not surprisingly, we also know that individuals impacted by PAE require a significant amount of support (Brownelle et al., 2013; Mills et al., 2006; Popova et al., 2016), and without it, adverse outcomes are common (Clark et al., 2004; Lynch et al., 2015; McLachlan et al., 2020; Rangmar et al., 2015; Streissguth et al., 2004). Overall, much of what is known about service use in this population comes from a deficit-focused perspective and is broad in nature. We know very little about the nuances of service use, particularly at the individual and family level. This study addresses this gap by providing much needed information about the trends in service use across systems, how service use intensity changes over time, and what it looks like during the transition into adulthood. Again, using a developmental contextual lens, it also provides information about the relationships between early brain-based functioning including EF, indicators of mental health, and adaptive functioning during adolescence and later service use trends during young adulthood. As with Paper 2, the results can be used to inform interventions and will provide a better understanding of when and where to focus supports with the goal of supporting individuals with FASD in addition to their caregivers.

To summarize, the central goal of this research was to explore the developmental trajectory of EF among individuals with FASD, longitudinally, between adolescence and young adulthood using a strengths-based lens. Additionally, associations between early EF and later indicators of healthy functioning were investigated. A secondary goal was to investigate service use trends among individuals with FASD and their families and again explore the associations between early brain-based functions and later trends in service use. Clinical implications of these findings were provided to help support professionals working in the field of FASD.

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Theories and Development of Executive Functioning: A Literature Review

Executive functioning (EF) refers to a set of cognitive control processes, mainly supported by the prefrontal cortex (PFC), that regulate the dynamics of human cognition and action (Miyake & Friedman, 2012). EF is essential for successfully navigating nearly all daily activities as they enable self-regulation and self-directed behaviour required to achieve goals, allow individuals to break habits, make decisions and evaluate risks and benefits, and support individuals in planning for the future, prioritizing and sequencing their actions, and coping with novel situations (e.g., Banich, 2009; Miyake & Friedman, 2012). As an important aspect of overall functioning, EF is involved in virtually all cognitive functions through the role it plays in control and self-regulation.

The emergence of EF typically begins during early childhood and undergoes dramatic changes as its core components develop. These core components (e.g., simple rehearsal) lay the foundation for later, more complex processes (e.g., suppression and response inhibition) that develop during adolescence and into adulthood (Garon et al., 2008). The development of EF skills during early childhood is especially important, as EF at this time robustly predicts outcomes including physical health, substance abuse, budgeting ability, and criminal offending much later in life, even after controlling for IQ, gender, and social class (Moffitt et al., 2011). EF is also an important factor when assessing school readiness as EF predicts math and reading performance throughout children's academic careers (Gathercole et al., 2004, Nesbitt et al., 2019, Wilkey et al., 2020). Even during adulthood, EF predicts marriage satisfaction, career satisfaction, and healthy mental and physical health, further emphasizing its important role (Dunn, 2010; Eakin et al., 2004; Prince et al., 2007).

Although the importance of EF has long been recognized among scholars and clinicians in this field, the theoretical organization of EF remains a topic of debate. Currently, there does not exist a universally agreed upon conceptualization of EF. Proposed theoretical frameworks range from viewing EF as a core unitary construct (e.g., Munakata, 1998, 2001; Zelazo & Frye, 1998; Zelazo & Müller, 2011) to viewing EF as a set of independent component constructs (Diamond, 2001, 2006). Despite this lack of theoretical consensus regarding the construct of EF, clinicians remain tasked with evaluating these skills due to the role they play in overall functioning (Snyder et al., 2015). Without a concrete theoretical framework from which to navigate this complex set of processes, clinicians are left assessing these skills without a clear lens to inform their choice of standardized tools, interpretation of results, and the development of recommendations and interventions. It is therefore imperative that clinicians stay informed about current research in the field of EF to ensure a thorough understanding of this construct. This knowledge will support their clinical practice and better position them to clinically evaluate this domain through a theory-informed approach, thus mitigating critical errors in conceptualization, subtest-driven assessment, and oversimplification of the EF assessment process.

The goal of this literature review is to provide a way forward in terms of adopting an evidence-based theory of EF and propose suggestions of how to integrate this knowledge in clinical practice. To achieve this goal, I first outline different theoretical perspectives of EF across a span of age ranges including early childhood to later adolescence. The relevance to adult EF development is briefly touched upon. Next, I examine the developmental trajectory of the components of EF (i.e., working memory, inhibition, shifting) during childhood and adolescence using an integrated framework highlighting important implications for clinicians. Finally, I suggest ways forward for clinicians to consider in their clinical assessment of EF.

Frameworks of EF Development

Having a theoretical framework to work from is important for clinicians as it provides a systematic broader conceptualization through which to view EF and integrate knowledge of their client's development and behaviour. As in scientific research, a theoretical framework in a clinical setting can serve to guide a clinician's assessment by helping them to determine what questions to ask, choose what skills or domains to measure, develop hypotheses about their client's functioning, and evaluate and interpret results via complex processes and relationships. Having a solid understanding of the framework one is practicing from also critically informs the development of appropriate recommendations and interventions. Without a framework from which to view EF, clinicians risk misunderstanding EF development in their clients.

Historically, two broad EF theoretical frameworks dominated the literature. Unitary frameworks conceptualize EF as anchored by a single source with constituent subprocesses. Evidence supporting these frameworks comes from studies showing that many measures of EF are intercorrelated for both children and adults, that many EF tasks are specifically correlated with a central attention process, and that there appears to be a general EF developmental spurt on multiple tasks from 3- to 6-years old (Garon et al., 2008). Conversely, dissociable frameworks conceptualize EF processes as separate and independent. Evidence supporting these frameworks come from studies examining individual developmental trajectories of EF processes such as working memory and inhibition (e.g., Diamond, 2001) and those using factor analysis to delineate components of executive skills that found EF performance on different tasks cluster into distinct domains (e.g., Hughes et al., 2008). A final and perhaps more current theoretical framework of EF combines these two perspectives into an integrated framework suggesting a common EF mechanism as well as partially dissociable EF components (Friedman et al., 2011;

Miyake, 2012; Miyake et al., 2000, Stuss & Alexander, 2000). This model was originally intended to describe EF development among adults; however, it has since been replicated in children and adolescence, but notable developmental difference have been observed (Müller & Kerns, 2015).

Importantly, the above frameworks conceptualize EF using factors referred to as “cool” EF skills. “Cool” EF skills are those which are evaluated using relatively arbitrary and decontextualized (laboratory) tasks that measure emotionally neutral skills including working memory, inhibition, and shifting (i.e., cognitive flexibility) (Laureys et al., 2022). Conversely, “hot” EF skills are those which arise during situations that evoke emotions, motivation, or conflict between immediate rewards and long-term rewards (Zelazo & Müller, 2002). “Hot” EF skills include those requiring emotion regulation including delay of gratification tasks, extinction tasks, and measures of reversal learning (Zelazo, 2020). The focus on this literature review is on “cool” EF.

Unitary Frameworks

One broad band approach to the development of an EF framework considers EF as a unitary construct with constituent subprocesses. Generally, proponents of this framework highlight the many EF processes that are intercorrelated for both children and adults, suggesting a common process underlying general EF ability (e.g., Munakata, 2001). Together, the majority of these theories depict the development of EF as the ability to increasingly resolve conflict. However, the ways in which conflict is resolved differs (Best & Miller, 2010).

In Munakata’s (2001) graded representation theory of the development of EF, EF is described as flexible behaviour/thought and it emphasizes the unitary nature of changes in EF during early childhood. Broadly, Munakata’s approach is centred around the view that improvements in working memory drive the development of EF. Specifically, graded representation theory indicates that conflicts are resolved in terms of graded knowledge rather than simply being present or absent (i.e., disassociations). Conceptually, representations are graded by their ability to cleanly signal the appropriate information, as opposed to the amount they are corrupted by noise or damage. The strength of representations is affected by factors such as environmental support, the individual, and the extent of neurological damage. Munakata suggests that there are two main types of representations: active and latent. Although active representations are associated with attention and working memory, latent representations are associated with habits and long-term memory storage. The development of these systems differs in that latent memory develops early followed by active representation development throughout childhood.

Munakata (2001) uses the example of problem solving, where stronger representations are required to resolve conflict. A weak prefrontal representation of a hidden object may be strong enough to allow an infant to gaze correctly at a location where an object is hidden. However, a stronger representation is required to overcome the prepotent response to reach back to a previous hidden location (Munakata, 1998). Additionally, Munakata and Yerys (2001) predicted that disassociation between a sort task and a verbal task would disappear when the amount of conflict was equal; this is what was found during a card sort task where children were required to resolve conflict when presented with new rules (e.g., between the new rule of colour and the previous rule of a shape). Resolving conflict was not required when answering a verbal question about the new rule (e.g., ‘Where do red things go in the colour game?’). However, the disassociation disappeared when the amount of conflict was equated by adding conflict to the verbal question (e.g., ‘Where do red trucks go in the colour game?’). Another example is the

Stroop task, where an individual is presented with written colour words (e.g., blue) printed in ink that does not correspond to the colour (e.g., red ink), and is required to indicate the colour of the ink essentially overriding the automatic tendency to read the word (e.g., blue).

Overall, Munakata and colleagues (2012) highlight the role of abstract and robust representations that occur in working memory in supporting three important transitions throughout childhood. First, children can overcome their habitual and perseverative responses through the maintenance of abstract goal representations that provide top-down support, allowing them to be flexible and adapt to changing environments. Second, the transition from reactive to proactive control is due to their ability to increasingly maintain robust representations. Third, the development of more abstract and robust goal representations in working memory supports the transition from externally driven to self-directed control.

Zelazo and colleagues put forth an alternative developmental theory that views EF as a unified construct (Zelazo & Frye, 1998; Zelazo & Müller, 2011; Zelazo et al., 2003). The cognitive complexity and control theory (CCC) is an information processing theory in which Zelazo explains EF development in terms of hierarchical rule representations. The theory was revised (CCC-r) to include the active nature of decision making that incorporated the dynamics of activation and inhibition of rule sets (Zelazo et al., 2003). According to this theory, EF is viewed as a function or behavioural construct defined in terms of its outcomes or what it accomplishes, rather than through a specific mechanism or cognitive structure (Zelazo et al., 1997). Broadly, CCC-r theory maintains that age-related differences in EF are due to increases in the complexity of rules that develop hierarchically, that children can formulate and then maintain in their working memory when engaged in problem solving (Zelazo et al., 2003). It is through these functions that EF is deliberate in problem solving. Similar to Munakata's theory, Zelazo's theory describes EF as goal-directed behaviour and focuses on the representation of information and how this changes throughout development. However, in CCC-r theory, Zelazo posits that age-related changes in EF are the result of increasing hierarchical complexity of rules that children construct, hold in their working memory, and use throughout problem solving, rather than due to changes in development of latent or active representations.

According to Zelazo's model of EF development during childhood, children first make plans that correspond literally to rules. This is seen in self-directed speech (e.g., in the case of an adult "If I see a mailbox, then I need to mail this letter."; Zelazo & Müller, 2002, p. 585). As children grow, they are increasingly able to reflect on their rules, compare them, and embed them under higher order rules (e.g., in the case of an adult, "If it is before 5 p.m., then if I see a mailbox, then I need to mail this letter [otherwise, I'll have to go directly to the post office]."; Zelazo & Frye, 1998, p. 122). Throughout the preschool period, a myriad of age-related changes take place, and the complexity of children's rule systems increase (e.g., in card sorting, social skills, morality, etc.). CCC-r theory accounts for this ability to consider complexity by measuring the number of levels of embedding in these rule systems. Using card sorting as an example, 2-year-olds represent only one rule at a time (e.g., "If red, … here."; Zelazo & Frye, 1998, p. 123). By 3 years of age, children can consider two rules simultaneously (e.g., "If red, … here; if blue, … there."; Zelazo & Frye, 1998, p. 123). By 5 years, children can successfully consider a higher order rule that allows them to choose between two conflicting rules (e.g., "If we're playing colour, then if red car, … here; and if blue flower, … there, but if we're playing shape, then if red car, … there, and if blue flower, … here."; Zelazo & Frye, 1998, p. 123). As children develop, they are able to recapitulate their rule system and apply it to new problems within their developmental level, thus resulting in more control over their behaviour and environment.

Notably, CCC-r theory has not been extended to explain increases in cognitive complexity beyond the preschool years (Müller & Kerns, 2015).

To account for the changes observed during early childhood, Zelazo (2006) implicated the development of different regions of the prefrontal cortex (PFC). Specifically, when focusing on relatively simple rules, the lateral PFC is activated allowing processing of these simple rules at higher levels of consciousness, thus formulating higher-order rules that control the application of these simpler rules (Bunge & Zelazo, 2006). Throughout development, more complex rule systems are formulated requiring increasingly complex hierarchical networks of PFC regions allowing preschool aged children to engage in varying degrees of reflection and view stimuli in terms of multiple dimensions (Zelazo & Müller, 2011). Zelazo (2015) posits that a main driver of this development is the improvement in the ability to reflect, or continuously reprocess information, leading to the formulation of increasingly complex rules, and hence improved or more efficient control of attention. However, what calls into question the unitary nature of EF is the consistent pattern of studies finding low correlations between different EF tasks (Jurado & Rosselli, 2007).

Dissociable Frameworks

An alternative broad theoretical framework of the development of EF views EF processes as dissociable or consisting of separate components. An early proponent of this view, Diamond (2001) defined EF as one's ability to overcome automatic, prepotent behaviour, essentially overriding previous experience. Diamond posits that EF is made up of three components (discussed later in more detail): (a) inhibition, (b) working memory, and (c) cognitive flexibility (shifting), all which follow *separate* developmental trajectories (Diamond, 2006). Similar to the CCC-r and graded representation theory, Diamond (2006) highlights conflict and ability to overcome automatic responses as a key component of EF development during the preschool period.

Integrative Framework

Over the past 20 years, perhaps the most prominent model of EF has been advanced by Miyake and colleagues. In their seminal article, Miyake et al. (2000) examined the separability of three common EFs – shifting, information updating and monitoring (i.e., working memory), and inhibition – and the role they play in more complex EF tasks among adults. Using confirmatory factor analysis (CFA), these three components were found to be clearly distinguishable, yet shared some underlying commonality (moderate correlations ranging from .42 to .63). Additionally, using structural equation modeling they found that these three functions contributed differentially to performance on separate complex executive tasks. As such, the unity and diversity model of EF was proposed suggesting that EFs can be characterized as separate but related functions that share an underlying commonality. Miyake and Friedman (2012) reinterpreted their factor structure to decompose each EF factor into variance that is shared by all three latent factors (common EF) and that is also unique to each EF factor. After accounting for the common EF, unique variance was left only for an updating factor and a shifting factor, but not for an inhibition factor, thus calling into question its role as a specific factor (Friedman et al., 2008, 2011). Currently, questions remain as to what accounts for the source(s) of commonality (i.e., attentional control or a shared inhibitory process) and how best to classify separable EFs.

Support for an integrative framework when investigating EF development in younger children is mixed, as relations with EF tasks appear to change with age. This is especially important for clinicians to consider, particularly those who are evaluating EF, as the underlying model of EF appears to change with respect to age. For example, Hughes (1998) examined preschoolers' performance on several EF tasks and extracted three distinct factors: attentional flexibility, inhibitory control, and working memory, suggesting independence of these factors. However, Miller et al. (2012), using CFA to examine the composition of EF in 3- to 5-year-olds, found a two-factor model consisting of working memory and inhibition fit better than both a single-factor model and three-factor model. Additionally, Senn et al. (2004), using path analysis, found that performance by preschoolers on the working memory and inhibition tasks were correlated and predicted complex task performance, but shifting performance was unrelated. These results suggest a complex interplay of dissociable EF components that are also interrelated to some degree (Best & Miller, 2010).

Wiebe et al. (2008, 2011) found evidence that EF structure among preschoolers is best described by a single factor. Specifically, using CFA the researchers investigated working memory and inhibition, two separable yet previously correlated factors. Results revealed a very high correlation between the two factors and the authors concluded that a single, unitary domain specific EF control factor is the best fit for the data; working memory and inhibition were not distinguishable in children up to the age of 6 years. Similarly, Shing et al. (2010) found evidence of a single factor model when examining working memory and inhibition in 4- to 7-year-olds and in children 7- to 9- years 6 months old. However, a distinct two-factor model was found in slightly older children aged 9 years 6 months to 14 years 6 months, again suggesting developmental change from a single factor model as children mature. Additionally, work by Willoughby et al. (2012) with 5-year-olds found that EF is best characterized by a single factor, although correlations between tasks were modest. In addition to these studies, multiple applications of CFA involving preschool children have found support for a unitary EF factor structure (e.g., Fuhs & Day, 2011; Hughes et al., 2009; Willoughby et al., 2010). It is possible that the common EF factor suggested by Miyake and Friedman (2012) is responsible for guiding preschoolers through EF tasks as they have not yet developed separate shifting and working memory abilities (Miller & Marcovitch, 2015).

Evidence of an integrated framework with older children and adults has been somewhat clearer. For example, using CFA, Lehto et al. (2003) measured EF ability with children aged 8 to 13 years and found that Miyake's three-factor model (i.e., both unity and diversity), provided the best fit evidenced by correlations (range *r*s = .63 to .65) and model fit statistics. Miyake's model was again replicated by Wu et al. (2011) who found similar associations between shifting, inhibition, and working memory/updating using factor correlations (range *r*s = .38 to .82) and model fit statistics in a group of children 7 to 14 years old. Additional evidence for diversity and unity in older children was found by Duan and colleagues (2010) when examining working memory, inhibition, and shifting in a group of children aged 11 to 12 years. Support for Miyake's model was reported via factor correlations (range *r*s = .33 to .71) and model fit statistics. Finally, a study using a developmental CFA across different age ranges (i.e., 7-, 11-, 15-, and 21-year-olds) by Huizinga et al. (2006) found partial support for Miyake's model, with working memory and shifting loading onto latent variables and not inhibition. Importantly, this model was consistent across all age groups suggesting the relative stability of these EF factors beginning during middle childhood. Overall, it is probable that Miyake's unity and diversity model is consistent across middle childhood, adolescence, and early adulthood and is likely a suitable framework for which to view the later development of EF.

Conclusions about the nature of EF rendered from factorial studies (and in general, all studies attempting to isolate specific EF skills) likely differ for many reasons. According to Müller and Kerns (2015), inconsistences are possibly the result of problems such as the use of different test batteries to the age of participants to low reliability of the EF measures. Another well documented matter is the problem of task impurity (Hughes & Graham, 2002). Task impurity refers to the problem that tasks designed to measure specific EF skills often include other nonexecutive skills that essentially cloud the EF skill initially targeted. As a result, specific EF skills can potentially load onto a factor because they share a nonexecutive process. Notably, studies using CFA (rather than principal component analysis or exploratory factor analysis) attempt to remedy this problem because they extract only the variance that is common across the tasks that are measuring the same EF skill (see Table 2.1 for a summary of studies examining the theoretical framework of EF). The common factor gleaned from CFA has been suggested to be a purer measure of EF than the individual tasks originally used to identify the EF skill (Müller & Kerns, 2015).

In summary, results of the literature currently support an integrative model of EF, from early childhood into adulthood, best provided by Miyake and colleagues' unity and diversity model. Study designs including a range of ages and statistical analyses have consistently shown both interrelated yet dissociable components of EF. However, these studies also call into question the degree to which these EF components remain united or independent throughout development, particularly during the preschool years and younger. This poses problems for clinicians, as the way in which they view EF can have a substantial impact on their method of assessment. For example, a clinician who views EF as uniformly independent throughout development and interprets subtest results as unrelated and independent (e.g., NEPSY-II), may inappropriately conclude that their 5-year-old client has significant EF deficits in working memory, shifting, and inhibition, therefore recommending categorized strategies for all three domains. The assumption made by the clinician that individual subtests reflect development of the corresponding latent EF constructs is inaccurate at this age and subsequently leads to misinformed recommendations. Additionally, these assessment results have the potential to follow the child over the next many years, with school staff and other adults assuming serious problems across all three areas. With a clearer understanding of the unity and diversity model, the same clinician would have viewed their 5-year-old client's performance from a different perspective. Rather than simply compartmentalizing domains, a discussion around a general EF problem that cannot yet be differentiated due to age and developmental level but possibly related to inhibition difficulties would have been more accurate, with later reassessment around age 7 years providing more clarity across domains. In addition to having a theoretical framework with which to view EF, detailed knowledge regarding the developmental patterns of EFs (discussed in the following section) would aid in the clinician's assessment and interpretation of results. To summarize, clinicians will benefit from organizing their assessment information using a theoretical and developmental structure that highlights relationships and organization between EF constructs to support the appropriate interpretation of results and future recommendations using developmental insight.

Table 2.1

Studies Examining the Theoretical Framework of EF

Authors	Participants	EF Measures Used	Analysis Used	Findings
Duan et al. (2010)	61 children, M_{age}: 11.88 years	Inhibition: Digit Go/No-Go; Figure Go/No-Go WM: Digit 2-back test; Figure Position 2-back test Shifting: Odd-More Task/Digit Shifting task; Local-Global task/Figure shifting task	CFA	Unity and diversity of WM, Shifting, Inhibition
Friedman et al. (2008)	582 twins; age not reported	Inhibition: Anti-saccade; Stop-signal; Stroop WM: Keep Track; Letter Memory; Spatial 2-back Shifting: Number-Setter; Colour-shape; Category Switching	CFA	After accounting for a common factor, only unique variance for WM and Shifting
Friedman et al. (2011)	813 twins, 17 years old	Inhibition: Stop Signal; Stroop; Anti-saccade WM: Keep Track; Letter-Memory; Spatial 2-back Shifting: Number-Letter; Colour-Shape; Category Switching	CFA	Common factor, with WM and Shifting
Fuchs & Day, (2011)	132 preschoolers; M_{age}: 4.7 years	Inhibition: Head/Feet Game; Day/Night Stoop task; BRIEF-P Inhibition scale Shifting: Flexible Item Selection; Spatial Reversal; BRIEF-P Shifting scale	CFA	Unitary model of EF
Hughes et al. (2008)	50 preschoolers; M_{age} 3.11 years	Inhibition: Detour Reaching Box; Fist and Finger hand game WM: Spin the Pots Visual Search; Noisy Book Auditory Sequencing Task Shifting: Colour-shape Switching; Magnets Pattern Making Task	PCA	Three distinct factors: WM, Shifting, Inhibition
Hughes et al. (2009)	191 children; Time 1 M_{age}: 4.3 years; Time 2 M_{age}: 6 years	Day/Night Stroop; Beads task; Tower of London;	CFA	Unitary model of EF at both time points

Huizinga et al. (2006)	Four age groups: 7-, 11, 15-, 21-year-olds.	WM: Tic Tac Toe; Mental Counters; Running Memory Shifting: Local-Global; Stroop Complex: WCST; Tower of London	CFA	Two common factors: WM and Shifting across all age groups.
Lehto et al. (2003)	108 children; 5 groups: age 8-, 9-, 10-, 11-, 12/13-year-olds.	Trail Making Test; Auditory Attention and Response Set; Word Fluency; Matching Familiar Figures; Mazes; CANTAB (psychomotor screening; spatial span; spatial working memory task; Tower of London)	EFA, CFA	Unity and diversity of WM, Shifting, Inhibition across all age groups.
Miller et al. (2012)	129 children; M_{age} 4 years	Inhibition: Preschool CPT Task; Boy girl Stroop Task; Tower of Hanoi; Go/No-Go WM: Backward Span Task; Boxes Task; Preschool CPT Switching: Go/No-Go; DCCS	CFA	Two factor model: WM and Inhibition
Miyake et al., (2000)	137 undergraduate students	Inhibition: Anti-saccade Task; Stop Signal task; Stroop Task WM: Keep Track Task; Tone Monitoring Task; Letter Memory Task Shifting: Plus-Minus Task; Number-Letter Task; Local Global Task Complex: WCST; Tower of Hanoi; Random Number Generation; Operation Span Task; Dual Task	CFA; SEM	Unity and diversity of WM, Shifting, Inhibition
Senn et al. (2004)	117 preschoolers; M_{age} 4.2 years	Inhibition: Shape School Stroop Task WM: Delayed Alternation Shifting: Spatial Reversal Task Outcome Variable: Tower of Hanoi	Path Analysis	WM and Inhibition best predicted complex problem solving
Shing et al. (2010)	263 children age 4 to 14. M_{age} gr 1: 5.2 years; M_{age} gr 2: 8.05; M_{age} gr. 3: 11.14	WM: Abstract Shapes Inhibition/WM: Dots-Incongruent/Mixed Inhibition: Pictures; Arrows	CFA	Unitary model for gr. 1 and 2; two-factor model for gr. 3
Wiebe et al. (2008)	243 preschoolers;	Inhibition: Delayed Response Task; Whisper Task; Statue Task; Visual Attention Task, CPT, Shape School Task	CFA	Unitary model of EF

	M_{age} 3.11 years	WM: Delayed Alternation Task; Six Boxes Task; Digit Span Task		
Wiebe et al. (2011)	228 preschoolers; M_{age} 3.01 years	Inhibition and WM: Nine Boxes; Nebraska Barnyard; Delayed Alternation; Big-Little Stroop; Shape School; Go/No-Go; Snack Delay	CFA	Unitary model of EF
Willoughby et al. (2010)	1292; 36-month-old visit	WM Span Task; SC Simon Talk Task; IS Flexible Attention Task; Silly Sounds Stroop Task; Animal Go/No-Go task	CFA	Unitary model of EF
Willoughby et al. (2012)	1292; 5-year-old visit	Working Memory Span task; Pick the Picture Task; Spatial Conflict Arrows tasks; Something's the Same Task; Silly Sounds Stroop; Animal Go/No Go task	CFA	Unitary model of EF
Wu at al. (2011)	185 children, ages 7 - 14	TEA-Ch-Creature Counting; TEA-Ch-Opposite Word; Contingency Naming Test; TEA-Ch-Code Transmission; TEA-Ch-Sky Search; Stroop Colour and Word Test; Tower of London	CFA	Unity and diversity of WM, Shifting, Inhibition

Note. WM = Working Memory; CFA = Confirmatory Factor Analysis; PCA = Principal Component Analysis; EFA = Exploratory Factor Analysis; SEM = Structural Equation Modeling

Foundational Executive Functions

As previously discussed, several theories exist that attempt to model EF. Some theories emphasize the importance of a single factor, while others take a more functional approach. Understanding EF through a theoretical framework is essential for clinicians as it provides a "big picture" in which to understand relationships and integrate information. However, understanding the organization of latent structures of EF does not provide enough detailed and tangible information about the developmental trajectories and intricacies of these structures to support clinical assessment. For clinicians who work with children and adolescents, having a developmental appreciation and comprehensive understanding of EF as a construct in addition to knowledge of how EF skills develop as children age, is imperative for thorough and accurate assessment (Koziol, 2014). Understanding functional developmental changes in EF is also important as it supports the changing theoretical model of EF from early childhood into later childhood and adolescence. In this section the three latent EF variables will be discussed (see Table 2.2), based largely on the work of Miyake et al. (2000): inhibition, shifting, and updating (i.e., working memory).

Table 2.2

Foundational Executive Functions

Working Memory	An individual's ability to hold information online for a temporary period of time while working to complete goal-directed tasks. It is comprised of two storage capacities (phonological loop, visual-spatial sketchpad), a central buffer (central executive) that works as an attention and control centre, and a backup storage system (episodic buffer) (Baddeley, 1992; 2000).
Inhibition	Also referred to as inhibitory control. It allows for the ability to suppress a dominant response. It is likely comprised of simple inhibition and complex inhibition, where the former requires less working memory demands (Moses et al., 2005).

Shifting	Also referred to as cognitive flexibility. It refers to one's ability to shift between responses, sets, strategies, attributes of stimuli, or tasks in an adaptive manner (Diamond, 2013).

Working Memory

Working memory refers to an individual's ability to hold information online for a temporary period of time while working to complete goal-directed tasks (Cowan, 2015). Likely the most influential model of working memory was developed by Baddeley (1992), in which he describes working memory as comprising of two storage capacities and a central buffer. The phonological loop stores auditory information, and the visual-spatial sketchpad stores visual-spatial information. Both storage centres work mainly as passive storage and rehearsal units. The central executive, however, works as an active attention control centre that manipulates online information via focused, divided, and shifting attention. It is the central executive that is often considered the EF component of working memory (Müller & Kerns, 2015). Evidence supporting this three-system model comes from studies using batteries of verbal working memory, visuospatial working memory, and executive working memory tasks. A CFA of children aged 4 to 15 years found simple and complex tasks cluster onto these three separate factors (Gathercole et al., 2004). Baddeley later added a fourth component, the episodic buffer, which essentially acts as a backup storage system that communicates with both long-term memory and components of working memory (Baddeley, 2000). Overall, working memory appears to develop steadily throughout childhood (Cowan, 2015) and into early adulthood (Huizinga et al., 2006).

One difficulty in measuring working memory capacity, as with other areas of EF, is the varying degree of difficulty across tasks and whether they require activation of more passive maintenance components (e.g., delayed response tasks, digit forward tasks) or use of the central executive/attentional control to coordinate multiple processes (e.g., counting span, self-ordered pointing tasks; Best & Miller, 2010). For instance, memory tasks for younger children (e.g., ages 1 to 4) often involve simple maintenance of information whereas adolescents and young adults are required to use more complex skills such as simultaneously updating, inhibiting, and transforming information in an effort to maintain relevant information (Linares et al., 2016). Understanding this developmental change and the differences in age-appropriate working memory tasks is important for clinicians and again is required for accurate assessment and interpretation. Additionally, knowledge of this developmental change is important because overall EF skills during the preschool-age period may be best explained by a unitary construct (rather than three separate abilities), thus causing difficulty when attempting to isolate specific EF skills (i.e., working memory) during this period (Miller & Marcovitch, 2015).

Developmental differences.

Preschool. The emergence of simple working memory is documented at 6 months of age using delayed response tasks where infants are required to look for a hidden object after a delay, with locations changing and/or increasing from trial to trial. From 6 to 12 months, the length of time an infant can hold these representations in mind increases from a few seconds to over 10 seconds and the capacity of information able to be held in memory also increases; they are also able to find hidden objects in an increasing number of locations (Diamond & Doar, 1989, Pelphrey et al., 2004).

After age 2, span tasks are often used to assess different components of simple working memory (i.e., phonological loop and visuo-spatial sketchpad). Increases in the amount of information retained from 3- to 5-years-old is well documented on digit and word span tasks and on object and spatial span tasks indicating increases in simple working memory capacity during this time (for a review see Garon et al., 2008). More complex working memory tasks that require updating information in the central executive develop later than simple retention. For instance, updating is assessed using self-ordered pointing tasks that use game formats. Children must remember which cup a prize is hidden under by tracking which ones they have uncovered when a screen is lowered after each choice. Diamond et al. (1997) found increases in spatial and object updating in a longitudinal study examining children aged 15 to 30 months and on a six-box stationary task from children aged 3.5 to 7 years. Finally, backward span tasks that also test a child's ability to manipulate representations in mind by measuring their ability to recall sequences in reverse order have found increases in the number of items recalled between ages 3 and 5 years (Carlson, 2005).

In conclusion, during the early years and throughout the preschool years, children's ability to hold representations in memory over a short delay appears to emerge as early as 6 months. During the preschool years, increases in the amount of information that can be held in the phonological loop and visual-spatial sketchpad (i.e., simple working memory demands) continue to increase. More complex working memory ability, specifically the use of the central executive, appears to begin development during the second year of life. Understanding this developmental trend is important for clinicians assessing working memory. Specifically, that complex working memory, which is what clinicians often refer to when discussing working memory, does not appear until approximately the second year of life.

Middle childhood and adolescence. Working memory continues to develop throughout middle childhood, adolescence, through to early adulthood. A linear increase in both simple and complex working memory development from age 4 to 14 years was found by Gathercole et al. (2004), while Luciana et al. (2005) reported that the complexity of the working memory task dictates the developmental course whereby less demanding tasks are mastered earlier than more complex tasks. Specifically, on a battery of nonverbal tasks the researchers found that performance on simple tasks is unchanging between ages 9 and 20 years. However, performance on more complex tasks continues to improve until age 16 years. Similar results were found when using a battery of verbal and spatial tasks with children aged 9 to 17 years; the authors reported that development is contingent on the degree of processing required rather than the content (Conklin et al., 2007). Further evidence of working memory development throughout childhood and into early adulthood was found by Huizinga et al. (2006). Using low to high memory load tasks with children aged 7, 11, 15, and 21 years, the researchers found that working memory develops throughout all ages until 21 years. Similar results were found by Peters and colleagues (2016) in their longitudinal study of participants between the ages 8 and 27 years; working memory peaked at approximately 17 years of age, after which both stable performance for some and decreases for others were noted. Overall, working memory development appears to continue during middle childhood and into adolescence and early adulthood and follows a protracted developmental trajectory (Crone et al., 2018). What is important for clinicians to consider during this time is the complexity of the memory tasks they are using during their assessments, as this appears to greatly influence performance, with more robust development occurring within more complex memory systems.

Inhibition

Inhibition, also referred to as inhibitory control, is the ability to suppress a dominant response and begins to develop during early childhood (Moriguchi, 2018). Similar to working memory, measuring pure inhibition is difficult, as tasks used in research likely tap into related processes such as working memory and cognitive flexibility (i.e., switching). In their review, Garon et al. (2008) distinguish simple response inhibition from complex response inhibition, where the former involves less working memory demands than the latter. Research findings lend support to these distinctions as factor analyses consistently show that simple and complex inhibition tasks cluster into different factors (for a review see Moses et al., 2005). Whereas simple inhibition begins to appear during the first year of life, complex inhibition emerges at approximately age 3 and undergoes significant changes until approximately age 5 (Garon et al., 2008). Throughout the remainder of childhood, evidence indicates a joint cognitive flexibility/inhibitory control mechanism at work, but this appears to parse out by age 15 (Lee et al., 2013). As with working memory, understanding the developmental trajectory of inhibition and the difficulties in isolating this skill during assessment is paramount for clinicians to ensure appropriate and accurate assessment.

Developmental differences.

Preschool. At approximately 12 months of age, children begin to develop the ability to supress a dominant response. This is observed in the 'don't paradigm', where children are required to inhibit a pleasurable behaviour such as playing with a desirable toy. For example, Kochanska et al. (1998) found that 8-month-olds can inhibit their behaviour 40% of the time, while this increases to 78% for 22-month-olds and 90% for 33-month-olds (Kochanska, 2002). The 'delay of gratification paradigm' is another popular test of simple inhibition where young children must inhibit their behaviour by either waiting or choosing. For example, a child is shown two treats; if they wait the full period, they can eat both or they can ring the bell at any time and eat one. Children's ability to delay (i.e., inhibit) their gratification appears to increase from 24 months to 4 years. Using a cross-sectional sample, Carlson (2005) found that only 50% of 24-month-olds can delay eating a treat for 20 seconds, however, this increases to 1 minute for 85% of 3-year-olds, and 5 minutes for 72% of 4-year-olds.

Further evidence of a developmental trend during the early preschool years in inhibition comes from conflict tasks, where children are required to overcome automatic responses. In an object retrieval task, where children are required inhibit their dominant response to reach in a straight line for an object and instead use a side opening, Diamond (1990) found improvements in inhibition from 6.5 months until 12 months, when children no longer required adult assistance. Further evidence comes from anti-saccade tasks, where children are required to inhibit their reflex to look at a lateral stimulus and instead look to the other side. Early on, children are able to inhibit their response (i.e., not look), however, they are unable to execute a subdominant response (i.e., look to the opposite side; Johnson, 1995). By 12 to 18 months, however, the ability to both inhibit and produce a subdominant response emerges (Scerif et al., 2004).

Many increasingly complex conflict tasks show developmental differences in the ability to coordinate the inhibition of responses and activation of alternative responses. However, different conflict tasks show different ages of mastery, likely attributing to varying cognitive demands (Best & Miller, 2010). For example, in Luria's hand game, where children are asked to make a fist when shown a finger and vice versa, improvement is made between 3 and 4 years of age (Hughes, 1998). However, when inhibition of verbal responses is required (i.e., say day when shown a picture of night and vice versa), both 3- and 4-year-olds experience difficulty (Carlson, 2005). The same difficulty is also observed at this age during inhibition tasks that require the suppression of more dominant responses such as Simon says, where the child must inhibit an action that is both verbalized and demonstrated to them (Carlson, 2005).

Finally, Stroop and the Dimensional Change Card Sort (DCCS) tasks also point to improvements in inhibition during early childhood. During a standard Stoop task, the participant is asked to name the ink colour a word is written in and not read the word (i.e., another type of conflict task where dominant responses are inhibited). As Stroop tasks increase in difficulty, so too do the ages in which children are able to successfully inhibit their dominant response. Longitudinal studies show that children can successfully complete simple pointing Stroop tasks by 24 months (Kochanska et al., 1997; Kochanska et al., 1998) and show increasing improvement across more difficult Stroop tasks from 2 to 4 years (Carlson et al., 2004; Hughes & Ensor, 2007). When conflict is increased further (i.e., point to white when they hear grass, point to green when they hear snow), it is not until age 4.5 years that 80% of children can successfully complete this task (Carlson, 2005).

The DCCS is a complex inhibition task that uses rules as prepotent responses that must be inhibited during the first phase of the task. For example, a child is given a set of cards that vary on two dimensions (e.g., shape and colour). During the first phase, the child is asked to sort the cards by one dimension (e.g., shape). In the second phase, the child is asked to sort the cards by the other dimension (e.g., colour). Like Stroop tasks, as children age, their ability to sort successfully (that is, make fewer perseveration mistakes) increases. From age 3 to 4, children can successfully complete simple DCCS tasks. However, when conflict is increased by adding a third dimension (e.g., if there is a star on the card, sort by colour, if there is not, sort by shape), less than 50% of 5- and 6-year-olds are successful (Carlson, 2005). Notably, the complexity of this task is reflected in the other EF skills it taps into for successful completion (i.e., shifting between rules and using working memory to hold information). In fact, as discussed in the following section, some researchers use sorting tasks as measures of cognitive flexibility. This is important for clinicians to consider during interpretation, as difficulties in other areas of EF have the potential to impact performance on this task.

Overall, children show the ability to inhibit during their first year of life, beginning with simple response inhibition. Gradually, during their second year of life, their inhibition ability appears to increase, and development continues throughout their preschool years. By age 5, significant improvements are made in the ability to inhibit stronger automatic responses, reinforced behavioural responses, and supress their responses for longer periods of time.

Middle childhood and adolescence. Best and Miller (2010) highlight some of the changes evident in inhibition ability after age 5 up until late adolescence. Unlike the plethora of research evidence indicating consistent improvements in inhibition during early childhood, studies investigating inhibition during later childhood and adolescence are limited and have found mixed results. This may be due to the types of tasks used and how performance is measured. For example, although improvements on the statue task (i.e., inhibiting distractors) and a conflict knock task (i.e., tap when the experimenter knocks and vice versa) are evident from ages 3 to 6 years, none are observed through to age 12 years (Klenberg et al., 2001). However, it is possible that ceiling effects play a role in older children's performance (Best & Miller, 2010). Despite challenges with tool selection and isolating EF skills, growth in more complex forms of inhibition continues throughout middle childhood. Whereas errors made by young children on inhibition tasks are often the result of distraction or irrelevant behaviour, as they mature, they develop a better understanding of rules and their ability to selectively attend increases, lending to more task-relevant errors (Clark et al., 2013). However, general consensus in the field views simple inhibition development as stabilizing by the early school years (Best & Miller, 2010).

Another common method of measuring inhibition in older children is using computerized tasks. On these tasks, further development of inhibition is observed after age 8. Tasks such as the

Go-No-Go and the Continuous Performance Task (CPT) require participants to respond to certain stimuli while inhibiting their response to others. However, clinicians should interpret results using caution because performance using these types of modalities is extremely sensitive (e.g., measuring multiple trials and extremely accurate timing) and the presence of possible effects of age-related improvements in computer skills may influence results. Nonetheless, Brocki and Bohlin (2004) found significant improvements from age 7 to 9 to 11 years on a combined factor measuring disinhibition, impulsivity, inattentiveness, and commission errors. Jonkman at al. (2003) and Casey et al. (1997) found a significant decrease in commission errors (i.e., a sign of inhibiting one's response) between age 9 years and young adulthood. On a computerized anti-saccade task, where children are required to inhibit their gaze at a target and instead look to the opposite side of the screen, significant improvements were found in their reaction times and accuracy during grade school and smaller improvements during early adolescence (Fischer et al., 1997).

Overall, improvements in inhibition are observed throughout middle childhood and adolescence. However, unlike the robust improvements that take place throughout the preschool years, more modest linear improvements are evident during adolescence (Best & Miller, 2010; Müller & Kerns, 2015). What is important for clinicians to consider, is that these changes may not represent the same type of cognitive changes that are taking place during the preschool years when children begin to understand greater rule representations such as during sorting tasks (Best & Miller, 2010). Rather, the improvements observed later in childhood and into adolescence may reflect improvements in accuracy as measured on computerized tasks or qualitative changes such as strategy use. It is possible that inhibition is multi-faceted and that development across different inhibition tasks does not follow the same trajectory, is dependent on the unique interplay of EF tasks that transpires throughout development and is dependent on the actual inhibition tasks being utilized (Crone et al., 2018). Finally, more longitudinal research is needed to clarify the relationship between inhibition, working memory, and other skills including processing speed (Müller & Kerns, 2015).

Shifting

Set-shifting (or cognitive flexibility or switching) refers to one's ability to shift between responses, sets, strategies, attributes of stimuli, or tasks in an adaptive manner (Diamond, 2013). When engaged in shifting, there is an understanding that within a situation, there are two or more perspectives or ways of acting. Shifting from one mental set to another occurs via two phases: forming a mental set where an association is made between a stimulus and a response, and then shifting to a new mental set that conflicts with the first (Garon et al., 2008). As inhibition and shifting are both often required to successfully navigate tasks, inhibition tasks are usually defined by the need to inhibit a single response, while shifting tasks require movement between two or more mental sets (Best & Miller, 2010).

In addition to inhibition, working memory is also believed to be involved in set-shifting, as participants must focus on relevant information while ignoring distractors and remembering rules (Diamond, 2013; Garon et al., 2008; Jacques & Marcovitch, 2010). However, developmental considerations likely play a role in the degree to which working memory and inhibition are involved in shifting ability, further complicating clinical assessment. For example, using path analysis to examine set shifting, working memory, inhibition, and problem solving in preschoolers, Senn et al. (2004) did not find evidence that shifting performance was related to these other areas. The authors concluded that during the preschool years, shifting is likely less developed and thus undifferentiated from working memory and inhibition. Additionally, the authors hypothesized that different shifting tasks may actually tap into different kinds of shifting; less complex motor/search tasks often used with younger children may not measure the complex cognitive flexibility of EF. Furthermore, researchers have also proposed that set-shifting during early childhood is not a skill on its own, rather the product of the overall system resulting from the interplay of multiple systems (Ezekiel et al., 2013; Ionescu, 2012).

Another important developmental consideration with regard to shifting is understanding that young children often perseverate on previously relevant information (referred to as poor control); however, this may be the first step toward developing flexible switching as they are able to consistently apply a new rule across trials and phases which they previously could not (Blakey et al., 2016). This is important for clinicians to consider developmentally, as the presence of perseveration errors may indicate a steppingstone toward shifting depending on age and performance, rather than simply reflect an area of deficit.

Developmental differences.

Preschool. Categorizing (i.e., shifting set), is first observed at 24 months in sorting tasks, where toddlers can judge what does not belong to one group (A) and still consider it as a possible member of another group (B). For instance, Sugarman (1983) found that children this age can shift between objects to organize into groups (e.g., red block into group A, blue block into group B). By age 3 to 4 years, shifting ability is observed in studies where toddlers are able to shift between two simple response sets presented in a story context where they must listen to rules about a teddy bear's favourite shape, followed by a decision regarding a second teddy bear's favourite colour (Hughes, 1998). In line with these findings, other researchers have observed a marked increase in children's ability to flexibly switch between different response sets by age 4 years if given cues or instructions when given the DCCS task (Clark et al., 2013). Notably, these tasks allude to the importance of children possessing prior working memory and inhibition skills, as they must be able to remember the response set and inhibit the activation of a previous response set to allow the activation of an alternative one (Garon et al., 2008).

Inductive categorization tasks are tasks that require children to categorize the same objects by different attributes (e.g., by shape, by colour, by size). These tasks assess children's flexible reclassification of objects and have shown steady increases in set-shifting from age 3 throughout ages 7 to 9 years. For example, Smidts et al., (2004) found that 42% of 5-year-olds, 60% of 6-year-olds, and 90% of the 9-year-olds were able to produce a second grouping while none of the 3- or 4-year-olds were able to produce a second grouping. After the children were given instructions on how to regroup a different way (e.g., "put the big ones in a pile and the small ones in a pile" if they were grouped by colour initially), 3- and 4-year-olds could produce a second group, but not a third. Furthermore, Blaye and colleagues (2006) found that 37% of 5-year-olds produced two or more groupings, with this increasing to 67% at 9 years old. When asked to label the sorts (conceptual flexibility), only 7% of 5-year-olds were successful while 60% of 9-year-olds could correctly label two or more sorts.

Middle childhood and adolescence. Further development of more complex switching ability is observed in older children and adolescents and it appears to continue through to young adulthood. Using the intradimensional-extradimensional set-shifting task from the CANTAB, Luciana and Nelson (1998) saw most improvement from age 5 to 6 years. During the simpler initial stages of the task, the children were required to utilize prior feedback and apply it to new trials to successfully complete the task. Notably, improvement throughout the nine increasingly complex stages of the task was evident in participants up through young adulthood. On another sorting task, where participants were required to use abstraction during feedback to determine the switching rule, growth was more gradual. Specifically, gain in growth and accuracy were found between 6 and 10 years of age (Chelune & Baer, 1986), while gains in speed were noted during middle childhood and adolescence (Anderson et al., 2001).

Overall, when examining the development of EF across middle childhood and adolescence, it appears that shifting can be distinguished as a latent factor. Further support comes from Huizinga et al., (2006), who estimated latent factors between tasks that measured the 3 basic EFs with children at 7 years, 11 years, 15 years, and 21 years and found that shifting ability was mature at age 15. Clinicians should keep in mind these developmental differences and the complexity of assessing shifting thereby considering the role of working memory and inhibition when examining this area.

Conclusion

A thorough understanding of the developmental nature of EF is critical. Clinicians are encouraged to keep in mind what appear to be important differences in the foundational makeup of EF skills, specifically that a unitary construct appears to best describe EF during the preschool years. This is critical as attempting to separate or measure isolated EF skills during this early period (e.g., working memory versus inhibition versus shifting) does not accurately reflect what appears to be the foundational makeup of EF during this time. Professionals evaluating EF skills should also have a thorough understanding of the complexity of measuring isolated EF skills, as this is often fraught with task impurity challenges such that parsing out “clean” abilities is unlikely.

For instance, the majority of EF tasks used to measure EF often differ in complexity to account for developmental differences, with simple tasks used during the early years and more complex tasks used as individuals develop. It is also often the case that more complex tasks tap into other areas of EF. For example, early working memory tasks used for children under the age of 2 years often measure simple span skills (e.g., phonological loop) while more complex working memory tasks are designed to tap into higher-level skills (e.g., central executive) but can also require other EF skills such as inhibition (e.g., Gathercole et al., 2004). Evaluating inhibition skills also encompasses the same complexity. Broadly, simple inhibition appears during the first year of life while complex inhibition begins to develop between ages 3 and 5 years (for a review see Garon et al., 2008). Until approximately age 15, inhibition and switching (i.e., cognitive flexibility) are especially difficult to parse out (Lee et al., 2013), a particularly relevant finding for clinicians who evaluate children during this time. Inhibition is also very sensitive to the type of task used. For example, ceiling effects might play a role on some simpler inhibition tasks up to age 12 years (e.g., statue task, conflict knock task; Klenberg et al., 2001) while more complex computer tasks (e.g., CPT) are more sensitive and have found improvements beyond age 7 and into adulthood (e.g., Brocki & Bohlin, 2004; Casey et al., 1997; Jonkman at al., 2003). Finally, shifting tasks are especially fraught with impurity problems and often involve inhibition and working memory involvement (Diamond, 2013; Garon et al., 2008; Jacques & Marcovitch, 2010). Furthermore, it is possible that shifting during early childhood may reflect multiple systems rather than an isolated skill (Ezekiel et al., 2013; Ionescu, 2012) and does not appear as a mature latent construct until approximately age 15 (Huizinga et al., 2006).

In conclusion, there are multiple factors to keep in mind when formulating an understanding of how EF is conceptualized at a broad level, what the development of individual EF skills looks like, and how both of these elements are influenced by development. Individuals working in the field of EF, particularly in an assessment capacity, require a thorough understanding of these constructs to accurately conceptualize and evaluate this complex domain.

Future Directions and Clinical Implications

The importance of EF in healthy functioning is understood by both researchers and clinicians. Despite this importance, a gap currently exists between what is known in the literature and how EF is often assessed by clinicians. Although there exists a lack of consensus in the field regarding a theoretical framework of EF, a large body of evidence is accumulating that supports an integrative framework that views EF as related yet separate processes (e.g., Miyake et al., 2000; Miyake & Friedman, 2012). Complicating this model are what appear to be developmental changes in EF that affect at a broad level, the organization (i.e., latent constructs) of EF, and at an individual level, the actual skills (e.g., simple versus complex) that are observed.

Despite the current state of the field of EF, clinical assessment is at risk of not reflecting this complexity if clinicians are not adequately trained and abreast regarding the complexities and nuances of evaluating EF (Suchy, 2009). This is dangerous for two reasons: First, clinicians might use test construction to guide their understanding (and hence assessment) of EF skills, and second, clinicians might oversimplify their assessment results. More specifically, clinicians risk assessing EF test-by-test, interpreting each test as a “pure” EF skill, and assume confidence in their results. Said differently, clinical assessment of EF that is not theory driven has the potential to negatively affect the confidence in results.

Moving forward, what can clinicians do to mitigate these potential problems? First, clinicians should have a deep theoretical understanding of EF and stay abreast of current literature in this quickly changing field. Aligning with a theoretical model will help guide their practice. Second, clinicians should have a thorough understanding of the developmental trajectories of EFs. This will allow for age-appropriate assessment and interpretation of EF tasks. Third, clinicians should be aware of task impurity when testing EF. Not only should clinicians have a deep understanding of the complexity of EF but understand the difficulty in trying to isolate specific EF skills during assessment. It is extremely important that clinicians are aware of what EF skills (and other skills, for example verbal ability) are involved in the tests that they choose. Additionally, as Miyake et al. (2000) noted, assuming labels noted on specific tasks are true indicators of what they actually measure is problematic because research (specifically latent analysis) does not often back up these claims. Fourth, clinicians should use multiple measures to test each EF rather than rely on a single test (Miyake et al., 2000). Aggregating results will help overcome (as best as possible) impurity and offset possible interference from other skills by looking for themes. Finally, clinicians should use a combination of simple and complex EF tasks in their assessments, rather than rely solely on complex EF tests. Because many complex EF tasks require different processes, comparing performance with simpler EF tasks will allow for a more thorough picture of EF functioning.

In summary, the field of EF is currently making considerable progress understanding the broad theoretical framework of EF and developmental trajectory of specific EF skills. However, there exists a gap between what is understood by researchers and how EF is assessed in clinical settings. To help bridge this gap it is imperative for clinicians to seek a thorough understanding of EF and adopt a theoretical framework in which to guide their practice. By doing so, they will better serve their clients by understanding the intricacies of EF and all that is involved in its assessment.

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Chapter 3: Longitudinal Development of Executive Functioning Among Individuals with Fetal Alcohol Spectrum Disorder

Children with Fetal Alcohol Spectrum Disorder (FASD) grow up to be adults with FASD. FASD is a neurodevelopment disorder that results from prenatal exposure to alcohol. The estimated prevalence of Canadian children with FASD is between 2% and 3% according to a recent population-based study (Popova et al., 2018) and over 30% in some specialized settings such a youth detention centre in Australia and a correctional facility in Northern Canada (Bower et al., 2018; McLachlan et al., 2019). FASD is a heterogenous disorder with a range of symptoms and outcomes including physical, cognitive, emotional, and behavioural challenges. Presentation can vary greatly depending on the timing, frequency, and amount of maternal alcohol consumption, genetics, environment, and other pre-and post-natal events (Davis et al., 2013). Diagnostic criteria for FASD includes identification of significant deficits in three or more neurodevelopmental domains including motor skills, neuroanatomy/neurophysiology, cognition, language, academic achievement, memory, attention, executive function (EF), and adaptive behavior. Due to the prevalence of mental health challenges in this population, the Canadian diagnostic criteria was updated to include an additional domain for affect regulation (Cook et al., 2016). Affect regulation includes several diagnostic mood or anxiety disorders defined in the *Diagnostic and Statistical Manual of Mental Disorders*, *Fifth Edition* (DSM-5; APA, 2013).

For individuals impacted by prenatal alcohol exposure, a defining characteristic of their neurodevelopmental profile is significant deficits in executive functioning (EF) including challenges with verbal and non-verbal fluency, problem-solving and planning, cognitive flexibility, inhibition, and working memory (Rasmussen & Bisanz, 2009. Rasmussen et al., 2013). EF is an essential area of neurocognitive functioning because of the role it plays in later healthy outcomes. Healthy outcomes are associated with domains of EF including attention, flexible thinking, goal setting, decision making, and problem solving (Greenspan et al., 2016; Schiebener et al., 2015). Understanding these potential prognostic indicators of EF will help to uncover important sources of variability in long-term outcomes for this population. For example, EF skills are important for successfully navigating nearly all daily activities as they enable self-regulation and self-directed behaviour required to achieve goals, allow individuals to break habits, make decisions and evaluate risks and benefits, and support individuals in planning for the future, prioritizing and sequencing their actions, and coping with novel situations (e.g., Banich, 2009; Miyake & Friedman, 2012).

Despite the plethora of studies focused on delineating EF trajectories in typical populations (e.g., Best & Miller, 2010; Garon et al., 2008), we know strikingly little about its development among individuals with FASD. Due to limited longitudinal studies investigating EF among this population, researchers have largely made assumptions about its development by referring to cross sectional research and results from studies examining individuals with other neurodevelopmental disorders. By employing a longitudinal design, the current study addresses this gap in the literature.

The relationship between EF skills and later healthy outcomes, in particular adaptive functioning and mental health, among individuals with FASD is another important area that has not been readily studied. Adaptive skills include domains such as social interaction ability, social and emotional skills, communication ability, and independence skills (Greenspan et al., 2016; Schonfeld et al., 2006; Ware et al., 2012). Children with FASD often demonstrate lower skills across these domains and frequently continue to have difficulty managing their independence into adolescence (Crocker et al., 2009; Fagerlund et al., 2012; Jirikowic et al., 2008; Reid et al., 2017; Whaley et al., 2001). Because this trajectory appears to be disrupted by prenatal alcohol exposure resulting in more pronounced adaptive functioning deficits into adolescence, targeting EF skills early on may help to mitigate these challenges (Crocker et al., 2009; Panczakiewicz et al., 2016; Thomas et al., 1998). The current study will provide important information about early EF skills and their relationship with later adaptive functioning.

In addition to adaptive functioning difficulties, mental health challenges are especially common among individuals with FASD with up to 90% of clinically referred individuals with FASD reporting at least one concurrent mental health diagnosis (Pei et al., 2011). This high rate of mental health disorders underscores the need for a better understanding of underlying or mitigating factors that might contribute to this presentation. Given that two of the key components of EF, namely efficient behavioural regulation and metacognitive skills, support healthy affect regulation, investigation into the relationship between EF and mental health is paramount. I examine this relationship and will provide important information that can be used to help to decrease the host of adverse outcomes too often experienced by this population including educational disruption, challenges with employment and independent living, justice involvement, substance abuse, and neurodevelopmental co-morbidity (Clark et al., 2004; McLachlan et al., 2020; Streissguth et al., 2004; Kambeitz et al., 2019). A better understanding of the relationship between EF skills and later mental health will also provide opportunities to utilize strengths and protective factors when developing interventions to support this population.

Finally, this research will add to the much-needed body of literature aimed at supporting clinical practices in the field of FASD. Notably, it focuses on the transition into young adulthood, a time when families are faced with abrupt changes in funding and service allocation. In addition, youth are often forced to leave systems that are designed to meet their needs and enter systems that are no longer equipped to do so as young adults (Osgood et al., 2010). This developmental period is chronically overlooked by systems and staff in supporting roles do not often receive appropriate training about the strengths and needs of their clients during this period (Osgood et al., 2010). Results of the current research will provide a clearer neurodevelopmental picture of the strengths and needs of individuals with FASD between adolescence and young adulthood. Clinically, this information can be used to develop more appropriate goals and help mitigate the many challenges often observed during this time when responsibilities and expectations are increasing.

In summary, longitudinal investigation of EF in individuals with FASD is crucial for three reasons. First, a better understanding of how this construct develops into early adulthood will help to elucidate what researchers have hypothesized using cohort studies; largely that EF skills among this population fail to develop at the same rate as their typical peers (Tamana et al., 2014). Second, it will provide a clearer picture of the association between EF, adaptive functioning, and mental health over time. Third, results will support clinical practice and decision making including the development of more clinically relevant, anticipatory, and appropriate recommendations (Bertrand, 2009). Having the ability to clearly explain EF needs and strengths and the impact that these types of challenges have on daily functioning into adulthood is vital to supporting successful living and independence skills.

What is EF?

EF refers to a set of cognitive control processes, mainly supported by the prefrontal cortex (PFC), that regulate the dynamics of human cognition and action (Miyake & Friedman, 2012). As a construct, EF can be thought to encompass several sub-abilities including planning, set-shifting, inhibition, strategy deployment, flexible thinking, and working memory. EF also involves the integration of more basic processes such as memory, attention, sensation, perception, and motor activity (Pennington & Ozonoff, 1996; Zelazo & Müller, 2002). Through its role in virtually all cognitive processing, EF is essential to successfully navigate nearly all daily activities as it enables self-regulation and self-directed behaviours that are required to achieve goals, break habits, make informed decisions, evaluate risks and benefits, and support individuals in planning for the future (Miyake & Friedman, 2012).

The emergence of EF typically begins during early childhood and undergoes dramatic changes throughout this period in which some of the core components of EF develop. These core components lay the foundation for later more complex processes that develop during adolescence and into adulthood (Garon et al., 2008). The early development of EF skills is especially important as they robustly predict important living skills and factors associated with mental health including physical health, substance abuse, budgeting ability, and criminal offending outcomes later in life, even after controlling for IQ, gender, and social class (Moffitt et al., 2011). During adulthood, EF predicts marriage satisfaction, career satisfaction, and mental and physical health, further emphasizing its role in healthy functioning (Dunn, 2010; Eakin et al., 2004; Prince et al., 2007).

Currently, researchers do not agree on a single framework of EF. This is problematic as the absence of a clear understanding of what this construct entails and how it develops over time, particularly within vulnerable populations, results in a field fraught with different opinions, recommendations, and clinical practices. A prominent model put forth by Miyake and colleagues (2012) posit that EF is made up of three separate yet related components, namely working memory, set shifting, and inhibition (Miyake et al., 2000; Miyake & Friedman, 2012). Evidence for this integrative framework is supported by studies highlighting the degree to which these components can be distinguished, yet share an underlying commonality (e.g., Duan et al., 2010; Huizinga et al., 2006; Lehto et al., 2003; Wu et al., 2011).

To summarize, EF is a robust domain involved in almost every aspect of daily living. Due to the critical nature of EF and its relationship with a wide array of life outcomes, it is not surprising that atypical EF development is associated with many neurodevelopmental disorders, including FASD. Although FASD involves multiple areas of impairment, difficulties across many components of EF are a hallmark of this disorder (Mattson et al., 1999, 2010).

EF and Developmental Trends

The developmental trajectory of EF among typically developing children and adolescents has been studied widely over the last few decades. Because there is not yet a consensus regarding the theoretical framework of EF, methodologies often differ in both the EF domains measured and tools employed to measure them. In addition, the domains of EF appear to develop unevenly, thus adding to the complexity of elucidating the developmental trajectory of this construct. Keeping these challenges in mind, Best and Miller (2010) compiled a developmental review examining inhibition, working memory, and cognitive flexibility.

In their review, Best and Miller (2010) note that inhibition first appears during preschool and continues to improve throughout early childhood with refinements in the strength at which individuals can use this skill during adolescence. Notably, the greatest improvements in inhibition appear to occur between age 5 and 8 years (Romaine & Reynolds, 2005). Working memory has also been found to improve during preschool (for a review see Garon et al., 2008). However, unlike inhibition where the greatest improvements are seen during preschool, the development of working memory is more linear with performance on complex tasks continuing to improve into adolescence (Best & Miller, 2010). Finally, the trajectory of set shifting (also referred to as cognitive flexibility) appears to follow a protracted development through adolescence. Preschoolers appear to handle simple set shifts and can later successfully navigate unexpected shifts during increasingly complex tasks. The ability to monitor one's errors appears during early adolescence and reaches adult levels on complex set shifting tasks by middle adolescence (Best & Miller, 2010).

EF Development and FASD

Although the developmental trajectory of EF among individuals with FASD has not yet been studied longitudinally, cross-sectional research suggests a pattern of greater relative neuropsychological impairment than controls among adolescents with FASD than for younger children with FASD on some measures of EF. Rasmussen and Bisanz (2009) reported EF impairments among children and adolescents aged 8 to 16 years on measures of flexibility, inhibition, verbal fluency, abstract thinking, deductive reasoning, and concept formation. Most notably, adolescents performed significantly worse (relative to the norm) than younger children on some verbal measures of EF (i.e., letter fluency, inhibition/switching). Similarly, Rasmussen and colleagues (2007) found that adolescents were rated as experiencing more significant EF deficits (relative to the norm) on parent-reported measures of EF compared to their younger counterparts. Finally, Tamana and colleagues (2014) reported that older adolescents with FASD (aged 13 to 17 years) performed worse (relative to the norm) than younger children with FASD (aged 9 to 12 years) on an EF task measuring sequencing and cognitive flexibility (i.e., Trails A and B tasks), with greater difficulty evidenced as task complexity increased. Together, these studies help elucidate the challenges in EF many of the individuals with FASD experience during adolescence and in part, may help to explain the deleterious outcomes later in life that are common among this population such as higher rates of mental health problems, school dropout, problems with the law, risk-taking and impulsive behaviours, and substance abuse given the relationship between EF skills and later functioning (e.g., Hanlon-Dearman et al., 2015; Hellemans et al., 2010; Streissguth et al., 2004).

Overall, the small but striking body of evidence leads researchers to conclude that that adolescents with FASD likely experience greater EF impairments (compared to the normative sample) than their younger peers. However, because most studies are cross-sectional in nature, true comparison of age groups is not possible, rendering conclusions about developmental trends in EF among youth with FASD hypothetical at best. Additionally, trajectories in EF development during the transition into adulthood has not been examined longitudinally. By using a longitudinal design, researchers can examine actual differences in skill acquisition across specific developmental stages. The adoption of a longitudinal design when examining EF among youth and young adults with FASD will provide a clearer understanding of these skills and increase our knowledge around the specific strengths and needs of individuals with FASD during this particularly challenging developmental period.

EF and Adaptive Functioning

Adaptive functioning is defined as "the performance of daily activities required for personal and social sufficiency" (Sparrow et al., 2005, p.6). An umbrella term, adaptive functioning includes the specific domains of social skills, practical skills, and conceptual skills (Tassé et al., 2012). Despite the role EF plays in healthy outcomes, strikingly little is known about its relationship with adaptive functioning, particularly for individuals with FASD. A small body of evidence has revealed a relationship between EF and adaptive functioning, in particular, social skills. Using behavioural reports, Schonfeld et al. (2006) found that ratings of children's social skills on the Social Skills Rating System (SSRS) were predicted by different EFs depending on informant. For children and adolescents with prenatal alcohol exposure (PAE), behavioural regulation challenges emerged as significant predictors of social skills by parents/caregivers, whereas challenges with metacognitive skills were predictive among teachers. Relatedly, the composite score on the Behaviour Rating Inventory of Executive Function (BRIEF), a questionnaire used to measure EF skills, was found to predict social problem solving among adolescents with PAE by McGee and colleagues (2008). More recently, Gardiner and colleagues (2021) extended these findings by examining EF at the subscale level on the BRIEF among children and adolescents with PAE. The authors found that challenges with shifting was associated with deficits across all areas of parent reported adaptive functioning.

A relationship between EF and adaptive skills has also been found in studies using performance-based measures of EF. Using non-verbal tasks of design fluency and trail making, Ware et al. (2012) found that deficits in these skills predicted poorer adaptive functioning among children and adolescence with PAE. Communication ability was predictive of inhibition and spatial working memory performance in a group of youth with heavy PAE (Doyle et al., 2018). Finally, using a developmental cohort design, Rockhold and colleagues (2021) measured the relationship between EF using measures of cognitive flexibility, inhibition, working memory and parent reported social functioning during preschool, early childhood, and adolescence. While no relationship was found during preschool, a significant relationship was observed at early childhood (mean age 8.45 years) that strengthened by adolescence.

The relationship between EF and adaptive behaviour extends to other neurodevelopmental populations such as attention-deficit/hyperactivity disorder (ADHD) and autism spectrum disorder (ASD). For example, EF challenges in childhood and middle school were found to be predictive of later behaviour problems and challenges in social and overall adaptive functioning among children with ADHD and ASD (Gardiner & Iarocci, 2018; Kenny et al., 2019; Miller & Hinshaw, 2010; Wahlstedt et al., 2008). Planning, cognitive flexibility, and inhibition deficits have also been linked to the presence of restricted and repetitive behaviours in ASD and challenges in managing everyday routines (Damasio & Maurer 1978; Ozonoff et al. 1991; Turner, 1997). In adults with ASD, EF skills (particularly cognitive flexibility) were found to be predictive prognostic markers for everyday adaptive skills (Berger et al. 2003; Pugliese et al., 2016).

To summarize, challenges with EF as measured by behavioural reports and performance-based tasks, appear to be important predictors of later adaptive functioning in both youth and adult populations with neurodevelopmental disorders. Understanding this relationship more clearly, particularly during the transition to adulthood, will provide much needed opportunities to mitigate these challenges and support critical independent functioning skills among individuals with FASD.

EF and Mental Health

The occurrence of mental health problems among individuals with FASD is well documented. Despite a lack of evidence, links between EF and mental health have been inferred for the FASD population largely through research with typically developing populations and other neurodevelopmental populations. In a large meta-analysis including 126 studies of individuals with ASD who engaged in antisocial behaviour (i.e., who were classified as having an externalizing disorder or antisocial personality disorder, exhibited physical aggression or violence, engaged in delinquency or criminality, or experienced psychopathy), a medium association was found between inhibitory control and working memory and externalizing behaviours (Ogilvie et al., 2011). Using a population-based cohort, inhibitory control, attention, and EF were found to be negatively associated with externalizing behaviours in a group of 1,177 6-year-olds (Blanken et al., 2017). Using a longitudinal design, Brophy and colleagues (2002) found an association between "hard to manage" preschoolers and inhibitory control (but not working memory) at age 4 and follow-up at age 7. With regard to internalizing behaviours such as anxiety and depression, an interaction was found between inhibitory control and behavioural inhibition in predicting anxiety in typically developing pre-schoolers (White et al., 2011), while clinical studies with adolescents and adults often find a negative association between EF and internalizing disorders including depression and rumination (Hilt et al., 2014; Boldrini et al., 2005; Matthews et al., 2008).

For those with ASD, mental health is often impacted with prevalence rates up to 84% for anxiety (White et al., 2009) and 38% for depression (Magnuson & Constantino, 2011). Lawson et al. (2015) demonstrated that the relationship between ASD and anxiety and depression was fully mediated by scores on a parent/caregiver report of EF skills, namely cognitive flexibility, among a group of children and adolescents. In adults with ASD, Wallace et al. (2016) found that cognitive flexibility also predicted anxiety while planning and organizing predicted depression. Performance-based measures have also been found to predict anxiety in this population including cognitive flexibility, inhibition, and attentional switching (Hollocks et al, 2014). Finally, Gardiner and Iarocci (2018) investigated the relationship between parent/caregiver-reported EF skills and mental health among a group of middle-aged children (mean age 10 years) with ASD and a matched control group (mean age 9.4 years). They found that behaviour regulation only was significantly associated with depressive symptoms for both groups.

Although the research appears to show that poorer EF skills are associated with poorer well-being, this interpretation cannot be made for certain because the nature and direction of this relationship is still not clear (O'Rourke et al., 2020). Moreover, we lack information regarding the association between these factors for individuals with FASD. To my knowledge, there are no studies that investigate the longitudinal relationship between EF and mental health among this population. Examining the FASD population and focusing on the transition between childhood and adolescence is important as this period encompasses vital developmental periods including identity exploration, unstable and transitionary relationships, increasing autonomy and responsibility, and the development of independence skills necessary for successful functioning as an adult (Arnett, 2000; Arnett, 2014). Navigating these domains is even more crucial when doing so with a neurodiversity.

Purpose and Research Questions

This research provides previously unexamined information about the development of EF among individuals with FASD, most noteworthy due to the design employed. It is twice novel in method as it uses a longitudinal design and examines EF development during a novel developmental period. The methodology used in the present study is vital to our understanding of EF development as it allows for direct comparison of the same individuals at different points in their development, thus direct conclusions can be made about trends in how EF develops. Our understanding of this area has largely been derived from previous literature that adopted cohort designs. This is insufficient at best, as conclusions consist of hypothetical inferences gleaned from examining different age groups rather than direct examination of the same individuals throughout their development. The current study also targets the transition between adolescence and young adulthood, a distinct and critical transition period that has not been previously investigated. In addition to novel methodology in the field, this study investigates the association between EF skill development and later adaptive functioning and mental health among individuals with FASD; this longitudinal association has not been previously examined despite the critical nature of this transition period. To fill these gaps, two research questions were addressed:

1. How does EF develop from adolescence into later young adulthood among individuals with FASD?

I hypothesized that EF development would change over this period. Specifically, that EF skills during adolescence would reflect significant impairment (relative to the normative population), in keeping with research findings suggesting significant EF impairments among this population (Mattson et al., 1999, 2010; Rasmussen et al., 2007; Rasmussen & Bisanz, 2009; Rasmussen et al., 2013). In addition, I hypothesized that these impairments would become more pronounced over time relative to the normative sample in keeping with cross-sectional research findings that suggest EF difficulty becomes more pronounced with age (relative to the normative sample) (Rasmussen & Bisanz, 2009).

2. Are EF skills during adolescence associated with mental health and adaptive functioning during young adulthood?

Based on previous findings, I hypothesized that EF development during adolescence would be positively associated with adaptive functioning outcomes during young adulthood (i.e., poor EF skills in adolescence would be associated with poor adaptive functioning skills in young adulthood), in keeping with research that has identified the relationship between EF skills and adaptive functioning (Doyle et al., 2018; Gardiner et al., 2021; McGee et al., 2008; Rockhold et al., 2021; Schonfeld et al., 2006; Ware et al., 2012). No *a priori* hypothesis was made regarding the relationship between EF and mental health as this has not yet been examined in the FASD population to my knowledge.

Method

Procedure

This research used a longitudinal cohort panel design that took place within a larger study examining longitudinal assessment of individuals with FASD. The Research Ethics Board at the University of Alberta and Alberta Health Services (AHS) approved this study. Informed consent and assent were gathered from all participants and caregivers.

This study took place at the Glenrose Rehabilitation Hospital in Edmonton, AB. Participants with FASD and their caregivers were recruited through the Glenrose Rehabilitation Hospital's FASD Clinic and participated in two testing sessions: Time 1 (i.e., the previous stage of the study) and Time 2 (i.e., the current stage of the study). Testing sessions took place approximately 5 years apart. Recruitment for Time 2 testing occurred via telephone; participants who volunteered for the first phase of the study (Time 1) were asked if they were interested in returning to the hospital for a follow-up assessment (Time 2).

Participants

Participants were 16 youth recruited from a purposive sample of 67 participants who participated in the initial phase of the research project. All participants were recruited from the Glenrose Rehabilitation Hospital's FASD Clinic and had a previously confirmed medical diagnosis of an alcohol-related disorder falling under the umbrella term FASD according to the 2005 Canadian FASD Diagnostic Guidelines (Chudley et al., 2005). Of the original 67 participants, only data from the 16 individuals who participated in both time points was used. Of the original 67 participants who were contacted at Time 2, 30% (*n* = 20) were not interested in participating, 46% (*n* = 31) could not be reached due to incorrect phone numbers or having moved, and 24% (*n* = 16; 7 female and 9 male) agreed to participate. The mean age of the 16 participants at Time 1 was 13.3 years (*SD* = 2.88; Range 6.9 – 17.2 years); the mean age of the

16 participants at Time 2 was 19.4 years (*SD* = 3.2). Time 1 assessment IQ scores were not available. Time 2 assessment IQ scores were available for all participants (see Table 3.1).

At Time 2, the majority of participants were residing with either an adoptive parent (*n* = 9) or foster parent (*n* = 5). The remaining participants were residing with a legal guardian or other adult (*n* = 2). In terms of placements to date, the majority of participants had lived in at least two different placements during their lifetime (*n* = 12), with one participant living in three, and three participants living in five or more different households. The majority of participants had at least one mental health disorder: 75% (*n* = 12) were diagnosed with ADHD, 43.8% (*n* = 7) were diagnosed with an anxiety disorder, and 43.8% (*n* = 7) were diagnosed with a Mood Disorder.

Table 3.1

Demographic Characteristics of Participants at Time 2

	n(%)	*M(SD)*	*Range*
Gender			
Female	7(43.8)		
Male	9(56.2)		
Age		19.4(3.2)	12-23
IQ			
Full Scale		88.44(9.2)	70-102
Verbal		85(10.68)	69-103
Visual		95.19(11.31)	76-117
No. of Placements			
0-2	12(75)		
3	1(6.3)		
5+	3(18.7)		
Mental Health Diagnosis			
ADHD	12(75)		
Anxiety	7(43.8)		
Depression	7(43.8)		

Measures

Assessment batteries were matched across time points, with some additional measures added at Time 2. Standardized forms were matched for age across time points (e.g., *BASC-2 Child Form* during Time 1, *Adolescent Form* during Time 2). For participants who aged-out of EF measures between time points, similar tools were administered using an age-appropriate measure (e.g., NEPSY at Time 1 and D-KEFS at Time 2). For the present study, intelligence, EF, mental health, and adaptive functioning measures were used. After their Time 2 assessment, an assessment report was written, and participants were invited back for a results meeting. During this meeting, the assessment results were discussed in detail and individualized recommendations were developed.

Demographic Questionnaire

Caregivers completed a demographic questionnaire developed by our research team. The questionnaire included standard demographic questions including sex, age, handedness, income, etc. In addition, it included select questions from Streissguth's *Life History Interview* (Streissguth et al., 2004), the Adverse Childhood Experiences Questionnaire (Dube et al., 2001), and the Hollingshead Four Factor Index of Socioeconomic Status (Hollingshead, 1975) to gather more in-depth information about background history, adverse life experiences, living situation, educational experiences, etc. Caregivers were instructed to answer only those questions which they felt comfortable answering.

Wide Range Intelligence Test (WRIT)

The WRIT is a brief measure of verbal and nonverbal cognitive ability for individuals ages 4 to 85 (Glutting et al., 2000) and was administered at Time 2 only. The WRIT is made up of two subtests that comprise a verbal (crystalized) IQ score including vocabulary and verbal analogies; and two that comprise a visual (fluid) IQ score including visual matrices and diamonds. The verbal and visual IQ scores together comprise an overall general intelligence score. The WRIT has high internal consistency reliability (.84-.90), test-retest reliability (>.90), and inter-rater reliability (.98-.99) for the three main scales. The WRIT additionally has acceptable construct, concurrent, and predicative validity as evidenced by high correlations with the Wechsler Intelligence Scale for Children (WISC-III, .90), Wechsler Abbreviated Scale of Intelligence (.79-.86), and moderate to high correlations with the Wide Range Achievement Test (WRAT, .36-.64; Canivez et al., 2009; Glutting et al., 2000).

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

The BASC-2 is a questionnaire that measures both adaptive, emotional, and behaviour problems in the community and home settings. It is commonly used as an indicator of mental health functioning. Only the Parent Rating Scale (PRS) for adolescents ages 12 to 21 and College Students was used during Time 2 (Reynolds & Kamphaus, 2004). Clinical scales included on these questionnaires assess: aggression, anxiety, attention problems, atypicality, conduct problems, depression, hyperactivity, learning problems, somatization, and withdrawal. Adaptive scales included on these questionnaires assess: activities of daily living, adaptability, functional communication, leadership, social skills, and study skills. Composite scales included Externalizing Problems, Internalizing Problems, Behavioural Symptoms Index, and Adaptive Skills. Norm-referenced scores (American sample) are included yielding *T*-scores ($M = 50$, $SD = 10$) and percentiles. The BASC-2 has strong test-retest reliability within one month and high internal validity of .80 with children and .90 with adolescents (Reynolds & Kamphaus, 2004).

Adaptive Behaviour Assessment System, Second Edition (ABAS-II)

The ABAS-II is a norm-referenced (American sample) assessment of adaptive skills for individuals ages birth to 89 years (Harrison & Oakland, 2003). Only the parent/caregiver form was completed. Skill areas assessed include communication, community use, functional academics, school/home living, health and safety, leisure, self-care, self-direction, social, and motor. Norm-referenced scores for skill areas are included yielding scaled scores (*M* = 10, *SD* = 3). Skill areas are combined to provide three broad composite domains of functioning, including Conceptual, Social, and Practical, in addition to an overall General Adaptive Composite (GAC). Norm-referenced scores for composite areas include standard scores (*M* = 100, *SD* = 15). Internal consistency reliability was estimated using coefficient alpha and suggests a high degree of internal consistency for all skill areas (.80-.97), domains (.91-.98), and GAC (.97-.99) scores. Test-retest reliability estimated using Pearson's product-moment correlation coefficient suggest moderate to high reliability for all skill areas (.80s and .90s), domains (upper .80s and .90s), and GAC (.90s). Vigorous validity studies were conducted with both clinical and non-clinical samples and suggest high levels of sensitivity in differentiating between these populations as well as individual levels of disability.

NEPSY-II

The NEPSY-II is a norm-referenced (American sample) assessment of functioning across six domains including executive functioning and attention, memory and learning, sensorimotor functioning, social perception, language, and visuospatial processing for individuals ages 3 to 16 (Korkman et al., 2007). Performance is reported in scaled scores (*M* = 10, *SD* = 3). For the current study, subtests that measure executive functioning and attention were administered including Inhibition and Animal Sorting. The Inhibition subtest is comprised of three parts including Naming, Inhibition, and Switching; only the Inhibition and Switching tasks were used. The Animal Sorting subtest is comprised of a single activity. The NEPSY-II has adequate-to-high reliability (including internal consistency and test-retest reliability), validity, and interscorer agreement (Korkman et al., 2007).

Delis-Kaplan Executive System (D-KEFS)

The D-KEFS is a norm-referenced (American sample) assessment of multiple executive function skills including problem solving, cognitive flexibility, planning, inhibition, and concept formation among individuals aged 8 to 89 (Delis et al., 2001). Performance is reported in scaled scores for all subtests (*M* = 10, *SD* = 3). During the Time 2 assessment, the Color-Word Interference and Sorting subtests were used. The Color-Word Interference subtest is comprised of four parts, Colour Naming, Word Reading, Inhibition, and Inhibition/Switching; only the Inhibition and Inhibition/Switching tasks were used. The sorting subtest is comprised of two parts, Free Sorting and Sort Recognition; only the Free Sorting task was used. The D-KEFS Sorting subtest was found to have moderate to high reliability, with slightly lower reliability for younger individuals (.59-.86) and moderate test-retest reliability for most age groups (.49-.73). The Colour-Word Interference subtest was found to have moderate to high reliability across all age groups (.72-.86) and moderate to high test-retest reliability for most age groups (.49-.90; Delis et al., 2001).

Behaviour Rating Inventory of Executive Function (BRIEF)

The BRIEF is an 86-item questionnaire designed to assess executive function behaviours in the home and school environment among individuals ages 5 to 18 years (Gioia et al., 2000). Only the BRIEF Parent Form was administered. Eight theoretically and empirically derived clinical scales that measure different aspects of EF are included: inhibit, shift, emotional control, initiate, working memory, plan/organize, organization of materials, and monitor. These clinical scales form two broad indexes, Behavioural Regulation (BRI) and Metacognition (MI), and an overall Global Executive Composite (GEC) score. Norm-referenced (American sample) scores for both clinical scales and indexes include *T*-scores (*M* = 50, *SD* = 10). Higher scores indicate increased difficulty in EF skill. Internal consistency on the BRIEF Parent was estimated using Cronbach’s alpha and suggests a high degree of internal consistency (.80-.98). Test-retest reliability for the indexes were examined in both clinical and non-clinical samples of the Parent Form with mean correlations suggesting high test-retest reliability for both populations (clinical sample: .72-.84; non-clinical sample: .76-.85). The BRIEF was developed having strong content validity through consultation with parents, teachers, and several pediatric neuropsychologists; the majority of items retained for each scale have high interrater agreement. Construct validity for the BRIEF is additionally high as indicated through the multitrait-multimethod matrix (Campbell & Fiske, 1959) that examined convergent and discriminant validity of the BRIEF with other related versus unrelated measures (e.g., Child Behaviour Checklist, Achenback, 1991; Behaviour Assessment System for Children, Reynolds & Kamphaus, 1992; Conners' Rating Scale, Conners, 1989).

Data Scoring and Analyses

Standard scores were derived for subtests on the BRIEF, NEPSY-II, D-KEFS, ABAS-II, and BASC-2 (See Table 3.2). Executive functioning was explored by examining behavioural report results (i.e., BRIEF) and performance-based results (i.e., NEPSY-II/D-KEFS) separately. BRIEF index scores (MI, BRI, and GEC) were examined for matching participants across both time points (*n* = 10). The performance-based EF scores that were evaluated varied between timepoints. At Time 1, all scores were NEPSY-II subtests. Specifically, inhibition was measured using the Inhibition-Inhibition scaled score, switching was measured using the Inhibition-Switching scaled score, and flexible thinking was measured using the Animal Sort scaled score. At Time 2, for participants who were again administered the NEPSY-II, the same matching subtests were used. For participants who were administered the D-KEFS at Time 2 due to advanced age, similar D-KEFS subtests capturing the same skills were used, each pair with moderate correlations as indicated in the NEPSY-II manual (Korkman et al., 2007). The matched pairs included the NEPSY-II Inhibition-Inhibition with the D-KEFS Colour-Word Inhibition (*r* =

.43) and NEPSY-II Inhibition-Switching with the D-KEFS Colour-Word Switching (r = .57). The NEPSY-II Animal Sorting was matched with the D-KEFS Sorting subtest based on aligning theory and similar task design; no formal statistical evidence of correlation was available from the test manual or other scientific literature to the team's knowledge.

Data was analyzed in multiple ways to address the research questions. Independent samples *t*-tests were conducted to compare individual performance to the normative mean on all measures (i.e., BRIEF, NEPSY-II, NEPSY-II/D-KEFS, ABAS-II, BASC-2) at both time points. To gain an understanding of the developmental trajectory of EF, paired samples *t*-tests were used to examine mean change in performance from Time 1 to Time 2. To examine change over time that may not be sensitive to group means, individual-level change in performance on all EF measures was calculated. Change was categorized into three groups based on standard scores: those who decreased in performance, remained stable, and increased in performance. A change in performance was considered clinically significant if scores changed more than or less than 1 SD (higher BRIEF scores indicate increased impairment; higher NEPSY/D-KEFS scores indicate increased skill and vice versa). This analysis allowed for nuanced examination of individual-level trajectories and provided important clinically relevant information for future interventions. Finally, Pearson Correlations and linear regression analyses were conducted to determine the association between variables and whether EF skills at Time 1 predicted mental health and adaptive functioning at time two. Holm - Bonferroni corrections were used during regression analyses to control for familywise error (Holm, 1979).

Results

Adaptive Functioning

Performance data is included in Table 3.2. Mean domain standard scores at Time 1 were in the borderline range for GAC (*M* = 70.08), Social Skills (*M* = 70.46), and Practical Skills (*M* = 70.46); Conceptual Skills were in the extremely low range (*M* = 69.92). At Time 2, all domain standard scores were in the borderline range: GAC (*M* = 72.92), Social Skills (*M* = 72.92), Conceptual Skills (*M* = 72.92), Practical Skills (*M* = 74.23).

Mental Health

Performance data is included in Table 3.2. Mean composite standard scores (Internalizing Problems, Externalizing Problems, Behavioural Symptoms) at Time 1 were all in the at-risk range: Internalizing Problems (*M* = 63.54), Externalizing Problems (*M* = 64.69), Behavioural Symptoms (*M* = 69.15). At Time 2, Internalizing (*M* = 65.54) and Externalizing Problems (*M* = 67.23) scores remained in the at-risk range while Behavioral Symptoms were in the clinically significant range (*M* = 72.23).

Development of Executive Function

BRIEF

Table 3.2 shows mean performance scores at both time points on the BRIEF and change in EF development across time points. All mean index scores at Time 1 were clinically elevated ($T \geq 65$). Higher scores denote increased impairment on this measure. Scores remained high and in the clinically significant range again at Time 2, suggesting parental reports of chronic and continued difficulty with EF skills into young adulthood.

Related to EF development across time points, no differences in Behavioural Regulation (BRI) scores were observed between Time 1 or Time 2 suggesting stable but continued impairment in behaviour regulation ($p = 0.507$). Conversely, Metacognitive (MI) performance was significantly more impaired (i.e., scores increased) at Time 2 compared to Time 1 (relative to the normative population) (*p* = 0.011). Overall EF skills (GEC) were also significantly more impaired (i.e., scores increased) at Time 2 compared to Time 1 (relative to the normative population) (*p* = 0.033).

Individual-level change between time points was also calculated. Table 3.3 shows the number of participants within each index whose performance decreased, increased, or remained stable. In total, 27% of participants showed a significant decrease in performance in at least one skill domain highlighting the variability in EF development among individuals with FASD. Although overall mean change on the BRI was not significant, 20% of participants (*n* = 2) experienced a significant decrease in performance and 1 participant experienced a significant increase in performance. On the MI, 40% of participants (*n* = 4) experienced a significant decrease in performance while 20% of participants (*n* = 2) experienced a significant decrease in the GEC.

NEPSY-II/D-KEFS

Table 3.2 shows mean performance data for all NEPSY-II/D-KEFS scores. The Inhibition and Sorting mean subtest scaled scores at Time 1 were significantly below the normative mean of 10 and at or below the clinical cutoff of 7. The Switching subtest at Time 1 was within normal limits. At Time 2, participants continued to score below the normative mean and clinical cutoff on the Sorting task and mean performance on the Switching task was again in the average range. The Inhibition mean score was also in the clinically average range indicating a clinical change, but this was not significant (explained in detail below).

Next, Table 3.2 shows EF development between Time 1 and Time 2. No significant mean changes (*p* > .05) were observed across any of the variables including Inhibition (*p* = .194), Switching (*p* = .753), or Sorting (*p* = .806). This suggests that these performance-based measures of EF skills remain stable at the mean level during this developmental period.

Table 3.3 shows individual-level changes on the Inhibition, Switching, and Sorting tasks. Again, standard score changes of more than or less than one standard deviation were considered to indicate clinical utility. Although overall mean change scores across all three variables remained stable, 45% of participants experienced a significant change in their performance. On the Inhibition, task 14% (*n* = 2) declined in performance while 50% (*n* = 7) improved. On the Switching task, 17% (*n* = 2) declined while 25% (*n* = 3) improved. Finally, on the Sorting task, 14% (*n* = 2) declined while the same number improved.

Table 3.2

Performance of Children with FASD on the BRIEF, NEPSY-II, D-KEFS, ABAS-II, and BASC-2

	Compared to Normative Mean				*Change Between Time 1 and Time*
Index	*M (SD)*		*p*		*p*
	Time 1	Time 2	Time 1	Time 2	
BRIEF					
BRI	73.70 (12.82)	75.60 (15.67)	$.000^{**}$	$.000^{**}$	.507
MI	67.50 (6.20)	74.20 (7.38)	$.000^{**}$	$.000^{**}$	$.011^{*}$
GEC	71.40 (7.96)	76.70 (8.37)	$.000^{**}$	$.000^{**}$	$.033^{*}$
NEPSY-II/ D-KEFS					
Inhibition	6.86 (4.24)	8.42 (3.06)	$.016^{*}$	.077	.194
Switching	8.08 (3.65)	8.42 (3.63)	.097	.159	.753
Sort	7.07 (2.76)	6.80 (2.91)	$.001^{**}$	.001	.806
ABAS-II					
GAC	70.08 (10.21)	72.92 (15.71)	$.000^{**}$	$.000^{**}$	.508
Social	70.46 (10.42)	72.92 (15.71)	$.000^{**}$	$.000^{**}$	.489
Concep.	69.92 (10.18)	72.92 (15.71)	$.000^{**}$	$.000^{**}$	.562
Practical	70.46 (15.25)	74.23 (16.71)	$.000^{**}$	$.000^{**}$	.477
BASC-2					
Internal.	63.54 (13.76)	65.54 (15.68)	$.004^{**}$	$.004^{**}$	.611
External.	64.69 (17.28)	67.23 (19.43)	$.010^{*}$	$.008^{**}$	.537
Beh. Symptoms	69.15 (13.21)	72.23 (18.34)	$.000^{**}$	$.001^{**}$	.516

Note. NEPSY-II/D-KEFS scores for Time 1 include NEPSY scores only (Inhibition-Inhibiting task, Inhibition-Switching task, and Animal Sort task). NEPSY-II/D-KEFS scores for Time 2 include combined NEPSY-II tasks and D-KEFS tasks (Colour-Word Inhibition, Colour-Word Switching, and Sorting), as required due to participant age.

$^{*}p < .05$, $^{**}p < .01$.

Table 3.3

Individual-Level Change in EF Scores Between Time Points

	Number of Participants (%)		
	Declined	Stable	Improved
BRIEF			
BRI	2(20)	7(70)	1(10)
MI	4(40)	6(60)	0(0)
GEC	2(20)	8(80)	0(0)
NEPSY-II/D-KEFS			
Inhibition	2(14.3)	5(35.7)	7(50)
Switching	2(16.7)	7(58.3)	3(25)
Sorting	2(14.3)	10(71.4)	2(14.3)

Note. BRI = Behavioural Regulation Index; MI = Metacognition Index; GEC = General Executive Composite

* Decline: BRIEF scores increased more than 1 SD; NEPSY/D-KEFS scores decreased more than 1 SD; Stable: BRIEF and NEPSY/D-KEFS scores remained within 1 SD; Improved: BRIEF scores decreased more than 1 SD; NEPSY/D-KEFS scores increased more than 1 SD

EF and the Association with Mental Health and Adaptive Functioning

The association between EF at Time 1 and Mental Health at Time 2 and EF at Time 1 and Adaptive Functioning at Time 2 was examined next by conducting Pearson Correlations (see Tables 3.4 and 3.5). With regard to EF and mental health, Switching at Time one was largely and negatively correlated with Behavioural Symptoms at Time 2 ($p < .05$), suggesting that as switching skills increase, behavioural symptoms decrease. There were multiple significant correlations found between EF and Adaptive Functioning. There was a statistically significant, large positive correlation between Switching skills and Practical Skills ($p < .05$). This suggests as Switching skills get stronger, Practical skills get stronger. On the BRIEF, the BRI was largely and negatively correlated with Social Skills, Practical Skills, and the GAC (*ps* < .05), suggesting that as behavioural regulation gets worse, adaptive skills decrease. The BRIEF MI was also largely and negatively correlated with Social Skills ($p < .05$), again suggesting that as metacognitive skills get worse, social skills also decrease. Finally, the GEC was largely and negatively correlated with Social Skills, Practical Skills, and GAC (*ps* < .05) again following the same pattern as overall EF skills get worse, adaptive skills also decrease.

Next, simple linear regressions (see Table 3.6 and Table 3.7) were conducted to examine the contribution EF skills play in later adaptive functioning and mental health. To limit the number of regression models and to address multicollinearity, only the NEPSY-II switching score at Time 1 and the BRIEF BRI score at Time 1 were used as independent variables in subsequent analysis as they were most strongly correlated with other dependent measures. Due to the small sample size, separate regression analyses were executed for each EF independent variable and adjusted R^2 was used to explain the variance. To address familywise error, Holm – Bonferonni post hoc tests were calculated to adjust alpha levels (Holm, 1979). Using adjusted *p* values, the BRIEF BRI score at Time 1 was a significant predictor of overall adaptive skills (GAC), Practical Skills, and Social Skills at Time 2. The NEPSY Switching skills at Time 1 were a significant predictor of Practical Skills at Time 2. No other significant relationships were found.

Table 3.4

Correlation between NEPSY-II and BRIEF Subtest Scores at Time 1 and ABAS-II Composite Scores at Time 2 (N = 13-16)

	ABAS-II (Time 2)			
EF Time 1	Conceptual	Social	Practical	GAC
NEPSY-II				
Inhibition	.09	-.05	.13	.13
Switching	.55	.22	$.62^{*}$	.55
Sorting	.13	-.05	-.03	.07
BRIEF				
BRI	-.48	$-.60^{*}$	$-.65^{*}$	$-.67^{*}$
MI	-.40	$-.56^{*}$	-.33	-.46

GEC	-.54	$-.69^{**}$	$-.58^{*}$	$-.69^{**}$

Note. BRI = Behaviour Regulation Index; MI; Metacognition Index; GEC = General Executive Composite

$^{*}p < .05$, $^{**}p < .01$.

Table 3.5

Correlation Between NEPSY-II and BRIEF Subtest Scores at Time 1 and BASC-2 Index Scores at Time 2 (N = 12-16)

		BASC-2 (Time 2)	
EF Time 1	Externalizing	Internalizing	Behaviour
NEPSY-II			
Inhibition	.20	.25	.14
Switching	-.43	-.35	$-.59^{*}$
Sorting	.32	-.23	.02
BRIEF			
BRI	.28	.27	.39
MI	.06	.07	.05
GEC	.18	.18	.26

Note. BRI = Behaviour Regulation Index; MI; Metacognition Index; GEC = General Executive Composite

$^{*}p < .05$, $^{**}p < .01$.

Table 3.6

Regression Analyses Between NEPSY-II Switching and Mental Health & Adaptive Functioning

Outcome Measure	*β*	*t*	*p*	*Adjusted* R^2	*Adjusted* *p*
BASC-2 Internalizing	-.345	-1.164	.272	.031	-
BASC-2 Externalizing	-.431	-1.510	.162	.104	-
BASC-2 Behvioural Symptoms	-.594	-2.336	.042	.288	-
ABAS-II GAC	.553	2.099	.062	.236	
ABAS-II Practical	.618	2.487	.032	.320	$.025^{*}$
ABAS-II Social	.220	.715	.491	-.047	-
ABAS-II Conceptual	.552	2.091	.063	.235	-

* = significant using adjusted *p* value

Table 3.7

Regression Analyses Between BRIEF-BRI and Mental Health & Adaptive Functioning

Outcome Measure	β	t	p	*Adjusted* R^2	*Adjusted* p
BASC-2 Internalizing	.265	.910	.382	-.015	-
BASC-2 Externalizing	.281	.973	.352	-.004	-
BASC-2 Behvioural Symptoms	.385	1.384	.194	.071	-
ABAS-II GAC	-.677	-3.051	.011	.409	$.017^*$
ABAS-II Practical	-.646	-2.809	.017	.365	$.025^*$
ABAS-II Social	-.598	-2.475	.031	.299	$.05^*$
ABAS-II Conceptual	-.485	-1.837	.093	.165	-

* = significant using adjusted *p* value

Discussion

The aim of this study was to examine EF performance among individuals with FASD including the development of EF from adolescence into young adulthood. I also investigated whether there was a relationship between early EF skills and later adaptive functioning and mental health. First, EF performance was measured on both a parent/caregiver reports and on performance-based measures of EF. Next, I examined the developmental trajectory of EF from adolescence to young adulthood at the mean and individual levels. Finally, I examined relationships between EF and adaptive functioning and mental health and determined whether early EF skills predicted later healthy functioning in the aforementioned domains.

Profile of EF Performance

I hypothesized that participants would experience significant challenges in all areas of EF and that these challenges would become more pronounced over time compared to the normative mean. My results partially support this hypothesize. Parent/caregiver behavioural reports of EF on the BRIEF suggested significant impairment of all areas of EF including Behavioural Regulation (BRI), Metacognitive skills (MI) and overall EF skills (GEC); all mean scores were well above the clinical cutoff (higher scores indicate increased challenges) in the clinically significant range at both time points. This pattern of challenges is in line with previous research indicating that youth with FASD tend to show impairment relative to the normative mean on behavioral rating scales of EF (Rasmussen et al., 2007).

On performance-based measures of EF, mean deficits on the Sorting task were observed at both time points. These results are in line with Mattson and colleagues (1999, 2010) and Rasmussen (2013) who found similar skill deficits among this population. Although mean deficits were also identified on the Inhibition task at Time 1, a change over time was measured. Specifically, performance improved (relative to the mean) and scores were within the average range at Time 2. It is possible that unlike typically developing children who experience the greatest improvements in inhibition during early to middle childhood (Romaine & Reynolds, 2005), individuals with FASD experience a delay in inhibition but catch up by young adulthood. Further investigation into the developmental trajectory of inhibition among individuals with FASD is needed.

In addition to typical performance in Inhibition at Time 2, normative average performance was observed on the Switching task at both time points, highlighting an important area of relative strength among this population that should not be overlooked. These results add to the small body of literature that has reported areas of relative strength among individuals with FASD. For instance, researchers observed typical performance on tasks measuring simple speed (Trails A) among children approximately 11 years old (Gautam et al., 2014; Rasmussen & Bisanz, 2009; Vaurio et al., 2008). Normative average scores were also found by Ware et al. (2012) on the colour-word interference-inhibition/switching task in a group of slightly older youth (mean age 12.10 years) with histories of heavy PAE. The current results extend these findings and suggest that older youth with FASD may possess a relative strength in some performance-based measures of cognitive flexibility. For individuals with FASD, providing well structured, supportive environments where they clearly understand tasks and expectations, may allow them to better leverage these strengths and apply them successfully in an effort to reach their goals.

The current results also shed light on differences observed between performance-based measures of EF and behavioural reports of EF. The aforementioned areas of average performance are in seeming contrast to the parent/caregiver reports of chronic, and in some respects worsening, EF challenges. It is possible that these isolated areas of relative strength are lost in the multitude of challenges that are present when faced with competing real-life demands. Although switching and inhibition are currently understood to be two of the foundational domains of EF and measured as such during clinical assessment, there is evidence that their behavioural presentation differs among this population. For example, Gross et al., (2014) found that children with FASD tend to show greater impairment on behavioural rating scales of EF than on performance measured ratings of EF in middle childhood. This is certainly the case in the current findings as the aforementioned areas of preserved EF were not evident in behavioural functioning results. This discrepancy may be connected to the differences in “hot” and “cool” EF as they relate to behaviour and issues with ecological validity, or the extent to which performance-based results reflect real world behaviour (Zelazo & Muller, 2002). Because testing environments are often quiet and calm with few competing demands, they largely tap into “cool” EF skills (cognition-based skills where rewards or punishments are not often tied to the task; Kodituwakku et al., 2001). Behavioural reports such as the BRIEF, however, better capture ecological validity through the ratings of behaviours that are manifested in real-world situations and unpredictable environments (Gioia & Isquith, 2004; Anderson et al., 2002). Specifically, respondents are asked to rate the ability to regulate emotions, motivation, and actions that are based on rewards and punishment, all “hot” EF skills. It will be important for clinicians to understand the interactive nature of EFs and of the issues present in measuring performance-based and behavioural reports that may contribute to intraindividual variability or scattered functioning often reported for this population. In summary, while aspects of cognitive flexibility and switching appear to be relative strengths for youth and young adults with FASD, providing the appropriate environment to allow access to these skills is vital.

Development of EF

When examining the developmental trajectory of EF skills, I hypothesized that EF skill difficulties among this group of youth would increase in severity (compared to the norm) in keeping with previous cross-sectional research comparing cohorts (Rasmussen & Bisanz, 2009). Again, my hypothesis was partially supported. When examining mean change on behavioural reports of EF, Metacognitive skills (MI) and thus overall EF skills (GEC) increased significantly in impairment from Time 1 to Time 2, suggesting more pronounced difficulty in these skills over time relative to the norm. The MI includes the subscales of initiate, working memory, planning and organizing, organization of materials, and monitor (Gioia et al., 2000). Skills captured within these subscales include the ability to get started on tasks independently, monitor oneself while working, set goals and anticipate future events, organize key concepts in learning, keep work, play, and storage places organized, and have a sense of interpersonal awareness (Gioia et al., 2000). Increased challenges in metacognition (compared to the norm) into later adolescence likely reflect many factors, one of which is the growing amount of responsibility and higher expectations placed on independence that accompanies this developmental period (Billari & Liefbroer 2010). The skills captured by the MI are integral to succeeding in advancing academic environments and are often required in employment settings where individuals are expected to work independently with minimal supervision. It is possible that weak MI skills during this period contribute to the challenges that individuals with FASD experience at home, work, and school and lead to a discrepancy between expectations placed on them and their actual skill level and level of independence. Contrary to my hypothesis, multiple EF skills remained stable at the mean level across time points with no discernable decline in performance at Time 2. On the BRIEF, behavioural regulation remained stable, as did all performance-based skills (i.e., Switching, Inhibition, Sorting).

When individual-level performance was examined, however, substantial variability was observed in both directions (i.e., improvement and decline), particularly on performance-based tasks, highlighting the heterogeneity of developmental trajectories among this population. Differences in an individual's performance is referred to as intraindividual variability (IIV), the systematic within-person variability observed across test sessions on the same measure (e.g., test/retest performance) or in a single session (e.g., differences in performance on multiple trials of the same task). Increased levels of IIV have been found among children with FASD compared to typical controls (Ali et al, 2018; Astley et al., 2009). In the current study, improvements and declines in performance well beyond one standard deviation were observed in 45% of the sample on at least one performance-based task. The Inhibition task was particularly susceptible to IIV, in line with Ali et al. (2018), with 64% (*n* = 9) of participants experiencing substantial changes (seven participants improved in performance and two participants declined). On the Switching task, 42% changed more or less than one standard deviation (three youth improved their performance and two decreased). Finally, on the Sorting task, 28% evidenced significant changes (two youth increased their performance and two youth decreased). Individual change was also observed on behavioural reports with 30% of participants being rated significantly differently in either direction. Specifically, 30% of participants were rated significantly differently on the BRI over time (two youth were rated as experiencing more difficulty while one was rated as improving) while 40% (*n* = 4) were rated as experiencing significant decline over time on the MI and 20% (*n* = 2) improved. Finally, 20% (*n* = 2) were rated as experiencing more challenges over time on the GEC. These findings clearly highlight the complexities when interpreting aggregate data, particularly on performance-based measures of EF skills, and portraying the illusion of stability in skill development in this area among youth with FASD. It appears that parent/caregiver reports of EF may be more consistent over time, possibly because real-world behaviours are more readily observed on a daily basis.

EF, Adaptive Functioning, and Mental Health

When examining the relationship that early EF skills have with later adaptive functioning, I hypothesized that early EF would be associated with all areas of adaptive functioning (Doyle et al., 2018; Gardiner et al., 2021; McGee et al., 2008; Rockhold et al., 2021; Schonfeld et al., 2006; Ware et al., 2012). In line with my prediction, multiple areas of early EF skills were strongly associated with later adaptive skills. Difficulty with regulation of behaviour as defined by the BRIEF BRI (e.g., ability to behave in an appropriate and flexible way in a situation and to regulate one’s emotions by being able to inhibit more automatic or competing responses) and overall EF ability (i.e., BRIEF GEC) were strongly associated with later challenges in Social Skills, Practical Skills, and overall adaptive skills (GAC) as reported by caregivers on the ABAS-II. Additionally, metacognitive challenges as defined by the BRIEF MI (e.g., one’s ability to cognitive self-manage tasks and monitor their performance and their ability to problem solve in multiple contexts) was strongly associated with later Social Skills as reported by caregivers on the ABAS-II. Related to performance-based measures of EF, early cognitive flexibility (i.e., Switching) was strongly associated with later Practical Skills, as reported by caregivers on the ABAS-II. These results underscore the pervasive relationships that early EF challenges have with later healthy functioning, specifically social and practical skills.

Extending this line of inquiry to examine the predictive nature of early EF skills and later adaptive functioning, the BRIEF BRI during early adolescence was a significant predictor of later Social Skills, Practical Skills, and overall adaptive skills (GAC). Moving beyond an association, this finding suggests that youth who display poor behavioural regulation (i.e., deficits in inhibition, cognitive flexibility, emotional control) according to parent/caregiver reports early in their teen years are more likely to struggle with social and practical skills and overall adaptive skills later on. This finding extends Schonfeld and colleagues' (2006) study that found a similar relationship between parent/caregiver reported BRI scores on the BRIEF and challenges in social skills on the SSRS (Gresham & Elliot, 1990) among younger children (age 6 to 11 years) with PAE. It is also partially in line with Gardiner et al., (2021) who found that the parent/caregiver reported behaviour regulation challenges on the BRIEF, specifically the shifting subscale of the BRI, predicted all areas of adaptive functioning including practical skills and conceptual skills in addition to social skills among children aged 5 to 18 years with confirmed PAE. Notably, the latter study did not use a longitudinal design. Overall, the relationship between early behaviour regulation and later social skills is not surprising given the importance of behavioural regulation when considering age-appropriate social skills. An individual's ability to inhibit their responses appropriately, engage in flexible thinking and behaviour, and tolerate change (i.e., aspects of emotion regulation) are critical foundational skills linked to later social competence (Blair et al., 2015).

When examining the relationship between EF and mental health, there were no *a priori* hypotheses noted as these associations have not been examined in the FASD population to my knowledge. Evidence of a relationship between inhibition and externalizing problems and behaviour problems has been identified in other populations. For example, lower levels of inhibitory control (in addition to attention and EF skills) were associated with higher levels of externalizing behaviours in a group of typically developing 6-year-olds (Blanken et al., 2017). Preschoolers with behavioural problems were also found to have later challenges with inhibition at age 7 (Brophy et al., 2002). Among adults who engaged in a range of antisocial behaviour, a relationship was found between working memory and inhibition challenges and externalizing behaviours (Ogilvie et al., 2011). Notably, although EF, including inhibition, was not found to be predictive of later mental health in the current study, a strong negative correlation was found between early cognitive flexibility skills (i.e., Switching) and later Behavioural Symptoms as reported by caregivers on the BASC-2. To my knowledge, this is a novel finding and suggests that stronger early cognitive flexibly skills in adolescents with FASD are associated with a decrease in later behavioural problems including caregiver reported attention challenges, withdrawal, and atypical behaviour, as defined on the BASC-2. Although this relationship is not causal, it does highlight a potential area for intervention. Future research that utilizes a larger sample size will help elucidate the association between cognitive flexibility and mental health among individuals with FASD.

Limitations

The findings in the current study are subject to several limitations. First, the sample size utilized was small and was further decreased by the necessity of matching data pairs required for the longitudinal design. As a result, statistical power was impacted and separate regression analyses were performed, thus increasing the margin of familywise error. Furthermore, due to the small and clinically recruited sample, results cannot be generalized to the larger FASD population. The participants in the study were generally well-supported with relatively consistent home environments; this is not the case for many youths with FASD (McLachlan, 2020), including the majority of the larger sample that could not be contacted due to disconnected phone numbers and no longer residing with the same families five years later.

Second, because some of the participants were too old to be administered the NEPSY-II at Time 2 and were therefore assessed using the D-KEFS, comparisons were made using two different measures. However, the subtests that were compared had moderate correlations (Korkman et al., 2007) and theoretically assessed the same EF domains. Future longitudinal research should be designed with age cut-offs in mind to ensure the appropriateness of each neuropsychologist measure chosen.

Related to EF measures, the third limitation to consider is the limited number of EF measures used in the current study and the complexity of measuring EF skills. Subtests were chosen to include two main components of EF (a switching and inhibition measure), but no working memory task was included. Conclusions made about isolated EF skills should also be made cautiously; isolating specific EF skills within individual tasks is difficult as they often measure other EF skills (O'Rourke et al., 2020). The current tasks were also carefully chosen to include both behavioural reports and performance-based measures. While the use of behavioural reports can increase the subjectivity of ratings (Ware et al., 2013), they also provide important information that would not be included when using performance-based measures alone (Silver, 2014). In addition, they often provide a more accurate real-world observation of functioning (Gioia & Isquith, 2004; Anderson et al., 2002).

The final limitation of the current study relates to the intra-individual differences that are present among individuals with FASD. Care in assigning finite conclusions based on single episode testing results is imperative, particularly in a population with such varied and ever-changing neurodevelopmental needs. Care was taken with every individual to ensure that they were comfortable, rested, and vested in the testing procedures. All individuals were aware that participation was voluntary, and that testing could be discontinued at any time. Positively, no participants discontinued their participation and validity indicators on every measure were strictly adhered to. In addition, research has shown that intra-individual variation decreases during adolescence and young adulthood, which comprised the age group of the current participants (Tamnes et al., 2012).

Clinical Implications

Results of the current study hold important clinical implications for professionals working in the field of FASD and for families, caregivers, and others who support individuals with FASD. First and foremost, the presence of relative strengths should not be overlooked or considered a “non-finding” as is common in clinical research. Although it is important to keep in mind the intra-individual differences in this population and that strengths may be unique for individuals with FASD, mean performance on the Switching task at both time points fell within the normative average range while Inhibition scores at Time 2 were also average indicating possible areas of relative strength. In the future, a thorough understanding of the developmental trajectory of EF should include a focus on both pathology and competence as understanding areas of typical performance and strength is an important aspect in supporting healthy functioning and evidence-based transition and care planning into adulthood (Flannigan et al., 2018; Jimerson et al., 2004; McLachlan et al., 2020; Sparrow et al, 2013). At the individual level, including strengths that can be capitalized on, particularly contextual variables as in the case of EF, may lead to a deeper and more appropriate understanding of the neurodevelopmental profile of individuals with FASD and awareness of their personal resources (Jimerson et al., 2004). Finally, the inclusion of strengths has the potential to support the development of positive, ability-focused self-perceptions in individuals with FASD that lead to empowerment and achievement of everyday successes (McLachlan et al., 2020; Olson & Sparrow, 2020).

A second important clinical implication gleaned from the current research is the issue of IIV and understanding the heterogeneity of EF development among youth with FASD. This is especially important in settings where goals and expectations are created and managed for these youth and emphasizes the importance of monitoring development regularly. Assessment results and recommendations made during childhood or even during early adolescence should be reviewed regularly as they may become inappropriate or obsolete in just a few years (Sattler, 2018). It is important for teachers, parents, caretakers, and others who work with this population to understand that each person who is impacted by PAE is unique and that their EF skills and functioning may increase or decrease over time (Ali et al., 2018; McLachlan et al., 2017). Although tempting due to the cost and challenges in accessing updated assessments, relying on old recommendations to support transitions in academic settings, employment, or independent living may be detrimental for this group of individuals who are already at increased risk for a myriad of adverse outcomes that intensify and accumulate with age (Burnside & Fuchs, 2013; Kambeitz et al., 2019; McLachlan et al., 2020; Streissguth et al., 2004). It is recommended that educators and other professionals work closely with each other and with the individuals they are supporting to adopt a flexible and responsive approach to managing challenges and successes through communication, documentation, and collaboration; this is particularly important during the transition from youth to adulthood (Burnside and Fuchs, 2013; Wilens et al., 2018).

A final clinical implication that is particularly relevant for professionals working in the field of FASD comes largely from caregiver intervention research. Parents of children with FASD are faced with considerable stress and often feel discouraged about their parenting practices (Olson et al., 2009; Payley et al., 2006; Petrenko et al., 2016). It is suggested that parents and caregivers who have increased knowledge about FASD are more likely to attribute their children's behaviour problems to the neurodevelopmental disability rather than willful disobedience, which results in decreased behavioural concerns (Bertrand, 2009; Olson & Montague, 2011; Olson et al., 2009; Petrenko et al., 2016). A better understanding of the neurodevelopmental mechanisms at play often results in improved and more appropriate parenting strategies leading to reduced conflict and more positive relationships, thus reducing some of the stress experienced by these caregivers (Flannigan et al., 2020). It is important that families have better access to evidence-based interventions and that education about FASD is more readily available. Specifically, interventions that appropriately address the complex cognitive and learning challenges experienced by individuals with FASD, including their areas of strength, rather than blanket programs that target disruptive or antisocial behaviour are needed (Olsen & Sparrow, 2020; Whaley et al., 2001).

Conclusions and Future Directions

Youth with FASD experience a wide range of challenges ranging from difficulty in school, to mental health problems, to frequent changes in living environments. One area often implicated in neurodevelopmental research is their challenges with EF. Although there is not yet a consensus among scholars regarding a framework of EF, a prominent model posits that EF is made up of three separate yet related components, namely working memory, set shifting, and inhibition (Miyake et al., 2000; Miyake & Friedman, 2012). These three domains of EF undergo complex changes and development during adolescence, but it is not yet known if youth with FASD follow a similar developmental trajectory (Garon et al., 2008). Because EF skills are crucial in later healthy functioning, a better understanding of this process among this population is critical. In an effort to help mitigate negative outcomes and support more relevant and individualized recommendations, understanding the predictive relationship EF has with later adaptive functioning and mental health is warranted.

The findings of this study suggest that youth with FASD experience significant and persistent deficits in EF, both during adolescence and young adulthood. Parent/caregiver reports are especially sensitive to capturing these challenges likely due to the differences in presentation between performance-based EF tasks and ecological or “hot” EF. According to parent/caregiver reports, MI skills become more impaired (compared to the norm) into young adulthood when these youth fall farther behind their typically developing peers. This is likely a result of increasing expectations and independent functioning as youth approach young adulthood. Contrary to this pattern, behavioural regulation challenges appear to remain chronic but stable during this developmental period.

Despite these group-level patterns, when EF was examined at the individual level, significant IIV was observed in almost half of the study sample highlighting the heterogeneity of EF development in this population. Performance-based inhibition skills were particularly susceptible to variability with multiple individuals improving their performance. This variability among individuals with FASD leads to challenges when developing blanket conclusions about the developmental trajectory of EF and care should be taken when reporting neurodevelopmental trends among this population.

When the relationship between EF and later mental health and adaptive functioning was examined, a significant relationship between behavioural regulation and later social skills deficits was found. Parent/caregiver reports of early challenges with inhibition, cognitive flexibility, and emotional control, all “hot” EF skills, appear to predict later difficulties with social skills. More specifically, young teens with FASD who struggle with regulation including “putting on the breaks”, perseveration, and who often display inappropriate emotional responses, are more likely to experience challenges with getting along with their peers, expressing affection appropriately, making friends, and following rules later in their adolescence. Targeting these skills deficits early may help to mitigate later social problems which is especially important during adolescence when fitting in and being an accepted member of a group is so important.

Finally, multiple areas of relative strength were identified in the current study that should not be overlooked. Specifically, clinically average (compared to the norm) cognitive flexibility was observed on performance-based tasks throughout this developmental timeframe while clinically average (compared to the norm) inhibition skills on performance-based tasks were observed during later adolescence/young adulthood. These strengths are important to include in intervention planning and can be used as building blocks for future skill development. In addition, improving regulation skills (i.e., “hot” EF) in this population may allow these cognitive or “cool” EF skills to improve in real-world environments.

In the future, it will be important for researchers to examine the developmental trajectory of EF and the relationship between EF and mental health and adaptive functioning longitudinally, using a larger sample size that can accommodate more complex models. Given that this research found significant results using adjusted *p* values is promising. The presence of multiple significant results prior to post hoc testing further emphasizes the relevance of this line of research. Finally, the addition of added EF tasks spanning all three domains (i.e., working memory, shifting, inhibition) is further recommended. Researchers are also encouraged to emphasize areas of strength among this population as a better understanding of typical neurodevelopmental performance is important in supporting overall functioning.

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Chapter 4: Supporting Individuals with FASD: Trends in Service Use

Understanding how to optimally support individuals with unique needs such as fetal alcohol spectrum disorder (FASD) is critical in our efforts to promote healthy outcomes. Recognizing that individuals with FASD have many areas of strength, it is incumbent on service providers to explore ways that we might leverage these strengths and optimize supports (Flannigan et al., 2021). This goal is challenging in a field in which intervention research is at an emerging state and when individual needs span multiple systems of support (Pei et al., 2021). Consequently, intervention efforts take many forms and encompass a dynamic and multiple embedded systems approach including but not limited to educational services, medical intervention, social services, and legal supports. As is the case with many complex populations, interventions also frequently extend to caregivers and family members. Currently, it is well understood that individuals with FASD require multifaceted and financially taxing support (Popova et al., 2016). However, strikingly little is known about what this support looks like for these individuals and their families. Even less is known about how these supports might change during key developmental periods, such as the emergence into adulthood. The current research addresses these unknowns by examining the service use trends among a cohort of individuals with FASD from adolescence into young adulthood. It also investigates whether a relationship exists between brain-based functioning during early adolescence and service use trends during young adulthood.

FASD

FASD is a neurodevelopment disorder than can result from prenatal exposure to alcohol. The estimated prevalence of FASD is between 2% and 3% according to a recent World Health Organization population-based study (Popova et al., 2018) and up to 36% in some specialized settings such a youth detention centres (Bower et al., 2018). FASD is a heterogenous disorder with a range of symptoms and outcomes including physical, cognitive, emotional, and behavioural challenges. Presentation can vary greatly depending on the timing, frequency, and amount of alcohol consumption, genetics, environment, and other pre-and post-natal events (Davis et al., 2013). Diagnostic criteria for FASD includes identification of significant deficits in three or more neurodevelopmental domains including motor skills, neuroanatomy/neurophysiology, cognition, language, academic achievement, memory, attention, executive functioning (EF), and adaptive behavior (Cook et al., 2016). Due to the prevalence of mental health challenges in this population, the Canadian diagnostic criteria was updated to include an additional domain for affect regulation (Cook et al., 2016). Affect regulation includes several diagnostic mood or anxiety disorders defined in the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-5; APA, 2013).

FASD and Strengths

Despite the emphasis on deficits and neurodevelopmental vulnerabilities, individuals with FASD also possess a range of strengths and resiliencies that can be used to foster positive outcomes and support their everyday lives (Currie et al., 2016; Pei et al., 2016; Rogers et al., 2013). In a review of neuropsychological profiles of children and adolescents with PAE/FASD, Kully-Martins and colleagues (2022) found that at the group level, stronger performance on nonverbal reasoning, learning, and memory tasks was common. In addition, children and adolescents with PAE/FASD tended to perform better on tasks with embedded strategies including semantic clustering and visualization and were more successful on less demanding tasks in general. In a narrative review of strengths among individuals with FASD, Flannigan et al. (2021) identified positive characteristics, talents, and abilities that had the potential to promote healthy outcomes and well-being. Consolidated from 19 studies examining strengths among this population across the lifespan, the authors outlined five broad categories including: (1) strong self-awareness; (2) receptiveness to supports; (3) capacity for human connection; (4) ability to persevere through challenges; and (5) hope for the future. Moving forward, the authors recommended that future research strive to include a focus on identifying strengths, but also improve how strengths are conceptualized in a meaningful way to better understand the association with positive impacts and outcomes. The use of evidence-based tools in identifying strengths, and a better understanding of how research can be applied to improve the daily lives of these individuals was also suggested. In summary, an understanding of strengths is important to help maintain positive, ability-focused self-views of these individuals to support their everyday successes.

FASD and EF

Despite the call to better balance research that identifies the strengths and abilities of individuals with FASD with research than investigates areas of vulnerability, the majority of what is known about the neurodevelopmental profile of individuals with FASD focuses on areas of need. A defining characteristic of their neurodevelopmental profile is significant deficits in EF. EF refers to a set of cognitive control processes, mainly supported by the prefrontal cortex, that regulate the dynamics of human cognition and action (Miyake & Friedman, 2012). An umbrella term, EF encompasses several sub-abilities including planning, set-shifting, inhibition, strategy deployment, flexible thinking, and working memory. EF also involves the integration of more basic processes such as memory, attention, sensation, perception, and motor activity (Pennington & Ozonoff, 1996; Zelazo & Müller, 2002). As an overarching domain, EF skills are a crucial component of daily functioning and healthy outcomes. Day to day, EF skills allow individuals to self-regulate, which in turn supports their ability to direct the behaviours they need to achieve goals, break negative habits, make informed decisions, evaluate risks and benefits, and support planning for the future (Banich, 2009; Miyake & Friedman, 2012). The central role of EF skills is further emphasized by the relationship between healthy functioning and specific EF processes including attention, flexible thinking, goal setting, decision making, and problem solving (Greenspan et al., 2016; Schiebener et al., 2015). Currently, the field of FASD research is beginning to understand the significance of EF skills and their potential to serve as prognostic indicators of healthy functioning. However, it is not yet known whether the degree of EF development in individuals with FASD is reflected in the intensity of services they receive. The current research will provide needed information about the relationship between EF and the intensity of supports accessed by these individuals.

FASD and Mental Health

In addition to challenges with EF, mental health problems are frequently experienced by individuals with FASD (Streissguth et al., 2004; Weyrauch et al., 2017). These include issues with anxiety, mood and depression disorders, attention-deficit/hyperactivity disorder (ADHD), and conduct disorder (CD), with estimates of comorbidity occurring in upwards of 90% of this population (Pei et al., 2011). In a seminal study investigating long term outcomes of individuals with FASD, researchers found that 19% of children and 43% of adults experienced suicidal threats and 2% of children and 24% of adults attempted suicide (Streissguth et al., 1996). In a recent Canadian study, 25.9% of individuals with FASD experienced suicidality, with adolescents (34.7%) and transitioned-age youth (35.2%) experiencing the highest rates (Flannigan et al., 2021). Most notably, individuals with FASD (and the larger population in general) are most at risk for suicide during the developmental period between adolescence and young adulthood, during which suicide is the second leading cause of death (Government of Canada, 2019). Within this developmental period, it is the transition into adulthood where the availability of FASD-informed supports and evidence-based interventions are especially important. Unfortunately, after ageing out of youth services, many of these individuals are faced with a decrease in supports at a time when expectations for independence and responsibilities are increasing, often at an inappropriate level given their functioning (Burnside & Fuchs, 2013; Coons-Harding et al., 2019).

Despite the strong relationship between FASD and mental health problems, the mental health system has not yet fully embraced this disorder (Anderson et al., 2018). According to Anderson et al., (2018), confusion and uncertainty exists within the healthcare system, where professionals often attempt to determine what role FASD plays in the development of mental health problems, or vice versa. This leads to challenges when trying to fit FASD into pre-existing service delivery models, as it is not possible to determine whether the disorder is a risk factor, a significant or mild etiological factor, or a separate, unrelated disorder. In essence, the relationship between FASD and mental health is complex; it appears to be reciprocal in nature and compounded by the presence of cognitive impairments, environmental factors, and behavioural difficulties (Anderson et al., 2018). Positively, intervention research is increasing, and researchers have recently identified some meaningful mechanisms for change to help inform FASD best practices, thus supporting clinical practice. Specifically, in a review of mental health interventions for individuals with FASD, Flannigan et al. (2020) noted that interventions support mental health and wellness in different ways across the life span. During early childhood, programs appear to be largely preventative, family-based programs aimed at fostering attachment and adjustment; during middle childhood, the focus shifts to acquiring skills and strategies to support optimal functioning. Finally, during later adolescence and into adulthood, supports are more responsive in nature aimed at meeting complex needs, mitigating risks, and reducing harm. Concerningly, the authors noted that no interventions in their review targeted mental health specifically, rather, mental health was managed through supporting adaptive and functional capacity. Additionally, there was a stark gap in information pertaining to interventions for adolescence, emerging adults, and adults with FASD. Given the complex needs during this developmental period, the present research will help provide important information about the trends in mental health service use during the transition into young adulthood.

FASD and Adaptive Functioning

Individuals with FASD also frequently experience challenges with adaptive functioning. Adaptive functioning is defined as “the performance of daily activities required for personal and social sufficiency” (Sparrow et al., 2005, p.6). An umbrella term, adaptive functioning includes the specific domains of social skills, practical skills, and conceptual skills (Tassé et al., 2012). Although adaptive skills are essential throughout all stages of life, they are especially important during adolescence and throughout the transition to adulthood during which rapidly unfolding maturational and developmental stressors and increasing expectations around independence and responsibility are occurring (Osgoode et al., 2004). Generally, studies examining adaptive functioning in clinically referred children tend to reveal similarly high rates of challenges that are not accounted for by IQ across all domains of daily living skills, communication, social skills, behaviour, educational development, employment success, and substance misuse (Day et al., 2013, Rangmar et al., 2015, Temple et al., 2011). However, few studies have examined the magnitude of adaptive function impairment in individuals with FASD, particularly during adulthood. In a meta-analytic review, Kautz-Turnbull and Petrenko (2021) compared adaptive functioning deficits in a group of individuals (mean ages 3.56 to 22.62 years) with FASD with nonexposed individuals and individuals with a diagnosis of ADHD. The authors found that people with FASD had significantly lower adaptive functioning than both nonexposed individuals and individuals with ADHD, regardless of IQ, EF, or age. These findings highlight a unique and pervasive need for individuals with FASD that cannot be predicted by their levels of functioning. Specific to adults with PAE, Lynch and colleagues (2015) found challenges with educational development, and additional challenges specific to skills required during adulthood including employment, lower socioeconomic status, managing money, and obtaining a driver's license.

Although adaptive functioning challenges seem to persist for individuals with FASD regardless of IQ, EF, and age, specific risk factors have been identified that appear to be linked to more severe challenges in everyday life. McLachlan and colleagues (2020) explored difficulty profiles based on possible risk factors in a group of adolescents, age-transitioned youth, and adults with PAE from the Canadian National FASD Database (*N* = 726). In line with previous studies, the authors found that all individuals, regardless of their age, experienced significant difficulties with housing, education, and employment. However, pertinent risk factors linked to more severe challenges were identified including age, extremely low IQ, gender, postnatal trauma, living in a system or independent placement (rather than with a parent or family member), and overall neurodevelopmental impairment. Difficulty rates increased by age, with adults experiencing the greatest number of cumulative challenges. Only 36% of adults in the sample reported living independently, with this group experiencing fewer challenges around housing and independent living skills than those with alternative living arrangements. The majority of transition-aged youth and adults experienced employment problems, and the most commonly impaired neurodevelopmental domain was adaptive functioning, with 80% of the sample experiencing significant difficulty despite of half (52%) having IQ scores less than 70.

Overall, these results both highlight the needs of individuals with FASD and the importance of mitigating risks through building on strengths, resiliency, and protective factors in this population. The authors concluded by emphasizing key implications including the importance of early assessment and intervention that is tailored to identify both the neurodevelopmental complexity and functional needs of individuals with PAE/FASD (McLachlan et al., 2020). In addition, early and integrated coordination of supports during the transition from adolescence to young adulthood, FASD informed workforce training across all age groups, and policy initiatives that ensure the availability of developmental sector community supports including employment, housing, and mental health that are based on functional need rather than IQ were recommended (McLachlan et al., 2020). Finally, access to stable and quality caregiving environments was noted as essential given the protective nature and window of opportunity to foster positive outcomes that this provides. The current study will help build on these implications by providing important information about the relationship between early functioning and later adaptive functioning supports accessed by individuals with FASD, and the intensity of these supports accessed over time.

FASD and Service Use

To ensure that strengths are supported, and that resilience and protective factors are fostered, individuals with FASD require broad and integrated services and interventions aimed at supporting their neurodevelopmental and functional needs (Brownell et al., 2013). To do this, supports need to encompasses multiple systems, including the health, legal, educational, and social services; due to the complexity of need, a call for an integrated systems approach to service delivery has been made by experts in the field (McLachlan et al., 2020; Pei et al., 2021; Skorka et al., 2020). In addition to the call for access to integrated services, the field is beginning to understand with more clarity, what the lived experiences of individuals with FASD and their families is like, thus providing a front-line understanding of where supports are required. Caregivers and families of children with FASD experience significant impacts on their emotional and physical well-being due to the behavioural needs of their children and their own experiences of grief and loss (Hanlon-Dearman et al., 2018; Sanders & Buck, 2018; Skorka et al., 2020). Caregivers of adolescents with FASD may be at even higher risk for experiencing greater concern than those caring for children with FASD, due to better availability of early intervention supports, again implicating the importance of continued access to services as individuals with FASD mature (Bobbitt et al., 2016). As such, a call for increased access to and increased caregiver supports has been made (Coons et al., 2016, 2018; Skorka et al., 2020).

With regard to the intensity of services being accessed, using a matched-cohort design, Brownelle et al. (2013) examined health, education, social services data and clinical records of individuals with FASD ages 6 years and older ($N = 717$). Matching was 2:1 with the general population and a group with a chronic disease (asthma) by age, sex, and income. Hospitalizations, education services use, and social services use were significantly higher for the FASD group than both the chronic disease group and the general population. Additionally, physician visits and overall prescription use were higher for the FASD group compared to the general population. When examining mental health care and other service use intensity among young children with FASD ($n = 14$) and ADHD ($n = 5$) in Alberta, Canada, Mills and colleagues (2006) also found that the majority of children in both groups received support from a wide range of services (e.g., family doctor, speech and language pathology, occupational therapy). However, children with FASD were less likely to be referred to mental health professionals by their primary care providers than children with ADHD, and no consistent pathway to mental health support access was apparent. This is especially troubling given the high prevalence of mental health problems among this population (Pei et al., 2011). Because data was collected via anonymous caregiver questionnaires, reasons for the discrepancy and specific information regarding the process of referrals was not available. Finally, in a cross-sectional study investigating service use within the health care system, Popova and colleagues (2016) obtained health care utilization data for individuals with a diagnosis of Fetal Alcohol Syndrome (FAS) from the Canadian Institute for Health Information (CIHI) and Statistics Canada between 2008 and 2009. The authors found that the number of hospitalization days among individuals with FAS were highest for ages 15-29 years, and second highest for ages birth to 14 years. The number of acute care and psychiatric care hospitalization days and the number of emergency department visits increased between these two time periods while the number of day surgery hospitalizations decreased. Results suggested that individuals with FASD access an increasing number of medical services throughout their childhood, adolescence, and into early adulthood.

To summarize, individuals with FASD face many challenges and are at increased risk of experiencing serious difficulties across many facets of functioning. Adverse life outcomes are unfortunately all too common and are likely related to the variable nature and encompassing scope of this disorder. Due to the complexity of caring for individuals with FASD, their caregivers and families experience challenges including stress and feelings of guilt and grief. Because of these unique challenges and needs, individuals with FASD and their families are best supported by integrated models of service delivery (Goodwin, 2016; Pei et al., 2021). Notably, continued research around strengths in this population is needed, not only as a vehicle to mitigate risk, but also as a source to promote well-being and foster resilience in this population. Despite the call for action around better access to FASD-informed care, there is a lack of research examining what this currently looks like for this population and their caregivers. Specifically, extremely little is known about the types of services being accessed and the intensity of these supports between adolescence and young adulthood. A more accurate understanding regarding the quantification and intensity of service use trends over time is needed to better inform planning, timing, and development of interventions.

Purpose and Research Questions

This research provides novel information about the service use patterns among individuals with FASD and their family/caregivers from adolescence into young adulthood in Alberta. To my knowledge, the trends in service use have not been previously studied in this population. In addition, it examines the relationship between brain-based functions including EF, mental health, and adaptive functioning during adolescence, and service use during young adulthood. A better understanding of the trends in service use among families caring for individuals with FASD and the associations between brain-based functioning and later service use among these individuals is important as it will provide pertinent information that can be used when developing interventions. Knowing when and where to focus interventions will support families caring for those with FASD while also fostering the well-being and promoting healthy outcomes in this population. To fill these gaps, three research questions were addressed:

1. **What does service use look like among individuals with FASD and their family members?**

   Hypothesis: I hypothesized that service use for individuals with FASD and their families will encompass a range of systems including medical services, mental health services, social services, educational services, and caregiver supports based on literature indicating the wide range of need and multitude of supports accessed by this population (Flannigan et al., 2020; Popova et al., 2016). Given the current state of need and focus on improving service delivery for individuals and families with FASD in Alberta and review of extant literature, I hypothesized that the intensity of service use will be high both during adolescence and during young adulthood.

2. **Does service use intensity among individuals with FASD and their family members change from adolescence into young adulthood?**

Hypothesis: Although service use trends among the FASD population have not been specifically examined, the following literature was used to guide the current hypotheses. Popova et al. (2016) found that medical service use was highest among individuals ages 15 – 29. As such, I hypothesized that medical service use would increase from Time 1 to Time 2. Based on literature that children and youth with FASD are overrepresented in the social services system (Streissguth et al., 2004), I hypothesized that social service use would remain high and stable across both time points. With regard to mental health among this population, challenges appear to persist and even increase over time (Pei et al., 2011). As such, I hypothesized that mental health service use would be high and increase from Time 1 to Time 2. There were no *a-priori* hypotheses for the remaining services (i.e., caregiver, educational).

3. **Is there an association between early brain-based functions during adolescence (i.e., executive functioning, mental health, adaptive functioning) and service use during young adulthood?**

As the investigation into the association between brain-based functions and service utilization in the FASD population is exploratory in nature, no *a-priori* hypotheses were developed.

Method

Procedure

This research used a longitudinal cohort panel design that took place within a larger study examining longitudinal assessment of individuals with FASD. The Research Ethics Board at the University of Alberta and Alberta Health Services (AHS) approved this study. Informed consent and assent were gathered from all participants and their caregivers.

This study took place at the Glenrose Rehabilitation Hospital in Edmonton, AB. Participants with FASD and their caregivers were recruited through the Glenrose Rehabilitation Hospital's FASD Clinic and participated in two testing sessions: Time 1 (adolescence) and Time 2 (young adulthood). Testing sessions took place approximately 5 years apart. Recruitment for Time 2 testing occurred via telephone; participants who volunteered for the first phase of the study (Time 1) were asked if they were interested in returning to the hospital for a follow-up assessment (Time 2). After their Time 2 assessment, an assessment report was written, and participants were invited back for a results meeting. During this meeting, the assessment results were discussed in detail and individualized recommendations were developed.

Participants

Participants were 16 youth recruited from a purposive sample of 67 participants who participated in the initial phase of the research project. All participants were recruited from the Glenrose Rehabilitation Hospital's FASD Clinic and had a previously confirmed medical diagnosis of an alcohol-related disorder falling under the umbrella term FASD according to the 2005 Canadian FASD Diagnostic Guidelines (Chudley et al., 2005). Of the original 67 participants, only data from the 16 individuals who participated in both time points was used. Of the original 67 participants who were contacted at Time 2, 30% (*n* = 20) were not interested in participating, 46% (*n* = 31) could not be reached due to incorrect phone numbers or having moved, and 24% (*n* = 16; 7 female and 9 male) agreed to participate. The mean age of the 16 participants at Time 1 was 13.3 years (*SD* = 2.88; Range 6.9 – 17.2 years); the mean age of the 16 participants at Time 2 was 19.4 years (*SD* = 3.2). Time 1 assessment IQ scores were not available. Time 2 assessment IQ scores were available for all participants (see Table 4.1).

At Time 2, the majority of participants were residing with either an adoptive parent (*n* = 9) or foster parent (*n* = 5). The remaining participants were residing with a legal guardian or other adult (*n* = 2). In terms of placements to date, the majority of participants had lived in at least two different placements during their lifetime (*n* = 12), with one participant living in three, and three participants living in five or more different households. The majority of participants had at least one mental health disorder: 75% (*n* = 12) were diagnosed with ADHD, 43.8% (*n* = 7) were diagnosed with an anxiety disorder, and 43.8% (*n* = 7) were diagnosed with a mood disorder.

Table 4.1

Demographic Characteristics of Participants at Time 2

	n(%)	*M(SD)*	*Range*
Gender			
Female	7(43.8)		
Male	9(56.2)		
Age		19.4(3.2)	12-23
IQ			
Full Scale		88.44(9.2)	70-102
Verbal		85(10.68)	69-103
Visual		95.19(11.31)	76-117
No. of Placements			
0-2	12(75)		
3	1(6.3)		
5+	3(18.7)		
Mental Health Diagnosis			
ADHD	12(75)		
Anxiety	7(43.8)		
Depression	7(43.8)		

Note: IQ was evaluated using the Wide Range Intelligence Test (WRIT)

Measures

For the present study, standardized tools were used to measure intelligence, EF, mental health, and adaptive functioning. A demographic questionnaire and the Services for Children and Adolescents Parent Interview (SCAPI) were used to gather information about life circumstances and service use.

Demographic Questionnaire

Caregivers completed a demographic questionnaire developed by our research team. The questionnaire included standard demographic questions including sex, age, handedness, income, etc. In addition, it included select questions from Streissguth's Life History Interview (Streissguth et al., 2004), the Adverse Childhood Experiences Questionnaire (Dube et al., 2001), and the Hollingshead Four Factor Index of Socioeconomic Status (Hollingshead, 1975) to gather more in-depth information about background history, adverse life experiences, living situation, educational experiences, etc. Caregivers were instructed to answer only those questions which they felt comfortable answering.

Services for Children and Adolescents Parent Interview (SCAPI)

The SCAPI is a semi-structured interview designed to assess parent/caregiver reports of their children's service use across 10 service categories (Jensen et al., 2004). Questions regarding respite services and reasons why specific services were not accessed were added by the researchers. SCAPI administration is completed between 5 and 30 minutes depending on the number of services accessed by the individual being interviewed. The SCAPI includes items pertaining to type, intensity, onset and offset, provider type, and content of services accessed. Additionally, the SCAPI is time variable such that researchers can individualize *"time of/since service use"* to match time periods from one interview to the next making it an ideal interview for use in longitudinal research. In the current study, services utilized were defined at two time points: from initial diagnosis until the first stage of the study (Time 1) and from Time 1 until the current stage of the study (Time 2). Finally, the SCAPI additionally captures service use by parent/caregivers allowing researchers to more fully understand the relationship between child and parent service use. Descriptive and criterion validity are described as encouraging by the authors; however, results of statistical analyses are not reported.

Wide Range Intelligence Test (WRIT)

The WRIT is a brief measure of verbal and nonverbal cognitive ability for individuals ages 4 to 85 (Glutting et al., 2000) and was administered at Time 2 only. The WRIT is made up of two subtests that comprise a verbal (crystalized) IQ score including vocabulary and verbal analogies; and two that comprise a visual (fluid) IQ score including visual matrices and diamonds. The verbal and visual IQ scores together comprise an overall general intelligence score. The WRIT has high internal consistency reliability (.84 - .90), test-retest reliability (>.90), and inter-rater reliability (.98 - .99) for the three main scales. The WRIT additionally has acceptable construct, concurrent, and predicative validity as evidenced by high correlations with the Wechsler Intelligence Scale for Children (WISC-III, .90), Wechsler Abbreviated Scale of Intelligence (.79-.86), and moderate to high correlations with the Wide Range Achievement Test (WRAT, .36-.64; Canivez et al., 2009; Glutting et al., 2000).

NEPSY-II

The NEPSY-II is a norm-referenced (American sample) assessment of functioning across six domains including executive functioning and attention, memory and learning, sensorimotor functioning, social perception, language, and visuospatial processing for individuals ages 3 to 16 (Korkman et al., 2007). Performance is reported in scaled scores ($M = 10$, $SD = 3$). For the current study, subtests that measure executive functioning and attention were administered including Inhibition and Animal Sorting. The Inhibition subtest is comprised of three parts including Naming, Inhibition, and Switching; only the Inhibition and Switching tasks were used. The Animal Sorting subtest is comprised of a single activity. The NEPSY-II has adequate-to-high reliability (including internal consistency and test-retest reliability), validity, and interscorer agreement (Korkman et al., 2007).

Behaviour Rating Inventory of Executive Function (BRIEF)

The BRIEF is an 86-item questionnaire designed to assess executive function behaviours in the home and school environment among individuals ages 5 to 18 years and has a parent report form, teacher report form, and self-report form (Gioia et al., 2000). Only the BRIEF parent form was administered. Eight theoretically and empirically derived clinical scales that measure different aspects of EF are included: inhibit, shift, emotional control, initiate, working memory, plan/organize, organization of materials, and monitor. These clinical scales form two broad indexes, Behavioural Regulation (BRI) and Metacognition (MI), and an overall Global Executive Composite (GEC) score. Norm-referenced (American sample) scores for both clinical scales and indexes include *T*-scores ($M = 50$, $SD = 10$). Higher scores indicate increased difficulty in EF skill. Internal consistency on the BRIEF Parent was estimated using Cronbach's alpha and suggests a high degree of internal consistency (.80 - .98). Test-retest reliability for the indexes were examined in both clinical and non-clinical samples of the Parent Form with mean correlations suggesting high test-retest reliability for both populations (clinical sample: .72 - .84; non-clinical sample: .76 - .85). The BRIEF was developed having strong content validity through consultation with parents, teachers, and several pediatric neuropsychologists; the majority of items retained for each scale have high interrater agreement. Construct validity for the BRIEF is additionally high as indicated through the multitrait-multimethod matrix (Campbell & Fiske, 1959) that examined convergent and discriminant validity of the BRIEF with other related versus unrelated measures (e.g., Child Behaviour Checklist, Achenback, 1991; Behaviour Assessment System for Children, Reynolds & Kamphaus, 1992; Conners' Rating Scale, Conners, 1989).

Behaviour Assessment System for Children (BASC-2)

The BASC-2 is a questionnaire that measures both adaptive and behaviour problems in the community and home settings. Scores can be used as indicators of possible mental health problems. The Parent Rating Scale (PRS) for adolescents ages 12 to 21 and College Students was used during Time 2 (Reynolds & Kamphaus, 2004). Clinical scales included on these questionnaires assess: aggression, anxiety, attention problems, atypicality, conduct problems, depression, hyperactivity, learning problems, somatization, and withdrawal. Adaptive scales included on these questionnaires assess: activities of daily living, adaptability, functional communication, leadership, social skills, and study skills. Composite scales included Externalizing Problems, Internalizing Problems, Behavioural Symptoms Index, and Adaptive Skills. Norm-referenced scores (American sample) are included yielding *T*-scores (*M* = 50, *SD* = 10) and percentiles. The BASC-2 has strong test-retest reliability within one month and high internal validity of .80 with children and .90 with adolescents (Reynolds & Kamphaus, 2004).

Adaptive Behaviour Assessment System, Second Edition (ABAS-II)

The ABAS-II is a norm-referenced (American sample) assessment of adaptive skills for individuals ages birth to 89 years (Harrison & Oakland, 2003). Only the parent/caregiver form was completed. Skill areas assessed include communication, community use, functional academics, school/home living, health and safety, leisure, self-care, self-direction, social, and motor. Norm-referenced scores for skill areas are included yielding scaled scores (*M* = 10, *SD* = 3). Skill areas are combined to provide three broad composite domains of functioning, including Conceptual, Social, and Practical, in addition to an overall General Adaptive Composite (GAC). Norm-referenced scores for composite areas include standard scores (*M* = 100, *SD* = 15).

Internal consistency reliability was estimated using coefficient alpha and suggests a high degree of internal consistency for all skill areas (.80 - .97), domains (.91 - .98), and GAC (.97 - .99) scores. Test-retest reliability estimated using Pearson's product-moment correlation coefficient suggest moderate to high reliability for all skill areas (.80s and .90s), domains (upper .80s and .90s), and GAC (.90s). Vigorous validity studies were conducted with both clinical and non-clinical samples and suggest high levels of sensitivity in differentiating between these populations as well as individual levels of disability.

Data Scoring and Analyses

Standard scores were derived for subtests on the WRIT, BRIEF, NEPSY-II, ABAS-II, and BASC-2. Performance at Time 1 (adolescence) was analyzed using independent samples *t*-tests to compare individual performance to the normative mean on all measures (Table 4.2).

Service use was measured using the SCAPI at both time points. Services of interest included medical (e.g., hospital visit, pharmacological treatment), mental health (e.g., individual therapy, group therapy), social (e.g., home visit from a social worker) educational (e.g., tutoring, adaptations at school), caregiver (e.g., parenting classes, support groups), and total (i.e., the total number of services across all categories). Each instance of a service was counted as one use and recorded under the corresponding service category. Instances that continued throughout both time points but clearly involved different services (e.g., tutoring that started during elementary school and continued throughout high school) were recorded at both time points. Instances that continued throughout both time points but remained the same (e.g., individual counselling with the same psychologist), were counted at Time 1 only. At Time 1 interviews, in situations where caregivers could not recall exact dates of service use, the examiners attempted to get the closest estimate of the year/age/grade of when the service was used and later cross referenced this with diagnosis dates on file. For all instances at Time 2 interviews where caregivers were unsure of timeframes, both interviews were cross referenced and service use was recorded appropriately.

Two raters independently coded the number of services reported in each category at Time 1 and Time 2. Five participants were chosen at random and scores from the two raters were compared. Inter rater reliability (percent agreement) from the five participants was 92%. Both raters then reviewed all data and rerecorded any discrepancies after a discussion.

To determine service use patterns, means and medians of services accessed within each category were calculated at Time 1 and at Time 2 (See Table 4.3). Separate Wilcoxon signed-rank tests were conducted to determine if there was a change in service use between adolescence (Time 1) and young adulthood (Time 2) for all categories (i.e., Medical, Mental Health, Social, Education, Parental, Total). To evaluate whether there was an association between brain-based functions at Time 1 (i.e., EF, mental health, adaptive functioning) and later service use at Time 2, Spearman Correlations were performed for each category (see Tables 4.4 – 4.6).

Results

EF, Mental Health, and Adaptive Functioning Performance at Time 1

Performance data for adaptive functioning, mental health, and EF is presented in Table 4.2. With regard to adaptive functioning (ABAS-II), mean domain standard scores at Time 1 were in the borderline range for GAC ($M = 70.08$), Social Skills ($M = 70.46$), and Practical Skills ($M = 70.46$); Conceptual Skills were in the extremely low range ($M = 69.92$). Lower scores on this measure indicate decreased skills. All scores were significantly lower than the normative mean ($ps < .01$). Overall, results suggest challenges in all areas of adaptive functioning.

With regard to indicators of mental health problems, (BASC-2), mean composite standard scores (Internalizing Problems, Externalizing Problems, Behavioural Symptoms) at

Time 1 were all in the at-risk range: Internalizing Problems (*M* = 63.54), Externalizing Problems (*M* = 64.69), Behavioural Symptoms (*M* = 69.15). Higher scores on this measure indicate increased likelihood of mental health problems. Again, all scores were significantly higher than the normative means (*ps* < .05). Overall results suggest concerns in all areas of mental health.

With regard to EF, all mean index scores at Time 1 on the BRIEF were clinically elevated (T ≥ 65) and significantly higher than the normative mean (*ps* < .01). Higher scores on the BRIEF indicate increased impairment in EF skills. On the NEPSY-II, lower scores indicate increased impairment. The Inhibition and Sorting mean subtest scaled scores at Time 1 were significantly below the normative mean of 10 and at or below the clinical cutoff of 7 (Inhibition *M* = 6.86, p < .05; Sorting *M* = 7.07; p < .01). The Switching subtest at Time 1 was within normal limits and not significantly different from the normative mean (*M* = 8.08, p > .05).

Table 4.2

Performance of Children with FASD on the BRIEF, NEPSY-II, ABAS-II, and BASC-2 at Time 1 Compared to the Normative Mean

Index	***M* (*SD*)**	***p***
BRIEF		
BRI	73.70 (12.82)	.000**
MI	67.50 (6.20)	.000**
GEC	71.40 (7.96)	.000**
NEPSY-II		
Inhibition	6.86 (4.24)	.016*
Switching	8.08 (3.65)	.097
Sort	7.07 (2.76)	.001**
ABAS-II		
GAC	70.08 (10.21)	.000**
Social	70.46 (10.42)	.000**
Conceptual	69.92 (10.18)	.000**
Practical	70.46 (15.25)	.000**
BASC-2		
Internalizing	63.54 (13.76)	.004**
Externalizing	64.69 (17.28)	.010*
Behavioural Symptoms	69.15 (13.21)	.000**

Note. For standard scores, *M* = 100, *SD* = 50; for scaled scores, *M* = 10, *SD* = 3. On the ABAS-II and NEPSY-II, higher scores indicate stronger skills. On the BRIEF and BASC-2 lower scores indicate stronger skills.

$^{*}p < .05$, $^{**}p < .01$.

Service Use Profiles

Service use frequencies (means and medians) were evaluated for each domain at both time points (see Table 4.3). Families accessed a similar number of total services at both time points (Time 1 *M* = 10.50, Time 2 *M* = 11.38). At Time 1, education services were the most frequently accessed (*M* = 4.56) followed by caregiver services (*M* = 2.31). Medical services (*M* = 1.81) and mental health services (*M* = 1.69) were similarly accessed by our families.

At Time 2, a similar pattern was observed. Education services (*M* = 3.75) and caregiver services (*M* = 3.50) were again the most accessed supports, with caregiver services increasing significantly at Time 2 (see following section for further explanation). Medical services (*M* = 2.13) followed by mental health services (*M* = 1.56) were accessed next.

Service Use Trends

Next, change in service use over time between Time 1 and Time 2 was examined using Wilcoxon signed-rank tests (see Table 4.3). A similar pattern was found in each domain apart from one. All difference scores in each domain were approximately symmetrically distributed, as assessed by a histogram with superimposed normal curve.

When analyzing medical services, seven of the 16 participants experienced an increase in medical services at Time 2 compared to Time 1, two experienced a decrease in medical services at Time 2 compared to Time 1, and seven participants did not experience a change between time points. There was no significant median change in medical service use (*Mdn* = 0.00 services) between Time 1 (*Mdn* = 2.00 services) and Time 2 (*Mdn* = 2.00), $z = 1.25$, $p = .212$.

When analyzing mental health services, seven of the 16 participants experienced an increase in mental health services at Time 2 compared to Time 1, five experienced a decrease in mental health services at Time 2 compared to Time 1, and four participants did not experience a change between time points. There was no significant median change in mental health service use (*Mdn* = 0.00 services) between Time 1 (*Mdn* = 1.00 services) and Time 2 (*Mdn* = 2.00), $z = -.36$, $p = .719$.

When analyzing education services, four of the 16 participants experienced an increase in education services at Time 2 compared to Time 1, nine experienced a decrease in education services at Time 2 compared to Time 1, and three participants did not experience a change between time points. There was no significant median change (*Mdn* = -1.00) in education service use between Time 1 (*Mdn* = 5.00 services) and Time 2 (*Mdn* = 3.50), $z = -.99$, $p = .324$.

When analyzing caregiver services, 10 of the 16 participants experienced an increase in caregiver services at Time 2 compared to Time 1, three experienced a decrease in caregiver services at Time 2 compared to Time 1, and three participants did not experience a change between time points. There was a significant increase in median change (*Mdn* = 1.00) in caregiver services use between Time 1 (*Mdn* = 2.00 services) and Time 2 (*Mdn* = 3.00), $z = 2.26$, $p = .024$).

When analyzing social services, four of the 16 participants experienced an increase in social services at Time 2 compared to Time 1, one experienced a decrease in social services at Time 2 compared to Time 1, and 11 participants did not experience a change between time points. There that there was no significant median change in social service use (*Mdn* = 0.00 services) between Time 1 (*Mdn* = 0.00 services) and Time 2 (*Mdn* = 0.00), $z = 1.52$, $p = .129$).

When analyzing total services, 10 of the 16 participants experienced an increase in total services at Time 2 compared to Time 1, five experienced a decrease in total services at Time 2 compared to Time 1, and one participant did not experience a change between time points. There was no significant median change in total service use (*Mdn* = -1.00 services) between Time 1 (*Mdn* = 10.50 services) and Time 2 (*Mdn* = 11.00), $z = .82$, $p = .408$).

Association Between Early Brain-Based Functions and Later Service Use

The association between EF, mental health, and adaptive functioning at Time 1 and service use (i.e., medical, mental health, education, social, caregiver, total) at Time 2 was examined by conducting Spearman Correlations (see Tables 4.4 – 4.6). A number of significant and moderately strong correlations were found. With regard to the BRIEF, the BRI was positively correlated with medical services ($p < .01$) suggesting that poor EF skills during early adolescence are associated with high medical services in young adulthood. Conversely, the MI was negatively correlated with education services ($p < .05$) suggesting a relationship between poor EF skills during adolescence and low education services during young adulthood. No significant correlations ($p > .05$) were found between the NEPSY-II and any services.

Eternalizing problems at Time 1 were positively correlated with medical services at Time 2 ($p < .05$), internalizing problems at Time 1 were positively correlated with mental health services at Time 2 ($p < .05$), and behavioural symptoms at Time 1 were positively correlated with both medical services and caregiver services at Time 2 ($p < .05$). These results suggest that high indicators of mental health symptoms at Time 1 are associated with high rates of services use at Time 2.

Finally, high social skills at Time 1 were associated with low medical services at Time 2 ($p < .05$) and high conceptual skills and overall adaptive skills (GAC) at Time 1 were associated with low caregiver services at Time 2 ($p < .05$). These results suggest a relationship between aspects of early strong adaptive skills and later utilization of fewer services.

Table 4.3

Service Use Profiles at Time 1 and Time 2 and Change Between Time Points (N = 16)

Service	Time 1			Time 2			Change	
	Mean	*Median*	*SD*	*Mean*	*Median*	*SD*	*Median*	*p*
Education	4.56	5.00	1.67	3.75	3.50	2.84	-1.00	.324
Caregiver	2.31	2.00	1.78	3.50	3.00	2.34	1.00	$.024^{*}$
Medical	1.81	2.00	0.98	2.13	2.00	1.09	0.00	.212
Mental Health	1.69	1.00	1.66	1.56	2.00	1.03	0.00	.719
Social	0.13	0.00	0.34	0.44	0.00	0.73	0.00	.129
Total	10.50	10.50	2.53	11.38	11.00	5.35	-1.00	.408

$^{*}p < .05$

Table 4.4

Correlations between EF at Time 1 and Service Use at Time 2 (N = 16)

	Service Use (Time 2)					
EF (Time 1)	Medical	Mental Health	Education	Social	Caregiver	Total
NEPSY-II						
Inhibition	-.25	-.10	-.47	-.16	-.34	-.47
Switching	-.29	-.40	-.28	.15	-.24	-.25
Sorting	-.04	-.32	-.31	-.24	-.43	-.42
BRIEF						
BRI	$.67^{**}$	.38	-.11	.12	.39	.41
MI	.12	.38	$-.59^{*}$	-.07	.16	.02
GEC	.49	.48	-.32	.03	.39	.33

$^{*}p < .05$, $^{**}p < .01$.

Table 4.5

Correlations between Mental Health at Time 1 and Service Use at Time 2 (N = 16)

	Service Use (Time 2)					
Mental Health (Time 1)	Medical	Mental Health	Education	Social	Caregiver	Total
BASC-2						
Externalizing	$.58^{*}$	.26	-.15	-.01	.46	.25
Internalizing	.13	$.55^{*}$	-.20	.29	.22	.18
Beh. Symptoms	$.55^{*}$	.47	-.15	-.14	$.52^{*}$	.36

$^{*}p < .05$, $^{**}p < .01$.

Table 4.6

Correlations between Adaptive Functioning at Time 1 and Service Use at Time 2 (N = 16)

	Service Use (Time 2)					
Adaptive Functioning (Time 1)	Medical	Mental Health	Education	Social	Caregiver	Total
ABAS-II						
GAC	-.38	-.23	.20	.25	$-.51^{*}$	-.19
Conceptual	-.25	-.45	.24	.31	$-.53^{*}$	-.29
Social	$-.59^{*}$	-.02	-.10	.07	-.46	-.39
Practical	-.35	-.07	.19	.28	-.45	-.08

$^{*}p < .05$, $^{**}p < .01$.

Discussion

The aim of the current study was to examine service use profiles and trends over time in a sample (*N* = 16) of individuals with FASD and their caregivers. In addition, the association between early brain-based functions including EF, mental health, and adaptive functioning during adolescence and later service use during young adulthood was examined. Although the field has historically focused on the complex needs of this population, research exploring interventions and how best to support individuals with FASD is just emerging. Increasing our knowledge of service utilization in the FASD population will allow for more tailored and timely access to supports and provide opportunities to mitigate the risks through building on strengths, resiliencies, and protective factors. Additionally, a clearer understanding of these trends will provide a current picture of service use among the FASD population in Alberta. A focus on the transition to adulthood is particularly relevant due to the changing nature of responsibilities and expectations during this period. In addition, because transition-age youth often age out of systems, they risk facing challenges accessing appropriate FASD-informed services despite the lifelong nature of their disability. The current research provided direct information regarding the intensity of service use for young Albertans with FASD who are transitioning to adulthood.

Service Use Profiles

I hypothesized that service use trends would encompass all services (i.e., medical services, mental health services, social services, educational services, and caregiver supports) given the complexity of need in this population (Brownell et al., 2013; Lynch et al., 2015; McLachlan et al., 2020; Pei et al., 2021; Streissguth et al., 2004). In line with my hypothesis, participants and their families accessed services across all sectors, at both Time 1 and Time 2. The most frequently accessed services also remained the same at both time points. Our results indicate that education services are the most frequently accessed service. Following education, caregiver services were accessed most frequently at both time points. The third most accessed service was medical services, followed by mental health services. Finally, the least accessed service was social services supports. Notably, the majority of participants did not report utilizing any interventions or supports offered through social services or by their social worker despite all participants having involvement with the provincial social (child and family) services system.

Service Use Changes Over Time

When examining the intensity of services utilized over time, I hypothesized that medical service use would increase from Time 1 to Time 2 given extant literature (Popova et al., 2016). Related to mental health, I additionally hypothesized an increase from Time 1 to Time 2 given that mental health needs of this population have been found to persist and increase over time (Pei et al., 2011). Access to these services for our population remained stable throughout this developmental period, with our sample accessing approximately two medical services (*mdn* = 2.00) at each time point and approximately 1.5 mental health services (*mdn* = 1.00; 2.00) at each time point. It is encouraging that both medical and mental health supports appear stable during this period; however, given the documented increasing mental health problems of this population, it is somewhat surprising that our sample did not appear to be accessing more supports. Notably, there are important distinctions that need to be considered when interpreting these numbers. Although the total number of services accessed did not increase, it is possible that the intensity of support *within* each service changed. For example, an increase in the number of therapy sessions accessed by the same provider would not be captured using the current methodology. Similarly, an increase in physician visits to adjust the same medication would not be captured. Therefore, our methodology indicates stability across overall medical and mental health services accessed rather than capturing intensity changes within the same service. Future research that examines the intensity of support within medical and mental health services will provide more nuanced information about service utilization of this population.

In contrast to my hypothesis that social service supports would remain high and stable at both time points given the prevalent involvement in social services agencies among individuals with FASD (Streissguth et al., 2004), our sample accessed this support the least, with less than one instance of use reported at each time point (*mdn* = 0.00). It appears that receiving supports through social services (e.g., a social worker), is an untapped resource for this population. This is somewhat alarming given recent research by McLachlan et al. (2020) indicating a range of significant needs reported by Canadian age-transitioning youth with FASD that would benefit, at the least, from liaison support from a social worker or case worker around supporting employment, securing housing, and accessing community supports. An absence of this type of involvement may be associated with current working conditions among social workers in Canada, many of whom report being chronically overworked and feeling rushed at their jobs (Began et al., 2014), thus hindering the amount and types of supports they are able to offer their clients. In addition, a lack of FASD-informed training for service providers (Boys et al., 2016; Carpenter, 2011; Clark et al., 2014; Peterenko et al., 2014) may impact the implementation of appropriate supports and services.

Finally, related to educational and caregiver services, there were no *a-priori* hypotheses stated due to the absence of research exploring service use trends in these areas. As noted previously, education services were the most accessed supports among our sample and remained stable across both time points, with participants accessing approximately 4 to 5 different supports, on average (*mdn* = 5.00, 3.50). Education services included any supports accessed within the school setting including developmental therapies (e.g., speech and language support, occupational therapy), behaviour specialist supports, social skills groups, and traditional academic supports (e.g., targeted instruction, individual program plans, small group instruction). Our results coincide with provincially reported needs of individuals with FASD and their families. For example, in their 7-year review of the Alberta Government's 10-Year FASD Strategic Plan, behaviour challenges, educational needs, and social skills were identified as the most pressing concerns for children with FASD, while social skills, adaptive skills, educational needs, and behaviour challenges were noted as the most salient concerns for youth with FASD (Government of Alberta, 2017; Wirzba & Cameron, 2014). Our results additionally complement Pei et al. (2017), who reported that all families caring for children with FASD in their sample ($N = 45$) accessed educational supports through individualized program plans, while 90% accessed developmental therapies. Currently, educational services appear to be a frequently accessed, key resource for youth and adolescents with FASD. Notably, because previous research has revealed challenges with accessing FASD-informed educational interventions (Boys et al., 2016; Carpenter, 2011; Clark et al., 2014; Peterenko et al., 2014), future research would benefit from extending the current line of inquiry to determine whether families are satisfied with the education services they received and to delineate the factors around access intensity. This is particularly relevant in the Albertan context given the Wellness, Resiliency and Partnership (WRaP) program (2009 – 2017) that aimed to provide individualized, strength-based supports in Alberta schools to children and youth affected by FASD (Trembley et al., 2021).

The final service that was examined was caregiver services, including supports such as respite, parenting classes, and mental health support, for example. Caregiver services increased significantly ($p < .05$) in our sample at Time 2, with usage increasing from just over 2 services to

3.5 (*mdn* = 2.00; 3.00). It is encouraging that caregivers are accessing supports given the challenges they face in caring for youth and young adults with FASD; it is well documented that they experience significant amounts of stress and worry (e.g., Bobbitt et al., 2016; Olson et al., 2009; Paley et al., 2006). Notably, the families that participated in this research were also knowledgeable about FASD and fairly well connected to the FASD community. All of the families had previously participated in phase one of this research, thus, they had already engaged with experts in the field and through their participation, were educated about FASD and organizations within the local area. That our sample is accessing more supports when caring for young adults is also encouraging, given the increasing amount of stress and concerns facing caregivers during this transition. For example, Bobbitt et al., (2016), found that caregivers of adolescents and adults with FASD reported increased concerns and stress compared to caregivers who cared for children with FASD under the age of 12. Because it is not possible to determine the cause of this increase, future research may benefit from exploring the kids of services being accessed and the reasons for seeking support.

It is also noteworthy to discuss the intensity of caregiver supports identified. Of all services explored, caregiver services were the second most frequently accessed supports found amongst our sample. Again, caution must be taken when interpreting these numbers as intensity *within* services was not measured, nonetheless, it is encouraging that caregivers are accessing multiple supports as the presence of a stable, predictive, and positive home environment can serve as a protective factor for individuals with FASD (Flannigan et al., 2020; McLachlan et al., 2020; Skorka et al., 2020; Streissguth, 1997; 2004) and has been found to potentially buffer some of the cognitive impacts experienced by this population (Jacobson et al., 2004). In addition, caregivers who seek support, whether through respite, education, or therapy, are likely increasing important areas of personal strength that have been found to help bolster their ability to support their dependents with FASD. For example, a literature review by Kapasi and Brown (2016) identified three major areas of strength that are salient for those caring for individuals with FASD: the first having sufficient knowledge of FASD and the impairments experienced by this group (Brown et al., 2007; Olson & Montague, 2011), second having access to support (Bailey, 2007; Brown et al., 2005; Parks & Novielli, 2000), and third having access to a positive home environment including caregivers with positive and flexible attitudes (Brown et al., 2005), strong communication skills (Streissguth, 1997), and who are able to provide a consistent, stable home environment (Olson & Montague, 2011). Overall, providing support to those caring for individuals with FASD is paramount for both the caregiver and their dependents.

Association Between Brain-Based Functioning and Service Use

With regard to EF skills during early adolescence, behavioural reports only (i.e., BREIF) were moderately correlated with later service use. First, poor MI skills during adolescence were associated with low educational services accessed during young adulthood. This finding is seemingly in contrast to previous research documenting a relationship between strong EF skills and academic success among typically developing and economically disadvantaged children and adolescents (e.g., Kotsopoulos & Lee, 2012; Latzman et al., 2010; Samuels et al., 2016; Waber et al., 2006). Although causality cannot be established, our results suggest that that those in our sample with weak EF skills in adolescence are accessing less educational services in young adulthood, rather than more. Despite the established finding that EF deficits are a hallmark of FASD (e.g., Mattson et al., 1999; 2010; 2019; Rasmussen & Bisanz, 2009, Rasmussen et al., 2007, Tamana et al., 2014) and that a large majority of youth with FASD experience prolonged academic challenges (Burnside & Fuchs, 2013; Kambeitz et al., 2019; McLachlan et al., 2020;

Streissguth et al., 2004), our sample does not appear to be accessing increasing education services (to support metacognitive skills). It is possible that these individuals seek support elsewhere, or that they are disengaged from school. Further research into the nature and causality of this relationship is needed. Second, high early behavioural regulation challenges (i.e., BRI) during adolescence were associated with a high number of medical services utilized during young adulthood. It is possible that the externalizing aspects of the BRI including challenges with inhibition, flexibility, and appropriately controlling one's emotions are especially visible to caregivers and pose unique problems that are more likely met with seeking medical support. This would be particularly relevant for the 75% of individuals in our sample with a comorbid diagnosis of ADHD. Again, future research into the nature and causality of this relationship is warranted.

Related to behavioural regulation challenges, results additionally indicated a positive and moderate correlation between high externalizing problems during adolescence as reported on the BASC-2 and later high medical service use. In addition, high behavioural symptoms (i.e., atypicality, withdrawal, attention problems) on the BASC-2 during adolescence was also positively and moderately correlated with both high medical and caregiver service use at Time 2. The same reasoning applies in that the presence of observable and challenging behaviours may warrant increased medical supports by young adulthood when the consequences of risky or dangerous behaviours increase in severity. It is possible that these challenges are related in some way with high caregiver supports, which coincides with our finding that caregiver supports also increase during this developmental period, again highlighting the likely challenges and responsibilities placed on caregivers during this developmental period.

Internalizing problems at Time 1 as reported on the BASC-2 were moderately positively correlated with mental health supports at Time 2, suggesting that high anxiety and mood symptoms during adolescence are associated with high mental health interventions during young adulthood. It is possible that while families turn to medical interventions and personal supports when dealing with externalizing and behaviour challenges, they are seeking mental health supports in the face of depression, anxiety, and somatization symptoms. Again, future research that can further delineate the link between internalizing problems and later service use trends and determine causality is warranted.

The final correlations explored the relationships between early adaptive functioning as reported on the ABAS-II and later service use. Moderate, negative correlations were found between overall adaptive skills and conceptual skills and caregiver supports, and early social skills and medical supports, suggesting that high adaptive skills at Time 1 are associated with low service use at Time 2. Because adaptive skills are a key factor in the ability to navigate virtually all aspects of daily life (Emily & Grace, 2016), stronger skills in this area may potentially support caregivers via the presence of a better home environment, leading to less stress, increased satisfaction, and the need for less caregiver intervention. This was certainly the case as documented by Emily and Grace (2016) who found that stronger adaptive skills were associated with better quality of life, as reported by caregivers of children and adolescents with autism spectrum disorder (ASD). The authors concluded that explicit and targeted intervention of adaptive skills can potentially lead to meaningful and beneficial impacts on family functioning. Future research exploring the relationship between adaptive functioning skills of individuals with FASD and caregiver need will help to elucidate this link and identify potential areas for intervention including secondary benefits for caregivers.

Clinical Implications

Results of the current research can be applied clinically, helping to bridge the gap between research and practice. It is clear that the education system is a critical, common, and accessible support for individuals with FASD. Given the call for better integrated service delivery for this population, schools could be in a position to serve as liaisons, or as a centralized service, for these families. This is particularly relevant for schools with access to consultant staff such as school psychologists and speech and language pathologists who have specialized knowledge and expertise, and who could serve as point people between organizations. Additionally, engagement with schools is vital as the environment is well suited to foster strengths in students with FASD including art, vocabulary, work habits, and sport (Flannigan et al, 2021). Engaging with and fostering areas of growth is particularly relevant for older students as graduating high school provides a sense of accomplishment, pride, and helps support future employment (Flannigan et al., 2021).

Our findings also highlight the importance of caregiver supports and add to the literature suggesting that caregivers likely require more support as their children with FASD mature (Bobbitt et al., 2016). Given the positive impacts of healthy caregivers and family functioning, clinicians are encouraged to continue recommending specific caregiver interventions including respite, mental health support, and personal wellness strategies to ensure their wellbeing. Extending this reasoning, practitioners are also encouraged to consider connecting families, including caregivers and their children, with medical and mental health services when dealing with externalizing and behavioural challenges. Ensuring these supports early on not only supports families but may also serve to mitigate more severe challenges later on.

Finally, in line with extant literature, the current results suggest that mental health symptoms (thus, an indicator of possible mental health problems) and adaptive functioning are specific areas of vulnerability within this population (Day et al., 2013; McLachlan et al., 2020; Pei et al., 2011; Rangmar et al., 2015; Streissguth et al., 2004; Temple et al., 2011; Weyrauch et al., 2017). In addition, the presence of these challenges during adolescence appears to impact in some way, the state of service use later on. It is incumbent on clinicians who work with this population to provide options for early mental health support and interventions that target adaptive skills. Specifically, individuals who present with internalizing problems (e.g., anxiety) will likely benefit from mental health treatment that specifically addresses these challenges. Again, this may not only provide adolescents with FASD an opportunity to develop coping skills and strategies early on but might also mitigate the need for more support as they mature, a finding that is especially relevant given decreased access to services when aging out of youth programs. Related to adaptive functioning, practitioners are also encouraged to provide recommendations or interventions that are aimed at developing these skills for adolescents with FASD. Strong independent living skills is not only important for individuals with FASD but appears to be particularly beneficial for caregivers later on, again highlighting the importance of relevant, specific, time-sensitive intervention (Pei et al., 2021).

Limitations and Future Research

There are a few limitations that are worth noting. Due to the exploratory nature of this research, future studies would benefit from utilizing a larger sample size, thus allowing for more in-depth analysis that can infer causality. Replication studies are also encouraged. However, despite the low power of the current research, the number of significant correlations that were found is promising. Having a clearer understanding of the associations between early brain-based functions and later service use will provide important information about the potential of early intervention and the benefits that occur later on in development. A better understanding of where to target early intervention is especially important given the potential for later economic impacts when service use is decreased.

The current study emphasized the link between services being accessed and areas of need reported in the FASD population. However, this link was hypothetical at best due to limitations in methodology and low power. Future research may wish to extend this area of inquiry to investigate whether caregivers feel their needs are being met through the services they are accessing. This will also help to contextualize service use intensity.

The final limitation relates to participant demographics. It is documented that a large majority of individuals with FASD do not have the opportunity to access early diagnosis and interventions, thus leading to increased challenges later on and unhealthy outcomes (McLachlan et al., 2020; Streissguth et al., 2004). Positively, this was not the case for the participants who volunteered in the current study. All individuals received early diagnosis and the majority were living in secure and fairly consistent home environments with caregivers who were knowledgeable and somewhat connected to FASD supports in their communities. Although this may limit the generalizability of the current results, it can serve as a “best case scenario” and continue to underscore the importance of interventions for individuals with FASD and their caregivers.

Conclusion

The current exploratory study investigated the pattern of service use, longitudinally, among a small group of individuals with FASD and their caregivers. It also examined the relationships between early brain-based functions including EF, mental health, and adaptive functioning, and later service use. Findings revealed that all areas of services were accessed both during adolescence and during young adulthood. Among the five services examined, education and caregiver services were accessed most frequently, followed by medical, mental health, and social services. The intensity of access remained stable across both time points with the exception of caregiver services, which increased at Time 2. Overall, these results suggest that families are accessing a wide range of services to support their dependents with FASD, with educational institutions serving as the most commonly accessed support. Positively, caregivers are also accessing supports for themselves, particularly when their children are transitioning to adulthood. Results additionally suggest that there is a relationship between early challenges with EF and mental health and an increase in later service use access. Finally, stronger adaptive skills appear to be related to a later decrease in service use. Future research that contextualizes the intensity of services accessed and that can delineate the relationships between brain-based functions and later service use is warranted.

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Chapter 5: Conclusion

Fetal Alcohol Spectrum Disorder (FASD) is a neurodevelopmental disorder that is caused by prenatal alcohol exposure (PAE). Decades of research has shown that individuals with FASD experience a wide array of cognitive, learning, emotional, and behavioural challenges that persist across the lifespan (Cook et al., 2016; Mattson et al., 2019). Due to these challenges and the complex interactions that take place between these individuals, their relationships, and their environment, adverse life outcomes for this population are also common. For example, individuals impacted by PAE commonly experience challenges securing housing and employment, graduating, abstaining from substances, and become involved in the legal system (e.g., criminal offending, victimization, incarceration) (Clark et al., 2004; Lynch et al., 2015; McLachlan et al., 2020; Rangmar et al., 2015; Streissguth et al., 2004). Historically, the majority of research attempting to delineate the neurocognitive profile and long-term outcomes of individuals with FASD has done so using a narrow, deficit-focused lens (Flannigan et al., 2021). Research adopting a strengths-based approach to FASD is needed, as this will provide a more holistic, multifaceted understanding of this disorder that includes the individual, their families, and their environment (Flannigan et al., 2020; Flannigan et al., 2021).

The foundation of my research rests upon the notion that development is influenced by the environment, and that the environment can influence development. Broadly, my theoretical orientation stems from Bronfenbrenner's (1979) ecological theory that individual development is transactional and is impacted by the many relationships and environments that interact with individuals. Through integration of ecological theory and using a strengths-based approach, my dissertation was developed around two overarching goals. First, I aimed to provide information about the longitudinal development of executive functioning (EF) in individuals with FASD, specifically during the transition into young adulthood. Second, I sought to provide information about how to better support healthy outcomes in individuals with FASD.

Three related but independent papers addressed these goals. In paper 1 (*Theories and Development of Executive Functioning: A Literature Review*), I discussed the current theories of EF and the development of EF among typically developing individuals. I also discussed the challenges surrounding this construct and provided implications for future directions and clinical practice. In paper 2 (*Longitudinal Development of Executive Functioning Among Individuals with Fetal Alcohol Spectrum Disorder*), I examined the longitudinal development of EF among individuals with FASD between adolescence and young adulthood. I found areas of both strength and need within the domain of EF and possible differences in its developmental trajectory during this period. This is a novel contribution to the literature and addressed an important gap in our understanding of EF development during this critical period. I also examined the relationships between EF development in adolescence and later functional outcomes in young adulthood in this population and found that EF both predicts and is significantly associated with areas of later healthy functioning. In paper 3 (*Supporting Individuals with Fetal Alcohol Spectrum Disorder: Trends in Service Use)*, I investigated service use patterns among individuals with FASD and their caregivers during adolescence and young adulthood. To my knowledge, there are no studies that have investigated service use trends (i.e., medical, social, educational, mental health, and caregiver services), longitudinally, during this critical period. I also examined the relationships between EF, adaptive functioning, and mental health during adolescence, and later service use intensity across the same services. In general, I found that a broad array of services are accessed throughout this critical period by both individuals with FASD and their caregivers. Multiple significant associations between early areas of functioning (i.e., EF, mental health, adaptive functioning) and later service utilization were indicated.

Findings

Paper 1: Theories and Development of EF: A Literature Review

Definitions of EF vary considerably in the literature. Broadly, as a psychological construct, EF refers to a set of cognitive control processes, mainly supported by the prefrontal cortex (PFC), that regulate the dynamics of human cognition and action (Miyake & Friedman, 2012). However, there is currently no agreement in the field about a precise definition of EF, nor have researchers agreed upon a theoretical conceptualization of this construct. Developmental theories of EF generally fall into three broad categories: 1) unitary frameworks that view EF as a unitary construct with constituent subprocesses (e.g., Munakata, 2001, Munakata et al., 2012; Zelazo & Frye, 1998; Zelazo et al., 2003; Zelazo & Müller, 2011); 2) dissociable frameworks that view EF as consisting of separate processes (e.g., Diamond, 2001, 2006); and 3) integrative frameworks that view EF as distinguishable but share some common underlying function (e.g., Miyake et al., 2000; Miyake and Friedman, 2012). Using an integrative framework, three latent variables of EF (i.e., working memory, inhibition, shifting) and their developmental trajectories were then reviewed. Finally, the complexities surrounding evaluation of EF was discussed.

Moving forward, it is imperative that clinicians have a solid understanding of EF, including knowledge of a theoretical framework and the developmental trajectories of EF constructs, to ensure a “big picture”, integrated approach to the evaluation of EF. It is also critical that clinicians understand the challenges in isolating EF skills and that our clinical tools are susceptible to task impurity. Thus, EF test labels are often not accurate indicators of what a test is truly measuring (Miyake et al., 2000). Finally, clinicians are encouraged to use multiple tests of EF including both simple and complex tasks; having an aggregate of results will help address task impurity and offset possible interference from other skills by looking for themes (Miyake et al., 2000).

Paper 2: Longitudinal Development of EF Among Individuals with FASD

Development of EF between adolescence and young adulthood in individuals with FASD is unique. In line with previous research (e.g., Mattson et al., 2019; Rasmussen & Bisanz, 2009; Rasmussen et al., 2013) I found that at the mean level, these individuals experienced significant challenges across the majority of EF tasks (compared to the norm) during adolesce and young adulthood and that most areas of EF remain stable throughout this developmental period. Of note, there were some exceptions. The areas of EF that increased in severity (compared to the norm) between adolescence and young adulthood were observed on behavioural reports of EF only. Specifically, metacognitive skills (MI) (e.g., initiating, working memory, planning and organizing, organizing materials, monitoring) and thus overall EF skills (i.e., GEC) increased in severity during this developmental period. Two areas of relative strength were also observed, both on performance-based asks. Specifically, mean performance on the switching task was within normal limits (i.e., normative average range) at both time points, while mean performance on the inhibition task during young adulthood only was also within the normative average range suggesting that not all areas of EF are significantly impaired among this population.

Intraindividual variation (IIV), or the individual variation in performance between time points on all EF tasks, was also examined. I found a significant amount of IIV in both directions. On performance-based tasks, 45% of the sample experienced IIV of at least one standard deviation on 1 or more tasks in either direction despite the finding of no significant mean-level changes between time points. Specifically, inhibition was especially susceptible, with 64% of the sample experiencing significant change in their performance (two participants decreased in performance while seven participants increased). On the switching task, 42% experienced significant change (two participants decreased in performance while three increased). Finally, on the sorting task, 28% experienced significant change (two participants decreased in performance while two participants increased). On behavioural reports of EF, 30% of the overall sample were rated significantly different on at least once score. Specifically, 0n the BRI, 30% were rated significantly different (two participants decreased in performance over time while one increased). On the MI, 60% were rated significantly different (4 participants decreased in performance over time while two increased). Notably, mean-level change was significant for the MI.

When examining the relationship between early EF skills and later healthy outcomes (i.e., indicators of mental health, adaptive functioning skills), early EF challenges were associated with poorer outcomes during young adulthood. Specifically, according to behavioural reports of EF, dysfunction in both behaviour regulation and metacognitive skills during adolescence were associated with later problems with social skills. In fact, behaviour regulation problems were not only correlated, but predicted later social skills challenges. In terms of performance-based tasks, only cognitive flexibility (i.e., switching task; notably, an area of relative strength) was associated with later outcomes. Specifically, stronger cognitive flexibility skills during adolescence were associated with higher practical skills, and lower behavioural symptoms during young adulthood.

Paper three: Supporting Individuals with FASD: Trends in Service Use

Previous research has indicated that individuals with FASD access a broad array of services due to the vast needs of this population (Brownell et al., 2013). My results are in-line with these findings as all five services were accessed at both time points. Despite the finding that individuals with FASD face challenges accessing services as they age out of child/youth systems (Chamberlain et al., 2017), the intensity of service use (i.e., number of services accessed) during this critical period remained stable across all services among my sample. One notable exception were caregiver services; caregivers of individuals with FASD significantly increased the number of services they accessed as their children entered young adulthood. Finally, education services were accessed most frequently, followed by caregiver services, medical services, mental health services, and social services.

In terms of the associations between early EF, indicators of mental health, and adaptive functioning and later service use, multiple moderate significant correlations were found. Specifically, behavioural reports of high behaviour regulation problems were associated with high use of medical services. Conversely, high metacognitive regulation problems were associated with low use of education services. Related to indicators of mental health, high externalizing problems were associated with high use of medical services, high internalizing problems were associated with high use of mental health services, and high behavioural symptom problems were associated with both high medical service use and high caregiver service use. Finally, with regard to early adaptive functioning skills, high early social skills were associated with low use of medical services, while high conceptual skills and high overall adaptive skills were both associated with low use of caregiver services.

Final Discussion and Implications

EF Development and FASD

In this dissertation I contributed to the understanding of the development of EF among individuals with FASD. Rather than view EF skills as uniformly weak among this population, my findings suggest the presence of some typically developed (i.e., areas of relative strength) skills. It is also possible that the developmental trajectory of inhibition among this population differs from what is observed in typically developing individuals. Rather than observing large improvements in inhibition during early to middle childhood (Romaine & Reynolds, 2005), it is possible that individuals with FASD experience a delay in this area and do not catch up until late into their teen years and early twenties. Future research that explores the longitudinal development of inhibition skills more robustly (i.e., using multiple measures of inhibition with a larger sample size) into adulthood among this population is needed.

These findings carry important implications. First, when given a structured, clam environment where task demands are well understood, individuals with FASD may be able to leverage their strengths more readily. This underscores the importance of providing appropriate and optimal environments for individuals with FASD, particularly in situations where they are expected to perform at their best and when stakes are high (e.g., academic and work settings). To do this, Pei et al. (2021) outlined a series of evidence-based guiding principles to consider when supporting individuals with complex needs, including those with FASD, some of which are particularly relevant to providing environments that foster success. For instance, employers are encouraged to have knowledge about complex case management as this allows for awareness and responsiveness to communication, learning styles, and cultural and socioeconomical circumstances of families. An emphasis on interdependence rather than independence was recommended as individuals with FASD often require support throughout their lives to support their success. Client-centered employment services that include individualized vocational counseling and supportive supervision and training that balance structure and flexibility in the workplace were suggested to support placements and sustaining employment. Finally, an individualized education/program plan (IEP or IPP) in academic setting was recommended as these can enhance learning and help to ensure the programming needs of these individuals. Both researchers and clinicians are also encouraged to note strengths, as doing so can promote a sense of competence, increase well-being and resilience, provide hope and optimism to caregivers, and can extend support to other environments (Carter et al., 2015; Grove et al., 2018; Lee et al., 2018; Riosa et al., 2017; Shochet et al., 2019).

Second, these results shed light on the differences between performance-based measures of EF and behavioural reports of EF, as the latter scores were chronically low and stable with no evidence of typical performance. Although exploring differences between "hot" and "cool" EF is beyond the scope of this manuscript, there is evidence that children with FASD tend to show greater impairment on behavioural rating scales than on performance-based measures of EF (Gross et al., 2014). The current findings extend this to include adolescents and young adults with FASD. It is also suggested that behavioural reports are more accurate indicators of "real world" functioning than performance-based results (Gioia & Isquith, 2004; Anderson et al., 2002). As such, both researchers and clinicians are encouraged to use multiple measures of EF when evaluating this construct to ensure they are gaining a broad picture of EF development across multiple settings and that areas of strength are captured.

Finally, the current results indicate that intraindividual variation (IIV) on both performance-based measures and behavioural reports of EF is common among adolescents and young adults with FASD. Significant IIV has also been found when examining children with FASD using a larger sample size (*n* = 67), but questions remained whether IIV in this population follows the typical U-shaped projection (i.e., that it decreases during late adolescence and into adulthood) that is observed in typically developing individuals across their lifespan (see

MacDonald et al., 2006 for a review). The current results provide preliminary evidence that IIV continues beyond childhood for this population; future research and/or replication studies using a larger sample size and a control group is warranted. These results also support the myriad of grey literature discussing the inconsistencies in performance of this group, that ‘on days’ and ‘off days’ are normal, and that at times, these children perform similarly to their typically developing peers on some days and not others (Kjellmer & Olswang, 2012). Such variability underscores the importance of training caregivers, educations, and other professionals who work in the field of FASD to ensure an understanding of the heterogeneity of this disorder. It is also in line with a call for more holistic assessment and treatment approaches of individuals with FASD that consider the changing needs, functionalities, abilities, and circumstances of these individual throughout their life (Flannigan et al., 2020).

Supporting Healthy Outcomes

Social Skills

The current findings also highlight the relationship between individuals with FASD and their environments. Results are in keeping with general developmental theory and the myriad of research indicating that early functioning is associated with later outcomes; more specifically, that early intervention is critical in supporting individuals with a range of needs (e.g., Casto & Mastropieri, 1986; Garces et al., 2002; Landa, 2018; Love et al., 2005). This appears especially salient for later social skills development as behavioural regulation skills during adolescence predicted later social skills during young adulthood. This finding extends earlier research that found the same relationship among a group of younger children with FASD (Schonfeld et al., 2006) and suggests that social skills continue to be impacted by poor behaviour regulation as individuals with FASD mature. Furthermore, early metacognitive regulation was also associated with later social skills development, although this association was not predictive. Nevertheless, it implies that at some level, an individual's ability to engage in higher-order regulation such as planning, working memory, and self-monitoring, is associated with social skills as a young adult. This extends previous research that found a high and significant correlation between metacognitive regulation and social skills among children with autism spectrum disorder (Berenguer et al., 2018; Freeman et al., 2017; Pugliese et al. 2015). Together these results suggest that targeting behaviour regulation skills in adolescence may help bolster later social functioning during young adulthood, thus mitigating further unhealthy outcomes related to poor socials skills.

Caregiver Support

Targeting social skills during adolescence might also play an important role in shaping what services are accessed later during young adulthood. The current results indicate a significant association between stronger early social skills and a reduction in later medical service access. Conversely, observable behavioural challenges during adolescence, including both behavioural symptoms (e.g., strange behaviour, withdrawal, attention problems) and externalizing problems (e.g., hyperactivity, aggression, conduct problems) were significantly associated with higher use of medical services. Together these findings imply that caregivers might be turning to medical services specifically to help support their children with FASD who are displaying observable behaviour and socialization problems (and perhaps the opposite is true). This is an interesting finding, particularly given that caregivers of children and youth with FASD often report feeling unsupported by medical professionals (Salmon, 2008; Sanders & Buck, 2010; Watson et al., 2013) and may perceive health professionals as unaware of the symptoms associate with FASD (Salmon, 2008; Whitehurst, 2012). It is possible that despite these challenges, caregivers are left with no alternatives for support or nowhere else to turn. Future research that explores in more depth, the nuances of seeking medical support and if this is indeed viewed as a solution to help with social skills and behavioural challenges is warranted. Clinicians are also encouraged to help families access medical supports and encourage information sharing.

Related to these findings, the current results also suggest that there is a relationship between caring for adolescents with FASD who are displaying significant behavioural challenges and caregivers themselves seeking more supports when their children with FASD reach young adulthood. Caution must be taken when extrapolating these findings due to the limitations around correlations. However, results are in line with a multitude of research indicating that caregivers of children and youth with FASD experience increased levels of stress (e.g., Bobbitt et al., 2016; Olson et al., 2009; Paley et al., 2006). In a recent review of the lived experiences of children with FASD and their caregivers and the impacts on their families, Skorka and colleagues (2020) found that caregivers frequently reported experiencing challenges in managing the complex needs of their children with FASD and felt they were struggling to effectively care for their children; caregivers additionally reported perceptions that teachers and health professionals considered poor parenting was contributing to their child's behaviours. The authors additionally indicated that caregiver burnout and experiencing negative impacts to their well-being was common. Caring for children with FASD has also been found to be more stressful on caregivers compared to other neurodevelopmental disabilities including autism spectrum disorder (ASD; Watson et al., 2013). Positively, it is promising that caregivers appear to be accessing increased supports for themselves.

Although research investigating how caregivers care for themselves is sparce, Kautz et al. (2021) found that caregivers who report higher confidence in their ability to engage in self-care also report higher family needs being met, higher satisfaction with their role as a parent, and lower parental stress. Common self-care strategies that were used included staying in the present, seeking social support, maintaining physical health, engaging in hobbies, consuming media, treating oneself to small luxuries, and seeking information. Interestingly, frequency of accessing self-care was not correlated with a reduction in caregiver stress, rather, it was the perception of their self-care abilities that mattered, thus suggesting that targeting attitudes and perceptions may be more important than providing more supports. Together these findings not only stress the importance of providing caregiver support, but also the importance of identifying caregiver strengths and working with caregivers so that they are better able to actualize where they are successful, in what ways they can support their well-being, and the skills that they have that are working. Although research exploring caregiver strengths among this population is sparce, Kapasi & Brown (2016) identified four themes that were reported by a group of caregivers including the ability to be flexible, staying patient and being understanding, using nonverbal and sensory strategies to support their children, and accessing external supports. Professionals working with caregivers for individuals with FASD are encouraged to identify these strengths while also leveraging them to help support these families.

Mental Health

The final major finding related to supporting healthy outcomes in individuals with FASD is related to mental health services. Current results suggest an association between adolescents with FASD experiencing significant internalizing symptoms (e.g., depression, anxiety, somatization) and accessing a high rate of mental health services during young adulthood. Again, these findings are correlational and do not imply causation. However, it is possible that teens with FASD who are distressed and exhibiting symptoms of anxiety and depression also seek high rates of mental health services when they are older. That these young adults are accessing services is encouraging as it is well understood that mental health challenges are especially common among this group (Pei et al., 2011). Clinicians and other professionals working with individuals with FASD and their families are strongly encouraged to assist all individuals with FASD in finding mental health supports. This is especially true for principal health care providers as they are trained in screening, prevention, and management of health needs and can coordinate referrals as required (Hanlon-Derman et al., 2015). Unfortunately, it is often the case that physicians (i.e., pediatricians) and other healthcare workers, despite knowledge about FASD, have limited access to training and do not feel equipped to manage the complexity of these patients (Corrigan et al., 2019; Gahagan et al., 2006, 2007). As such, anticipatory guidelines have been developed by Hanlon-Derman and colleagues (2015) in an effort to guide primary health care providers in supporting these patients. A full summary of their guidelines is beyond the scope of this paper; however, it is worth reviewing some relevant anticipatory guidance points recommended in the care of adolescent and young adult patients with FASD, particularly as they pertain to impacting mental health and healthy functioning. For example, it is recommended that physicians discuss their physical health needs; review medications including transitioning to independence, side effects, and preferences; discuss the harm of alcohol use during pregnancy; discuss mental health concerns and make appropriate referrals as necessary (trauma-informed therapy may be required); advocate for educational supports and/or updated assessment if required; advocate for community supports and a high level of supervision; discuss the process of transitioning to adult supports with caregivers starting at age 12 years; discuss with teens their diagnoses and the importance of lifelong mentors and supports; take care not to blame caregivers; and discuss respite and support for caregivers, particularly if there are mental health issues present. I also encourage psychologists who work with these individuals and their families to adopt these recommendations, as appropriate, to help provide more thorough care.

Final Thoughts

FASD is a lifelong neurodevelopmental disorder that has a broad array of impacts on the brain and body. Although much is understood about the range of challenges and adverse life outcomes experienced by this population, researchers are slowly beginning to focus on the kinds of strengths these individuals possess and emphasize on ways to not only mitigate risks but support healthy outcomes (e.g., Flannigan et al., 2020, 2021; Kully-Martins et al., 2021; Petrenko & Kautz-Turnbull, 2021). It is my hope that this manuscript adds to this literature and provides relevant and tangible strength-based suggestions and helps to identify where individuals with FASD can flourish. It is also my hope that as more evidence of how to best ensure healthy outcomes becomes available, increases in supports and appropriate FASD-informed interventions will follow.

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