

THE LIFE STORIES OF INDIVIDUALS WHO AS ADULTS WERE IDENTIFIED AS  
EXPERIENCING THE EFFECTS OF FETAL ALCOHOL SPECTRUM DISORDER

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A DISSERTATION

in

Social Work

Presented to the Faculties of the University of Pennsylvania

In

Partial Fulfillment of the Requirements for the

Degree of Doctor of Social Work

2015

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## Acknowledgments

The writing of this dissertation has been one of the most significant academic endeavors I have undertaken. Completion of this dissertation was only possible because of the support and encouragement of my interview participants, dissertation committee, family and friends. I cherish each individual's contribution to my development as a scholar and clinician.

I am indebted to the participants interviewed for this dissertation. Their courage and generosity of spirit is inspiring. It is my deepest hope that I have honored the stories and experiences shared with me. I am grateful for each participant's enthusiasm and patience during the interview process.

I am deeply grateful to my dissertation chair, Jeffrey Applegate, PhD. for his fundamental role in my doctoral education. His kindness, wisdom and commitment to the highest standards both inspired and motivated me while writing this dissertation. He embodies the ideal of a compassionate and wise mentor. His spirit of patience and gentle direction encouraged me to challenge myself and grow in ways I could not have foreseen. I am fortunate to have completed this dissertation under his tutelage.

I would like to thank the rest of my committee members: Deborah Rutman, PhD. and Robert Carey, Psy.D. They each provided valuable insight and feedback to ensure that the experiences of persons with FASD were captured accurately and respectfully. I greatly appreciate their patience in what became a lengthy dissertation process.

I would like to acknowledge my editors Christian and Steff for reading and responding to countless drafts. I appreciate all of their suggested edits and encouraging sentiments.

Additionally, I would like to express my gratitude to two members of my cohort: Michelle and

Shiloh. They dedicated time to review each interview and engage in a scholarly discussion of themes.

To my valuable network of friends and colleagues, without your support and forgiveness I would have lost my way on numerous occasions.

I am genuinely grateful for the love, encouragement and sacrifice of my parents, Tim and Deb. Thank you for your tireless support during my many long years of education. I am proud to be your daughter.

Finally, I am overwhelmed by the selfless love and support of my husband Brent, who I met during my first month of doctoral studies. He read countless drafts, served as a sounding board and always believed I could finish this dissertation. These past four years have been wonderful and I can't wait to see what is on the trail ahead!

## **Abstract**

### THE LIFE STORIES OF INDIVIDUALS WHO AS ADULTS WERE IDENTIFIED AS EXPERIENCING THE EFFECTS OF FETAL ALCOHOL SPECTRUM DISORDER

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The teratogenic effects of prenatal alcohol exposure (PAE) can cause irreversible physical and neurological impairments that are present at birth and can have lifelong implications (McGee & Riley, 2007). One's capacity to interact productively and effectively with one's surroundings can be influenced further by positive and negative life events and access to appropriate social support services (Center for Disease Control and Prevention, 2004). Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe a group of diagnoses and effects related to prenatal alcohol exposure (Center for Disease Control and Prevention, 2004).

Since the effects of alcohol on a fetus were not recognized formally until the mid-twentieth century, it is likely there are generations of people who are affected by this condition but remain unidentified because they were born before the sequelae of gestational alcohol exposure were understood and well documented (Massey, 2011). Few scholarly works exist that accurately represent the subjective experience of adults who have lived with the unidentified characteristics of prenatal alcohol exposure and the social and cultural factors that influence the development of their individual identity.

A narrative-style qualitative research methodology was used to explore the identity of adults living with FASD, in particular those who learned about this during adulthood. The researcher interviewed four adults living with the effects of FASD who became aware of their FASD as adults and reviewed several published autobiographical accounts as additional data

sources. Upon analysis, themes of identity emerged and parallels between the life stories of the participants and other studies that address the psycho-social effects of FASD were identified. The research results suggest implications for social work practice, bring positive attention to a disenfranchised group, identify areas of needed study and shed insight into how adults living with the effects of FASD conceptualize their identity.

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## Preface

Volunteering at a Special Olympics event in 1994 was life changing. I was captivated and knew that I wanted to positively impact people with special needs and help them become engaged members of their communities. Since the initial encounter at the Special Olympics, I have successfully provided support to those with special needs through advocacy, system change, trainings and individual intervention. That is until approximately 2008 when I met Mike<sup>1</sup>. He was full of life but consistently struggled with impulsivity, destructive behavior and the consequences of poor decision making. It felt as if all of the textbook techniques and tools that I possessed proved to be ineffective in assisting Mike. It felt like “nothing worked.” As I researched ways to support him, I came across three letters: F-A-S. This became a turning point in the personal and professional support I provided Mike, as well as the effect it would have on my future career.

I was aware that drinking alcohol while pregnant could affect an unborn child, yet I was unfamiliar with the diagnosis of Fetal Alcohol Syndrome (FAS) and the term Fetal Alcohol Spectrum Disorder (FASD). As I began to research the neurological effects of prenatal alcohol exposure, its behavioral manifestations and which interventions were more effective when working with persons living with FAS, a light bulb went off. The supports I had been providing were not only inadequate and ineffective, but also potentially counterproductive to his actual needs.

This prompted me to review the history and case files of several other clients who exhibited similar characteristics, including experiencing difficulty in meeting their personal goals and trouble managing various aspects of daily life. Buried in the old case notes, evaluations and

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<sup>1</sup> Name changed to protect identity.

assessments of several clients were diagnoses of FAS, partial fetal alcohol syndrome (pFAS), fetal alcohol effects (FAE) or a notation of reports indicating maternal drinking while pregnant. While these individuals and their support teams continue to identify and manage challenges, they are able to equip themselves with better support tools and a deeper understanding of the reason behind many of the challenging behaviors being exhibited.

I began actively and voraciously searching for references, resources and a clinical mentor to help me navigate these various new tools so I could provide the best possible support services for adults living with FASD and ultimately assist them in living productive, fulfilling lives. It quickly became clear that there are a significant number of people living with the effects of FASD, yet a paucity of research into their lived experiences to inform and influence social work practice.

Following this realization, I applied to the Clinical Social Work Doctoral program at the University of Pennsylvania. An admissions essay outlined a personal and professional desire to increase my practitioner, educator and researcher skills while simultaneously adding to the scholarly literature available to those supporting adults with FASD.

This dissertation process has opened my eyes to the complexity of FASD. FASD does not solely impact an individual living with FASD. It affects families and communities, impacts other support services and has far-reaching system and policy implications. These experiences and implications need to have great consideration when investigating FASD. I have learned much during this dissertation. I hope any of my imperfections do not overshadow the needs, resiliency and strength of those impacted by FASD.

Since beginning this research process, there continue to be more personal stories told via websites and a growing interest in providing personalized and appropriate support for adults

living with the effects of FASD. Yet, research focused on personal deficits, children, adolescents or the medical perspective continues to be overrepresented. The following research will address some of the gaps in current literature by exploring the life experiences of adults living with the effects of FASD whose condition was identified during adulthood.

## **Chapter One: Introduction**

### **Purpose**

The purpose of this qualitative research is to enhance practitioners' understanding of the experiences and self-identity of those identified with FASD during adulthood. The study investigates how these adults understand their lives as well as the social and cultural factors that have influenced their understanding.

### **Problem statement**

The teratogenic effects of prenatal alcohol exposure can cause irreversible physical and neurological challenges present at birth that may have lifelong implications (McGee & Riley, 2007). These permanent conditions may be observed through a person's social, emotional and cognitive behavior (Kelly, Day, & Streissguth, 2000). One's capacity to interact productively and effectively with one's surroundings is influenced further by life events and access to appropriate social support services (Center for Disease Control and Prevention, 2004).

Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe a group of diagnoses related to prenatal alcohol exposure. This group includes Fetal Alcohol Syndrome (FAS), which is a medical diagnosis characterized by growth problems, specific facial features and central nervous system issues (Davis, Desrocher, & Moore, 2010).

The Center for Disease Control (CDC) previously estimated that Fetal Alcohol Syndrome (FAS) occurs in 0.2 to 1.5 per 1,000 live births (Center for Disease Control, 2004). A recent study authored by May, et al. (2014) found the prevalence of children with FAS to be 6 to 9 children per 1,000 live births and Partial Fetal Alcohol Syndrome (pFAS) to be 11 to 17 children per 1,000 live births. The estimated total prevalence of Fetal Alcohol Spectrum Disorder (FASD) was found to be 24 to 48 per 1000 children per live births (i.e., potentially, 2.4% to 4.8% of



children in this community have FASD) (May et. al., 2014). There are currently no accurate estimates of the prevalence of FASD or the number of adults living with the effects of prenatal alcohol exposure who do not meet specific diagnostic criteria (Chudley, Kilgour, Cranston & Edwards, 2007).

Although the effects of gestational alcohol exposure were formally published in 1972, an accurate diagnosis continues to be challenging for the medical community. Frequently, the need for diagnosis is challenged, often by physicians and psychiatrists (Devries & Waller, 2004, p. 122). Physicians and health professionals (Diekman, et al., 2000; Abel & Kruger, 1998), psychologists (Wedding, et al., 2007) and obstetrician-gynecologists (Anderson, et al., 2010) report significant knowledge, skill and attitude deficits which could contribute to the ongoing under-recognition of the possible effects of gestational alcohol exposure. Due to lack of awareness and diagnostic capacity, there continues to be overall challenges accessing diagnostic services in the United States (Astley & Grant, 2014). It was not until the second half of the twentieth century that this exposure received sufficient attention to encourage the current lifestyle recommendations during pregnancy, i.e., that women should abstain from alcohol when pregnant (Armstrong, 1998; Davis, Desrocher, & Moore, 2011; Streissguth & O'Malley, 2000).

Those with FASD are often overrepresented in systems in which social workers and other social support workers are present. A high number of persons with FASD and their families seek assistance for mental health issues (Streissguth & O'Malley, 2000). Persons with FASD are thought to be overrepresented both within the correctional (Burd, Selfridge, Klug & Bakko, 2004) and foster care systems (Astley, Stachowiak, Clarren, & Clausen, 2002). A person living with FASD likely has accessed a variety of support services, including those provided by social workers, educators and mental health professionals (O'Connor & Paley, 2009; Paley &

O’Conner, 2011) which have varied in appropriateness and effectiveness throughout his or her lifetime.

The lack of a diagnosis does not negate the fact that those affected by prenatal alcohol exposure struggle with a spectrum of complex issues, including: difficulties with problem solving and planning (Green, et al., 2009; Kodituwakku, 2009; Mattson et al., 1997; Streissguth, et al., 1991), executive functioning (Rasmussen & Bisanz, 2009) and generalizing knowledge (Streissguth & O’Malley, 2000). Additionally, while a history of PAE can alert support professionals to potential need areas, a diagnosis related to FASD does not provide sufficient information for social support professionals. This is due to the heterogeneity that exists amongst people with FASD and the variance in their life experiences and circumstances (Paley & O’Conner, 2009). To be representative of the experience of all persons living with the effects of gestational alcohol exposure, the non-diagnostic umbrella term FASD, which includes the FAS diagnosis, will be used. This is meant to include all people living with prenatal alcohol exposure regardless of formal diagnosis. When citing source material, original terminology will be used.

Current literature favors the largely deficit-based perspective of studies that focus on social or behavioral functioning and those related to describing physical and neurological differences. In recent years, there have been a few published studies aimed at providing a more balanced perspective. These include studies related to the following: education interventions (Bertrand, 2009), advocacy (Grant, Ernst, Streissguth, & Porter, 1997), community intervention (Grant, et al., 2004), the experience of parenting with an FASD (Rutman & Van Bibber, 2010), insight into the young adult experience with FASD (Ryan & Ferguson, 2006), experience of women with FASD and substance abuse issues (Rutman, 2011), experiences of transitioning to adulthood from child welfare care (Burnside & Fuchs, 2013) and parenting a child with FASD (Leenaars,

Denys, Henneveld, & Rasmussen, 2011). There are few scholarly works that represent the lived experiences and identity of adults with FASD, as well as the factors that influence the development of individual identity.

The ongoing challenges associated with the diagnosis and awareness of the effects of prenatal alcohol exposure mean that there are adults and children who have significant difficulty in everyday life who can benefit from access to appropriate and effective health and social supports. This population has compelling yet unheard life stories and an unexplored identity. Gaining insight into how adults with FASD understand their life experiences is critical for improving social work knowledge and practice.

## Chapter Two: Literature Review

### Fetal Alcohol Spectrum Disorder and Prenatal Alcohol Exposure

**Historical context.** Throughout history, alcohol has been used for a variety of purposes including the following: as medicine, a nutritional food source, an alternative for contaminated water, part of religious worship, a way to define gender roles, as well as for celebration and recreation (Mandelbaum, 1965; Vallee, 1998).

The Roman and Greek empires recorded the possible effects of gestational alcohol exposure. Aristotle declared that “foolish, drunken, harebrained women most often bring forth children like unto themselves, morose and languid” (Calhoun & Warren, 2007). Judeo-Christian philosophies warned against drinking while pregnant. “You have conceived a son...now drink no wine or strong drink” (Old Testament, Judges 13:7).

The first scientific inquiry into the effects of gestational alcohol exposure was completed by Dr. William Sullivan in 1899 while working with incarcerated women. Sullivan observed higher rates of pregnancies resulting in stillbirths in women who actively used alcohol in comparison to mothers who did not actively use alcohol during pregnancy (Sullivan, 1899, as cited in Calhoun & Warren, 2007; Spohr & Steinhausen, 2008).

During most of the twentieth century, there was insufficient investigation of the effects of alcohol exposure on unborn fetuses. Research was not conducted, in large part, due to the temperance movement, social mores of alcohol use and the late recognition of females who chronically use alcohol in society (Armstrong, 1998; Musto, 1996). It was not until 1968 that a study published by Dr. Paul Lemoine appeared in the French medical journal *Ouest Medical* and outlined trait commonalities of children whose mothers actively drank during pregnancy. In 1973, Drs. Kenneth Jones and David Smith of the United States published the first international

article detailing FAS and describing common physical traits of children born to women who actively drank during pregnancy (Jones, Smith, Ulleland, & Streissguth, 1973; Jones & Smith, 1973). Shortly thereafter, research about the physical and biological attributes of those with FAS captured the interest of the medical community.

Medical and scientific professionals recognized the implications of these findings, though the process of raising social awareness and changing public policy is ongoing. In 1977, the National Institute on Alcohol Abuse and Alcoholism (NIAAA) released the first published warning regarding alcohol use during pregnancy (Thomas, Warren, & Hewitt, 2010). The initial guidelines recommended a daily two drink limit and suggested that consuming more than six drinks per day was potentially dangerous. In 1981, the Surgeon General's Office issued another warning stating "drinking alcohol while pregnant can lead to birth defects" (Office of the Surgeon General, *News Release*, 2005). In 1989 this became a mandatory warning label placed on alcohol bottles (Thomas, Warren, & Hewitt, 2010). Based on contemporary scientific findings, the Surgeon General's office reissued this warning in 2005. It stated that women who are pregnant or planning to become pregnant should abstain from alcohol use (Office of the Surgeon General, *News Release*, 2005).

**Terminology.** Since the possible consequences of gestational alcohol exposure were published formally in 1972 by Drs. Jones and Smith, there have been many diagnostic terms used to describe the various effects of prenatal alcohol exposure. Fetal Alcohol Spectrum Disorder (FASD) is the current, inclusive, non-diagnostic term used when describing the spectrum of challenges caused by gestational alcohol exposure.

Fetal Alcohol Syndrome (FAS) is one of the diagnoses captured under the umbrella of FASD. Fetal Alcohol Syndrome is a medical diagnosis associated with impairments caused by

in-utero alcohol exposure and is characterized by specific neurodevelopmental challenges, characteristic facial features and growth problems (Streissguth, 2007). Additional diagnoses captured under the umbrella of FASD are Alcohol Related Birth Defects (ARBD), Alcohol Related Neurodevelopmental Disorders (ARND) and Partial Fetal Alcohol Syndrome (PFAS) (Chudley, Kilgor, Cranston, & Edwards, 2007). Partial FAS is characterized by only some of the growth, characteristic facial features or central nervous system challenges being apparent. Alcohol Related Birth Defects is primarily characterized by physical characteristics and Alcohol Related Neurodevelopmental Disorder is largely characterized by neurobehavioral challenges. However, the failure to meet diagnostic criteria does not mean that the cognitive and behavioral development of persons with prenatal alcohol exposure is unaffected (Stratton, Howe, & Battaglia, 1996).

The recently revised *Diagnostic and Statistical Manual V* (American Psychiatric Association, 2013) introduced new terminology related to prenatal alcohol exposure: neuro-developmental disorder associated with prenatal alcohol exposure is included, as an example, under the heading *Other specified neuro-developmental disorders* with a diagnostic code of 315.8. The DSM V provides the following example explanation: “Neuro-developmental disorder associated with prenatal alcohol exposure is characterized by a range of developmental disabilities following exposure to alcohol in utero” (American Psychiatric Association, 2013, p. 86).

While the information regarding neuro-developmental disorders associated with prenatal alcohol exposure can be described as sparse, an additional diagnosis of *Neurobehavioral disorder associated with prenatal alcohol exposure* (ND-PAE) was included in the DSM-V and contains substantially more information. ND-PAE was included in the section titled *Conditions*

*for further study* and includes proposed criteria, diagnostic features, aspects of differential diagnosis and co-morbidity.

According to the DSM-V, the intent is that ND-PAE will allow a diagnosis to be made, related to the effects of prenatal alcohol exposure, in the presence and absence of specific physical features (American Psychiatric Association, 2013, p. 798-801). The proposed diagnostic criteria for ND- PAE include:

- confirmation of more than minimal exposure to alcohol during gestation;
  - impaired neurocognitive functioning as manifested by at least one of five deficits in intellectual performance, executive functioning, learning, memory or visual-spatial reasoning;
  - impaired self-regulation as manifested by at least one of three deficits in mood or behavior regulation, attention or impulse control;
  - impaired adaptive function as manifested by at least two of four deficits in (one must be from the first two examples) communication, social communication or interaction, daily living skills or motor skills; onset of the disorder occurs in childhood;
- causes clinically significant distress and
- it is not better explained by the postnatal use of substances (American Psychiatric Association, 2013, p. 798-799).

On February 19, 2014, Julie Kable, PhD. conducted a webinar titled *Updates on Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)* for The National Organization on Fetal Alcohol Syndrome (NOFAS). During the webinar, Dr. Kable discussed the implications for the inclusion of ND-PAE in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Dr. Kable is a member of the Interagency Coordinating

Committee on Fetal Alcohol Spectrum Disorders (ICCFASD). The ICCFASD coordinates with federal agencies to solve challenges associated with FASD. As a member of this committee, Dr. Kable served on the diagnostic work group subcommittee, which specifically responded to the DSM-5 revisions. During her February, 2014 presentation, Dr. Kable further clarified the history, intent and significance of the inclusion of ND-PAE in the DSM-V.

Neurobehavioral disorder associated with prenatal alcohol exposure was included to address the issue that there is currently no diagnostic code or criteria that adequately and accurately detail the cognitive and mental health implications of PAE. Goals for the inclusion of this diagnosis include:

- providing an accurate code for the reimbursement of support services;
- providing an accurate diagnosis to guide treatment, supports and interventions; and
- legitimizing the issue of prenatal alcohol exposure [Kable, J. (February 19, 2014).

*Updates on Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)*. NOFAS, webinar].

Diagnoses such as FAS or pFAS are medical in nature and do not adequately capture the mental health needs of this population. This is important since many individuals with FASD may not respond to intervention, treatment or medication regimens that are associated with commonly diagnosed co-occurring conditions, such as attention deficit disorder. The intent of ND-PAE is not to replace FAS or pFAS. Rather, it should be used as a complementary diagnosis. ND-PAE could replace the term alcohol related neuro-developmental disorder, for which there are currently no formal diagnostic criteria [Kable, J. (February 19, 2014). *Updates on Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)*. NOFAS, webinar].



Some of the challenges associated with ND-PAE that will continue to be addressed, debated and interpreted include individuals with FASD or PAE may not meet the criteria for the major symptom areas and the inclusion of *more than minimal exposure* within the proposed criteria. The supporting text proposes that more than minimum exposure constitutes more than 13 drinks per month or more than two drinks on any one occasion. This information can be obtained from maternal report, clinical observation and through record reviews. [Kable, J. (February 19, 2014). *Updates on Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)*. NOFAS, webinar].

At a recent professional summit, *Back (and) to the future 1973-2013: 40 years of prenatal alcohol and FASD*, Claire Coles, a leader in the field of FASD research, informally commented on the new terminology. At that time, she was unsure how and when this language would be adopted, stating that further clarification was needed [Coles, C (September, 2013). *Back (and) to the future*. The Arc of New Jersey, Atlantic City, NJ]. Mattson, Kable & Olson continue to provide background and information on ND-PAE so that professionals can become familiar with the criteria [Mattson, Kable & Olson (March, 2015). *6<sup>th</sup> International conference on FASD: Research, results and relevance*. Vancouver, BC., Canada].

The inclusion of neuro-developmental disorder associated with prenatal alcohol exposure and ND-PAE could prove incredibly helpful for those living with FASD and those supporting persons with FASD. As the proposed criteria are further evaluated, debated and critiqued, leaders in the field of FASD research will likely provide further comments and directions on the use of the new terminology.

**Challenges and implications of assessment and diagnosis.** Although the effects of gestational alcohol exposure were formally published in 1973, an accurate diagnosis continues to

be challenging for the medical community due to numerous variables. Newborns who have specific, overt physical signs of FAS often go undiagnosed (Little, Snell, Rosenfield, Gilstrap, & Gant, 1990); it is presumed that cases of FAS are missed during newborn period (Stoler & Holmes, 2004); FASD is rarely identified in settings where children are referred for developmental or behavioral problems (Bertrand et al. 2005; Ryan & Ferguson, 2006); adults present themselves at programs with suspected FASD but operate below diagnostic radar (Clarren & Lutke, 2007); and those adults with subtle signs of FASD present an even greater challenge for accurate diagnosis (Spohr & Steinhausen, 1987). Additionally, adults often do not have access to affordable diagnostic evaluation services (Astley & Grant, 2014). Since deficits in adaptive skills are reported to increase with age (Whaley et al., 2001), individuals with subtle signs of FASD could be overlooked until they exhibit concerning behavioral symptoms. Many people with FASD continue to remain undiagnosed or misdiagnosed (Greenbaum, Stevens, Nash, Koren, & Rovet, 2009). A recent study sampled 547 foster and adopted youth utilizing services at a children's mental health center. This study found that 156 of the youth met the criteria for an FASD diagnosis. Of these youth, 125 had never been identified as being affected by prenatal alcohol exposure. This is a missed diagnosis rate of 80.1% (Chasnoff, Wells & King, 2015).

Health care professionals may be less likely to identify children with FASD because they lack the appropriate attitude and knowledge, are unaware of the possibility of intervention options, have attitudes that may discourage families from seeking support (Paley & O'Conner, 2009) or are uncomfortable making a diagnosis due to lack of training (Elliot, Payne, Haan, & Bower, 2006). There may be inadequate evidence of maternal drinking (Coles, 2011) or no biological markers that can accurately identify those who are affected (Sokol, Delaney, &

Norstrom, 2003). The National Center on Birth Defects and Developmental Disabilities, The Centers for Disease Control and Prevention and The Department of Health and Human Services published *Fetal Alcohol Syndrome: Guidelines for referral and diagnosis in 2004*. These guidelines identify four challenges regarding the widespread failure to recognize FAS in pediatric care facilities (*Center for Disease Control, 2004*).

- The lack of uniformly accepted diagnostic criteria.
- An FAS diagnosis is based on clinical features, though not all children with FAS look or act the same.
- The lack of knowledge and misconceptions of physicians.
- The lack of criteria to distinguish FAS from other alcohol related conditions.

Social workers, advocacy workers, employers, probation officers and family members are the primary sources of identifying adults who need a referral for an FASD evaluation (Chudley, et al, 2007; Lockhart, 2001). Thus, it is of the utmost importance that this group is trained to recognize the signs of possible FASD (Gahagan et al., 2006).

A diagnosis related to gestational alcohol exposure is most easily and accurately given between the ages of four and 14. During this period, physical features are most pronounced and a maternal history may be more readily available (Little, Snell, Rosenfeld, & Gilstrap, 1990). As a person matures into late adolescence and adulthood, facial features associated with gestational alcohol exposure become more subtle and family background and history are more difficult to access, making an accurate diagnosis more challenging (Lupton, Burd, & Harwood, 2004; Spohr & Steihsin, 2008).

As part of the differential diagnosis process, an evaluator must discriminate between FASD and other possible causes of delay or disability. This includes an understanding of co-morbid

diagnosis such as ADHD, issues related to the exposure to other teratogens in utero and possible underlying genetic conditions such as Fanconi anaemia, Smith-Lemli-Opitz Syndrome, Stickler Syndrome, Turner Syndrome and Kabuki Syndrome with overlapping features of FASD (Leibson, Neuman, Chudley & Koren, 2014; Public Health Agency of Canada, 2011). Dr. Claire Coles (2011) speaks of the special considerations that diagnosticians must make when identifying FAS, which include evaluation of the evidence of prenatal alcohol exposure, effects of postnatal caregiving environment, comorbidities and differential diagnosis which discriminates from other conditions.

**Social perception.** The social perception of FASD is often stigmatized. There is often a judgment attached to alcohol use and pregnancy (Badry and Wight Felske, 2013). Greene, Cook, Racine and Bell (undated) state that feeling judged by others and the stigma of FASD leads to discrimination. This judgment prevents individuals with FASD and their families from seeking services and interventions and supports, which could increase quality of life (Stewart & Glowatski, 2014). Kathleen Mitchell, president of the National Organization on Fetal Alcohol Syndrome reflects on stigma and the social perception of FASD.

Both alcoholism and FASD remain highly stigmatized disorders... Recognizing that your child lives with a disability because you drank during pregnancy is a painful realization. Birth mothers typically experience significant guilt, shame and remorse. The diagnosis suggests intentional harm by a mother. In reality, there are many different reasons why women drink during pregnancy.

Unfortunately, most people still believe that birth mothers “should have known better.” Having a birth child diagnosed with a FASD is like being branded with a Scarlet Letter. The family faces continuing shame and stigma as well. (Mitchell, 2013, para. 4)

Dr. Dorothy Badry (2014) states that there is a societal obligation to move past this stigma and create dynamic supports.

FASD is a disability that is misunderstood, often not recognized and still blanketed with stigma. We must move forward in our understanding of FASD as a disabling condition which many individuals live with, and somehow manage to keep going – despite many struggles and challenges. Individuals with FASD need and demand excellence from service providers and community members to support living with FASD, not just surviving and struggling. (Badry, 2014, para. 6)

**Ethical considerations.** Ethical concerns and considerations are an important part of the diagnostic process. Bertrand, Floyd, and Weber (2005), reflect that deciding to refer a person or family for a full diagnostic evaluation can be a difficult decision. Especially since “social stigma might be associated with any evaluation concerning prenatal alcohol exposure“ (Center for Disease Control, 2004, p. 21)

The 2004 CDC publication “Fetal Alcohol Syndrome Guidelines for Referral and Diagnosis” appropriately asserts, “Diagnosis is never an endpoint for any individual with a developmental disability and his or her family” (pg. 1). While a diagnosis of FASD may be helpful in many ways, it is also potentially hurtful for the person with FASD and their family. The Substance Abuse and Mental Health Services Administration explains that:

Discussion of a possible FASD can cause feelings of shame, or possibly even anger or disbelief, about being identified with a “brain disorder.” For the family of the individual, particularly for a birth mother, suggesting the possible presence of an FASD can lead to feelings of guilt or a feeling of being ‘blamed,’ and a perception that service systems are unhelpful or even a negative

experience. It is critical for a counselor to take a no-fault, no-shame approach to the topic of FASD, continually reassuring the individual and the family that you are examining the possibility of an FASD only as a way to achieve the best possible treatment outcome.

(TIP, 2014, pg. 4).

While a diagnosis of FASD may lead to better support and service options, mental health professionals recognize pitfalls to this type of labeling (American Psychological Association, 2000), one of which is the impact on stigma. For a person with FASD, “While assessments and diagnosis can be supportive for individuals living with FASD, labels are not. Labels limit” (Community Living British Columbia, 2011, pg. 5). Labels can interfere with support provision, willingness to seek out assistance, family members’ experiences and willingness to participate in research (Garand, Lingler, Conner & Dew, 2009).

Dr. Bell, a researcher in the field of neuroethics, speaks to some of the ethical incongruity between research and policy:

Of course, a mission to carve out more attention for FASD is also hampered by the fact that beliefs about the risk and acceptability of drinking during pregnancy vary considerably. This may lead to confusion about whether those in the field even have the same ideas about the problem itself, or if their priorities for research are aligned with those of the public (Bell, 2014, para. 4).

Unpublished scholarly works authored by Ilona Autti-Ramo could also provide much needed insight into the ethics of diagnosing FASD. Additionally, an article currently under review, “It’s a Shame! Stigma Against Fetal Alcohol Spectrum Disorder: Examining the Ethical Implications for Public Health Practices and Policies” (Bell, et al., under review), will likely add to the discussion of ethical considerations related to FASD.

In the United States, diagnostic systems that could be used to assist in the diagnosis of FAS and other specified diagnoses such as partial FAS are hotly debated. Two common systems include the Astley/Clarren Four Digit Diagnostic Code, 3<sup>rd</sup> edition, as developed at the University of Washington (2004), and the Institute of Medicine's Criteria for Diagnosing Fetal Alcohol Spectrum Disorders with Hoyme's clarification (2005). Presently, there are no generally accepted or standardized recommendations regarding how to diagnose those living with the neuro-developmental effects of prenatal alcohol exposure but do not present with the physical manifestations of this exposure and for whom confirmed maternal alcohol use is nonexistent (Coles, 2011).

Currently, there is no definitive test or methodology for diagnosing the adult population (Public Health Agency of Canada, 2011). When physical features are not present and maternal drinking is uncertain, accurate identification and diagnosis is challenging (Goodlett, 2010; Hoyme, et al., 2005). To receive an FASD diagnosis as an adult, a multi-disciplinary, differential evaluation is recommended [Cook, Greene & Lilley (March, 2015). *6<sup>th</sup> International conference on FASD: Research, results and relevance*. Vancouver, BC., Canada]. This assessment can include input from social workers, psychiatrists, health care providers, psychologists and family members. Welfare agents, employers, vocational teachers, parole officers and advocacy workers can also be excellent resources and important members of the multi-disciplinary team (Chudley, et al., 2007). The evaluation includes a review of medical reports, psychosocial assessments and a thorough review of history (Public Health Agency of Canada, 2011). Neuropsychiatric evaluations and brain imaging scans might be completed as part of the multi-disciplinary evaluation (Chudley, et al, 2007). A neuropsychological assessment is a valuable component of

the evaluation process and can inform treatment and service provision (Astley & Grant, 2014; Sparrow, Grant, Conner & Whitney, 2013).

Hoyme, Kalberg & May (2014) recommend that FASD is “best diagnosed by a medical team headed by a geneticist/dysmorphologist with multidisciplinary input” (para. 1). Geneticists can be vital members of the team as they have specialized training and skill related to syndrome recognition (Chudley, et al., 2007). Part of the assessment and diagnostic process should be the development of an effective treatment plan that minimizes risk factors and promotes protective factors across the lifespan (Bertrand, Floyd & Weber, 2005).

The Lakeland Centre for Fetal Alcohol Spectrum Disorder (LCFASD) in northeastern Alberta uses a multi-disciplinary approach to assess and diagnosis adults with FASD. The LCFASD adopted this community-based service delivery model to address regional and cultural concerns. The Canadian diagnostic guidelines for FASD and the model of service provision employed at the Washington Diagnostic Clinic are utilized as part of this model.

The local diagnostic team consists of: “a physician, neuropsychologist, mental health therapist, psychiatrist, career counselor, addictions counselor, cultural liaison, legal representative, disability services coordinator, team coordinator and post-diagnostic outreach worker (McFarlane, 2001, p. 26).” The diagnostic process includes: clinical interviews, review of available historical documents, a case conference and emotional support for the patient, family and support team. The adult, newly diagnosed with FASD, is given take-home resources and has access to post-diagnostic outreach workers who provide ongoing support (McFarlane, 2011). The LCFASD believes that this model has proved to be effective in the provincial areas of Alberta and it would be appropriate for other communities (McFarlane, 2011).



REACH, a multi-disciplinary FASD diagnostic clinic in Juneau, Alaska, employs a similar approach (Pastorino, 2015). In addition to accurate diagnoses, REACH identifies the strengths and needs of individuals and families. “As a result, meaningful intervention plans for relevant services and supports were effectively created” (Pastorino, 2015, para. 13).

Dr. Therese Grant and Mr. Dan Dubovsky, experts in the field of FASD, are piloting the use of an FASD screening tool called the Life History Screen (LHS). This tool looks at common, but not inherent, life history patterns that occur in the lives of those with FASD. This screening tool could alert support professionals that a more thorough FASD assessment is needed and modifications of support approaches are required. Dr. Grant and her colleagues use this screening tool as part of a substance abuse treatment program (Grant & Dubovsky, 2014).

Since the characteristic facial features of FAS can become less pronounced in adulthood, some multi-disciplinary teams will reference childhood pictures in order to assess physical characteristics [(September, 2013) *Back (and) to the future*. The Arc of New Jersey, Atlantic City, NJ]. The FAS Facial Photographic Screening Tool has been found to be an effective screening tool when referencing childhood photos (Astley, Stachowiak, Clarren & Clausen, 2002). If FASD is present and an inappropriate diagnosis is assigned, it does a disservice to the family (Public Health Agency of Canada, 2011).

The lack of a formal diagnosis does not negate the fact that those affected by prenatal alcohol exposure struggle with a spectrum of complex issues. Significant cognitive and behavioral effects are often observed and reported in those who have few sentinel features of FAS (Chudley, et al., 2007). A current challenge is to develop empirical methods to classify and identify cases that do not exhibit classic morphology (Hoyme, et al., 2005). Receiving a formal diagnosis may not be realistic for some adults with FASD due to barriers in the health and social services

system, but understanding the root cause of struggles and challenges can provide a frame of reference to assist with therapeutic intervention, planning and assessment for those supporting adults with FASD.

Gaining knowledge of history of a FASD could provide insight as to why an adult with a high rate of behavioral problems (Chandrasena, Mukherjee, & Turk, 2009) might not improve when tertiary characteristics such as psychiatric symptoms or issues of alcohol and drug dependency are alleviated (Chudley, et al., 2007). Chudley, et al., (2007) hypothesized that the effect of receiving knowledge of a FASD in adulthood reflects “a paradigm shift in attitude and perception towards the affected individual...to that of an individual who is neurologically impaired and who needs appropriate assistance, with specific management and treatment” (p. 270). Chudley, et al., also stated that “A diagnosis (in adulthood) may mitigate progression or reduce secondary disabilities, provide an answer to the individual for his or her disabilities and failures, and improve their likelihood of being connected to interventions and services for FASD adults” (p. 270). Sparrow, Grant, Conner & Whitney (2013) echo this sentiment stating “Quality of life for an adult with FASD may be substantially improved when assessment results and recommendations are shared with supportive family members and service providers, who can apply this information on a daily basis and build on the person’s strengths while shoring up areas of weakness” (p. 83).

**Prevalence.** It is difficult to accurately ascertain the number of people living with the effects of FASD, largely because of the challenges related to assessment and diagnosis previously cited. Most studies have based prevalence on passive methods (e.g., surveillance or clinic-based studies), further underestimating the prevalence of FASD (May, et al., 2014). In the United States, previous estimates state that between 0.5 and 2 live births will meet the criteria for the

full expression of FAS (May & Gossage, 2001) and FASD may be prevalent in 10 per 1,000 of all live births (May & Gossage, 2001). Most reported numbers largely underestimate the number of people affected (Sokol, Delaney, & Norstrom, 2003).

A recent report authored by May, et al. (2014) found that the prevalence of FASD could be greater than earlier reports suggest. This study sampled first grade students from a representative, middle class community in the United States. In this sample, 6 to 9 children per 1,000 were found to have FAS and 11 to 17 children per 1,000 were found to have PFAS. The total prevalence of FASD was found to be 24 to 48 per 1,000 children (May et. al., 2014). May et. al. (2014) used the diagnostic guidelines for FASD as developed and endorsed by the Institute of Medicine.

Dr. Susan Astley (2014) and Dr. Julian Davies (2014), researchers in the field of FASD, responded to the study's claim that the prevalence of FAS could be three times higher than previously estimated. Drs. Astley and Davies cited that the study's methodology could lead to overestimation of prevalence. May & Hoyme (2014) replied to these concerns in part stating that "the opportunity to perform in-person examinations of children in representative schools provides access to more cases, and therefore uncovers high rates of fetal alcohol syndrome (FAS) and also other fetal alcohol spectrum disorders (FASD)" (para. 1). A potential trigger for this exchange could be the ongoing debate related to the diagnostic measures of the Four Digit Diagnostic Code, advanced by Dr. Astley, and the Institute of Medicine's Criteria for Diagnosing Fetal Alcohol Spectrum Disorders with Hoyme's clarification.

While many persons with FASD may reside with their biological families, it is estimated that FAS is likely to be 10 times more prevalent in the foster care system (Astley, Stachowiak, Clarren & Clausen, 2001) and rates of children with PAE associated features are high among

those residing in Russian orphanages (Miller, et al., 2006). FASD and other neuro-developmental disorders were more commonly found in children adopted from orphanages in Eastern Europe (Landgren, Svensson, Strömmland & Grönlund, 2010). It is estimated that in the United States the cost for one individual across a lifespan is at least two million dollars, and the accumulated cost of FAS alone is close to six billion dollars per year (Lupton, Burd, & Harwood, 2004).

**Neurological effects.** The developing brain of a fetus is susceptible to damage from any alcohol consumption during pregnancy (Streissguth & O'Malley, 2000). Some infants exposed to alcohol in utero will not experience adverse effects or show outward signs associated with exposure, while others develop FAS and exhibit a range of neurological effects (Mattson, Crocker, & Nguyen, 1997; Streissguth & O'Malley, 2000). The severity of effects is thought to be influenced by quantity, timing and frequency of alcohol use, as well as genetic susceptibility, nutritional and metabolic factors (Maier & West, 2001; Stratton, Howe, & Battaglia, 1996). Following birth, potentially significant effects can be ameliorated or magnified by life experience, causing a person with a neurologically-based challenge to exhibit a spectrum of mild to severe impairments.

Specific brain structures found to be most affected by gestational alcohol exposure include the cerebellum, corpus callosum, basal ganglia and frontal lobe. Resulting primary structural changes constitute the underlying, invisible cause of neurological difficulties found in persons with FASD. Primary challenges related to executive functioning, arousal, attention, decision making, problem solving and planning can be traced to changes in these specific brain structures. Understanding these structural brain changes can provide support persons with an understanding of the root cause of challenges.

The cerebellum assists in the process of coordinating movement and dexterity (Broussard, 2014). The cerebellum controls routine tasks, such as walking, while allowing people to concentrate on other issues or talk (Broussard, 2014). Changes in the cerebellum have been reported in the population with FAS (Norman, Crocker, Mattson & Riley, 2009; Mattson & Riley, 1996). Children with FASD exhibit difficulties with fine and gross motor skills (Mattson, Riley, Gramling, Delis & Jones, 1998; Jacobson, et al., 1993), which are functions associated with the cerebellum.

The corpus callosum is the fiber tract that connects the two brain hemispheres. The corpus callosum helps transfer motor, sensory and cognitive information across hemispheres and helps maintain arousal and attention (Bloom & Hynd, 2005). This is one of the brain structures most significantly altered by gestational alcohol exposure (Norman, et al., 2009; Clark, Li, Conry, Conry, & Loock, 2000; Riley, et al., 1995). Deficits in attention and memory tasks (Olson, Feldman, Streissguth, Sampson, & Bookstein, 1998;) and attention function (Kodituwakku et al., 1995) are seen in the population with FASD and are associated with corpus callosum.

The basal ganglia, a group of subcortical nuclei, are especially sensitive to the effects of gestational alcohol exposure (Archibald et al., 2001; Mattson, et al., 1992; 1996). The basal ganglia are responsible for learning related to routine behaviors; cognitive and emotional functions; behavioral decision making and executive functioning (Albin, Young & Penney, 1989). Difficulties with executive function (Rasmussen, 2005) and poor socio-emotional development (Thomas, Kelly, Mattson & Riley, 1998; Olson et al. 1998) are commonly heard in reports regarding FASD.

The frontal lobe, a region at the front of the cerebral cortex, is also affected by gestational alcohol exposure (Archibald, et al., 2001). The frontal lobe is associated with decision making, problem solving and planning functions. Difficulties with cognitive flexibility and planning (Kodituwakku et al. 1995; Olson, Feldman, Streissguth, Sampson, & Bookstein, 1998;) are commonly associated deficits in those with FASD.

**Hypothalamic-pituitary-adrenal (HPA) axis.** The hypothalamic-pituitary-adrenal axis (HPA) refers to the complex interactions between three endocrine glands: the hypothalamus, pituitary and adrenal glands. The exchanges between these three endocrine glands play an important role in the neuroendocrine system (Wolf, 2003). The HPA hormones assist in regulating the body's reaction to stress. These hormones also regulate mood, emotions, the immune system and digestion (Zhang, Sliwowska & Weinberg, 2005). Increased activity of the HPA axis is one of the more consistent biological findings related to major depression (Pariante & Lightman, 2008).

The HPA axis is susceptible to changes at the cellular level during fetal development. During this time, environmental influences including exposure to alcohol can reprogram the HPA axis causing possible dysfunction across the lifespan. HPA hormones play a significant role in behavioral and physiological functioning, thus the dysfunction of this system can have dire consequences (Hellemans, Sliwowska, Verma, & Weinberg, 2010; Zhang, Sliwowska & Weinberg, 2005). Researchers working with animal models hypothesize that the changes in HPA function, regulation and response due to prenatal alcohol exposure could help explain some of the behavioral, cognitive and immune deficits that are often reported in those with FASD (Zhang, Sliwowska & Weinberg, 2005). Changes in fetal programming of HPA, due to PAE, alters the stress response which in later life can potentially increase an adult's vulnerability to

depression and anxiety disorders (Hellemans, Sliwowska, Verma, & Weinberg, 2010; Hellemans, Verma, Yoon, Ye, & Weinberg, 2008).

**Primary effects.** Each person living with FASD is like any other individual with unique life experiences and personalities, although she or he may exhibit certain medically recognized patterns of social, cognitive and emotional behavior, which are the result of damage to the brain and central nervous system (Kyffin, Shepard, Shepard, & Kapil, undated). These primary symptoms can be seen in difficulties with problem solving and planning (Green, et al., 2009; Kodituwakku, 2009; Mattson et al., 1997; Streissguth, et al., 1991), executive functioning (Rasmussen & Bisanz, 2009), learning and memory (Mattson, Riley, et al., 1996), inattention and hyperactivity (Riley & McGee, 2005), generalizing knowledge (Streissguth & O'Malley, 2000), self-regulation, shifting responses to meet a new demand and making connections between behavior and consequences (Burd, Klug, Martsof, & Kerbeshian, 2003; Keil, Paley, Frankel, & O'Conner, 2010; Kodituwakku, 2009; Olson, Oti, Gelo, & Beck, 2009; Streissguth, et al., 1991; Streissguth, 2007; Warren & Hewitt, 2009). Difficulty with emotional regulation, including reading social cues, understanding and expressing emotions, showing remorse and controlling anger, also can be considered primary symptoms (Rutman, LaBerge, & Wheway, 2005). Some persons with FASD may have poor expressive and receptive language, difficulty recalling verbal and non-verbal information (Coles, Lynch, Kable, Johnson, & Goldstein, 2010; Kerns, Don, Mateer, & Streissguth, 1997) and exhibit poor working memory (Coles, et. al., 2010; Kerns, et a., 1997).

Specific facial and bodily features are seen in those affected by gestational alcohol exposure. These features are most likely attributed to the fetus being exposed to high doses of alcohol early in the first trimester (Astley & Clarren, 2000; Bonthius, Bonthius, Napper, & et al., 1996). Short

palpebral fissures, flat mid face, smooth philtrum, thin upper lip and a short nose are the most common characteristics and are part of a diagnostic criterion for FAS (Streissguth & O'Malley, 2000).

All persons who exhibit the effects of prenatal alcohol exposure may have associated physical and behavioral characteristics. While cognitive effects vary, most people with FASD do not meet the criteria for a mental retardation (MR) diagnosis (Mattson, Crocker, & Nguyen, 2001). The combination of subtle physical features and average intelligence have contributed to the generations of people who struggled, and continue to struggle, with the effects and symptoms of FASD but have little insight into the root cause of these difficulties. While many people may be unaware of their underlying FASD (Bertrand, 2009), they have first-hand knowledge of the associated day-to-day life challenges (Grant, et al., 2013). With appropriate acknowledgement, adults are better armed to understand their unique set of strengths and needs and supporters are better prepared to provide assistance (Public Health Agency of Canada, 2010).

**Life experiences.** According to Streissguth, et al. (2004), persons with FASD are more likely to experience adverse life events beginning in early childhood and continuing throughout life. They are more likely to have an unstable home environment as infants, experience poor quality parenting, have frequent out-of-home placements, lack access to adequate support services and have a family history of substance abuse and unmet basic needs (Streissguth, et al., 2004; Streissguth, 2007). When a person with FASD is faced with these adverse environmental stressors, the effects could be considerably more damaging than for those persons without a neurological impairment. Adverse experiences can intensify an already difficult vulnerability, especially when the symptoms or behaviors are targeted for a treatment modality that does not address the neurological challenges present at birth (Malbin, 2008).



Other protective life experiences that could improve long-term outcomes include living in a stable, nurturing and non-violent home; receiving a diagnosis before school age; remaining in each living situation for three or more years; experiencing a positive home life between ages eight and 12; and being found eligible for developmental disability (DD) services (Streissguth, et al., 1991; Streissguth 1994; Streissguth, et al., 2004).

**Secondary characteristics.** When life experiences, intervention and environment do not adequately support a person with a neurological impairment, a person with FASD may develop a pattern of secondary defensive behaviors (Malbin, 2008). The spectrum of secondary characteristics of brain-based issues indicates a poor fit between personal needs and the surrounding environment (Malbin, 2008). Common but not inherent characteristics related to FASD include depression, anxiety, withdrawal, hyperactivity (Roebuck, Mattson, & Riley, 1999), lack of guilt, disobedience (Nash, et al., 2006), issues with attachment (O’Conner, Sigman & Kasari, 1992), indiscriminate social behavior, poor judgment, impulsivity and trouble expressing and understanding emotions (Streissguth & O’Malley, 2000). Recent publications by Weinberg and colleagues propose that secondary effects such as vulnerability to depression and response to stress could be primary symptoms. These mental health related issues could be influenced by changes to the hypothalamic-pituitary-adrenal axis during fetal development (Uban, et al., 2011; Weinberg, 2010).

**Secondary effects and tertiary characteristics.** Drs. Anne Streissguth and Keiran O’Malley, researchers in the field of FASD, described a way of viewing how primary physical effects within the FASD population could present themselves in frequently occurring secondary effects.

Persons with FASD often experienced a variety of adverse environmental conditions that are associated with the cause of this disorder. These adverse background factors can interact with the primary organic deficit experienced by the patients to produce secondary disabilities of significant proportions. Thus, individuals with a basic birth defect of the brain are propelled into circumstances that exacerbate their problems and impede proper management and care.

(Streissguth & O'Malley, 2000, p.183)

Diane Malbin, a social worker and published author, further identified these phenomena as tertiary characteristics that are the “net effect of chronic failure and frustration and are preventable” (Malbin, 2008, p. 8). These characteristics are the result of the combination of learned defensive behaviors, life experiences and a poor fit between interventions and environments that do not adequately support a person with a neurological impairment.

The tertiary effects of prenatal alcohol exposure can manifest in increased psychiatric confinement, delinquency, school failure, incarceration, poor social adjustment, increased risk of suicide, greater likelihood of substance abuse issues, greater history of trauma and abuse (Greenbaum et al., 2009), increased prevalence of mental health problems (Burd, et al., 2003; Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004; Fast & Conry, 2009; Keil, et. al., 2010; Kodituwakku, 2009; Olson, et al., 2009; Streissguth, 2007) and risk of suicide (Huggins, Grant, O'Malley & Streissguth, 2008).

**Neurological maturity.** Informal reports describe that as some adults with FASD age they have greater insight into their challenges, better coping skills and find it easier to relate to others (Trusler, Trusler, Mousmanis, Grier, & Graves, 2014). There is little direct evidence for the cause of this type of developmental ‘catch-up’; however, Dr. Edward Riley, a researcher with 40

years of experience in the field of FASD, speculates that brain changes in adulthood could explain the behavioral changes and personal growth observed in some adults with FASD (Riley, 2014). This is similar to youth with Attention Deficit Hyperactivity Disorder (ADHD), whose brain maturation is delayed in certain regions (National Institute of Mental Health, 2007).

The brain, specifically the frontal lobe, continues to mature into the 20s. This is the area of the brain involved in executive functioning.

Additionally, myelin, white matter in the brain, accumulates over time (Raz, et al., 2005). Myelin allows communication between areas of the brain and is particularly vulnerable to prenatal alcohol exposure (Sowell, et al., 2008). The accumulation of white matter over time allows regions of the brain to communicate better, which is important for decision-making (Riley, 2014). Dr. Riley hypothesizes that since the brain changes into adulthood, some adults with FASD are able to learn and employ better strategies towards a successful life (Riley, 2014).

**Therapeutic support and intervention trends.** The areas of therapeutic supports and service provision for adults with FASD require further development. Common evidence-based techniques used to support a person with a primary mental health (MH) diagnosis often do not address the impaired neurological abilities of someone who has a dual diagnosis of a FASD and a mental disorder (Chandrasena, et al., 2009). Currently, there are no evidence-based supports that are recommended for adults with FASD. Leper (2015) described a randomized controlled intervention for youth and young adults with FASD. This intervention was deemed moderately effective and included in-home therapy, mentorship and caregiver support groups. [Leper (March, 2015). *6<sup>th</sup> International conference on FASD: Research, results and relevance*. Vancouver, BC., Canada].

Adults with FASD and PAE typically do not respond to standard therapeutic modalities due to neurological impairment (Lockhart, 2001); therefore, receiving an incorrect diagnosis could lead to exposure to ineffective and frustrating supports, such as behavior modification (Grant, et al, 2013), and can contribute to a lack of success academically and professionally (Olsen et al., 2009). Other interventions that are viewed as ineffective include the following: those that are consequence driven, talk therapies that rely solely on verbal communication (Grant, et. al., 2013) and approaches that do not take into account a neurobehavioral or neurodevelopmental approach to supports and intervention (Malbin, 2008).

It is recommended that services be multi-disciplinary and include a combination of behavioral, social, cognitive, education-based interventions and mentoring techniques (Chandrasena, et al., 2009). A comprehensive neuro-psychiatric assessment can assist caregivers and professionals to identify and implement appropriate strategies (Sparrow, Grant, Connor, & Whitney, 2013). There is also a need for adapted trauma informed strategies, possibly including a family systems framework when supporting individuals and families impacted by FASD and trauma [Antrobus & West (March, 2015). *6<sup>th</sup> International conference on FASD: Research, results and relevance*. Vancouver, BC., Canada]. Practice should be based on a neurobehavioral/neurodevelopmental perspective encouraging clear evidence-based approaches, as opposed to a list of possible strategies and accepted practices currently available (Chudley, et al., 2007). Specific techniques that professionals working in the field of FASD recommend include: utilizing role play for social situations, establishing structure and consistency, using positive reinforcement, using multiple modes to present information, practicing and teaching effective coping strategies and reducing distracting stimuli (Grant, et. al, 2013). Gelb and

Rutman (2011) cite the importance of a relational approach to substance use treatment when supporting women with FASD. The Substance Abuse and Mental Health Administration state:

Promising strategies that have been proposed for working with clients with an FASD reflect some of the successful approaches used in advocacy programs, including mentoring and family involvement. Persons with an FASD seem to respond well to mentoring, one-on-one relationships where they feel a personal bond with a person who acts as an advocate (SAMHSA, undated, competency 3, para. 2)

When developing supports, acknowledgement that lifelong interventions may be necessary because new life challenges manifest themselves across the life span.

### **Personal Reports of Living with FASD**

Investigating the first hand life experiences of adults living with FASD is critical to understanding them, although first-hand stories are difficult to find in contemporary scholarly works. Published personal experiences typically are compiled in two categories: narratives of parent-experts and individual-experts or people living with the effects of FASD. Both perspectives have provided valuable insight into the supports needed, successes and challenges and an understanding of how FASD is situated in the social and cultural environment.

**Parent-driven stories.** Most of the stories about living with FASD are written from the perspective of parents, and these accounts have shed light on many aspects of living with FASD. The parent-expert voice can be heard in the informal parent-driven publications, conferences, website support pages, blogs, newspaper articles and parent-initiated advocacy groups. Most of what is known about the life experiences and appropriate interventions of those living with the condition has been extracted from parent accounts and parent-led publications. Parents have a wealth of information about effective support techniques, the needed unique life-planning

considerations and the daily challenges to and triumphs of their loved ones living with FASD. Unfortunately, even with this great expertise many often feel their knowledge continues to be under-utilized or unheard by professionals (Brown & Bednar, 2004). Parent-driven literature describes:

- the impact FASD has on the family and the family relationships;
- narratives about their child's challenges, struggles and accomplishments;
- frustration with the system and available professional supports;
- concerns for their child's safety;
- financial costs associated with FASD;
- the rewards of raising a child with FASD;
- the frustrations of managing challenging behaviors;
- the need for advocacy;
- interactions with the judicial system and
- confronting public perception and stereotypes.

These first-hand experiences have led to valuable grassroots recommendations for:

- supporting and raising children affected by FASD,
- increasing awareness of FASD,
- understanding the dangers associated with gestational alcohol exposure,
- making recommendations for areas of future research and
- making policy changes within local judicial and educational systems.

In the study *Raising a child with fetal alcohol syndrome: Hearing the parent voice*, Whitehurst (2011) reported on a sample of four families living in the United Kingdom who were raising children with Fetal Alcohol Syndrome. This study highlights struggles that are often

addressed in parent-driven literature. Participants in this study spoke of their own emotions and the difficulties they have supporting a child with FASD.

When speaking about daily struggles and the challenges posed by FASD, one participant noted “Every day I wake up and think what am I going to be faced with today, what’s today going to be like and that’s hard on families” (p. 191). Another family member spoke of frustration with the lack of services and supports stating “You sit down and cry because you think I am alone here because nobody has a clue” (p. 191). A parent interviewed by Whitehurst (2011) also briefly noted feelings of relief when receiving the knowledge and/or diagnosis of the FASD and described it as “knowing about it is easier than not knowing about it” (p. 192).

All of the parents in this study expressed frustration with finding appropriate social services and aid because their child did not fall into a mental health or learning disability category. Subsequently, parents say they are always advocating for supports and basic needs, whether educational, behavioral or medical. These experiences are not unlike those of American families who often highlight that appropriate supports and services, especially for adults, are difficult to find (DeJoseph, 2011).

For a study titled *Challenges of parenting children with a Fetal Alcohol Spectrum Disorder: A concept map*, Brown & Bednar (2004) interviewed nineteen parents who were raising children with FASD. Some common themes parents identified as challenges included preventing setbacks, establishing personal time, keeping plans, collaborating home school needs, keeping a child involved, lacking proper support and experiencing social isolation and behavior problems. While many parents identify these as challenging areas, and the themes are consistent with current literature, Brown and Bednar’s research question of “What are the challenges you face parenting a child with a fetal alcohol spectrum disorder?” did not allow for a more balanced story

of what it is like to parent a child with FASD. Unfortunately, this study exemplifies the body of literature that is largely deficit-focused and propagates narratives that focus on those struggles and deficits.

In the 2006 publication *On, yet under, the radar: Students with Fetal Alcohol Syndrome Disorder*, Ryan and Ferguson reported on the experiences of teachers and family members. Commonly heard themes from parents included the anguish and frustration regarding the lack of supports and the difficulty of not knowing what to do when their child exhibits challenging behavior.

Narratives from a parent's perspective that present a balanced view of living with the effects of FASD can be found in the parent-driven literature. One notable collection of narratives includes *Fantastic Antone Succeeds* (1993) and *Fantastic Antone Grows Up* (2000). These two volumes provide valuable information while also challenging the deficit-driven literature. These collected works provide stories of success, hope, courage and recognize struggles, challenges and setbacks.

**The stories of adults living with FASD.** The personal stories of people with FASD are becoming increasingly prevalent on FASD support group websites, advocacy websites, Facebook pages, blogs, published autobiographies, and interviews in magazine and newspaper articles. These valuable informal reports provide a window into the life experiences of those with FASD guidance for supporters, a platform for discussion and inspiration for researchers who want to further explore the experiences and needs of people with FASD. While there is a recognition of the need to hear and understand the experiences of persons with FASD qualitative studies are difficult to find. The qualitative research includes experiences of people with FASD and consists of one doctoral dissertation, master's theses, several studies that report on school experiences



and a comprehensive report titled *Adults living with FAS/E: Experiences and support issues in British Columbia* by Rutman, LaBerge, & Wheway (2002).

McGregor (2009) explored the collected life stories of five young adults with FASD in her dissertation *Never say never: Struggle and determination in the lives of young adults with FASD*. The participants in this study spoke of a brief time in their childhood when they felt that they were accepted. As they moved into later childhood and adolescence, the feeling of acceptance soon was replaced by feelings of frustration and difference as they began to have difficulty with school and social interactions. Knorr (2011) echoed these sentiments in her master's thesis entitled *Overcoming adversity: The stories of four resilient adults with Fetal Alcohol Spectrum Disorders*. The four participants in her study reported the feeling of "not fitting in" during their time in school and had common experiences of being bullied, having difficulty making friends, getting into arguments and having difficulty with school. Duquette & Stodel (2005) and Duquette, Stodel, Fullarton, & Hagglund, (2006) also found that students with FASD experienced difficulty in school and with social relationships, though parental advocacy and support contributed to their experiences of greater success while in school.

Knorr (2011) found that these negative experiences often led to anger and frustration towards living with an FASD. One participant (when talking about his FASD) stated, "It makes me angry sometimes. The way I am and the stuff I do sometimes it gets me angry. I can't do most things that other people can and it makes me angry" (p. 39).

As McGregor's and Knorr's groups moved through the teenage years and into early adulthood, they began to experience feelings of loneliness, despair, homelessness, trouble with drugs and alcohol. There were also unintended pregnancies. Their stories also revealed a strong thread of internal resilience and determination. In her master's thesis *The experiences and needs*

*of young people with FASD: Silenced voices from youth in care*, Chatterley-Gonzalez (2010) described the experiences of five young people in care. She found that youth with greater awareness of their FASD were better able to describe their support needs than other participants with less insight into their FASD. Participants in McGregor's study reflected upon the importance of having a supporter and someone they trusted to provide guidance. Several reported a period in their lives when they became aware of the importance of accepting this support in order to move forward into a more fulfilling adult life armed with better skills for success. In adulthood, Knorr's group found success, strength and healing through a calling to help others with one participant stating, "I have gone through a lot of things in my life and my whole existence: my calling in life is to help others" (p. 43).

Each person living with the effects of FASD will respond differently to receiving a diagnosis or learning about his or her FASD in another manner. McGregor found that there are some emotional commonalities that are experienced depending upon the developmental timing of when the information is received. In McGregor's study, those who received a diagnosis in childhood referred to their FASD as "just something I knew in the back of my head" and "just something I always knew" (p. 136).

A diagnosis or learning about FASD in adolescence, in contrast, could be met with push back and rebellion. Participants stated, "Like, I grew up mostly ADHD. OK, I am hyperactive. But now I am Fetal Alcohol Syndrome? Oh, crap!" (p. 125) and "I kind of rebelled against it, saying, hey, I am fine! There is nothing wrong" (p. 125).

McGregor found that "During adolescence, however, being told you have a disability such as FASD can significantly impact how the self is understood and a common reaction during this time is to reject or ignore what others are saying" (p. 125).

When adults receive a diagnosis of FASD and subsequently learn that many of their behaviors were or are typical for persons affected by FASD, the experience appeared to be more normalizing. As one participant reported, “I was happy to hear it because it explained a lot of things, like a lot of ways of how I was” (p. 125).

Regardless of the age of when the participants first learned about their FASD, many experienced a period of reflection on its impact on their lives. Resulting self-awareness enabled them to move forward with more success. Making sense of the FASD label/diagnosis came to many as they matured and began to use the diagnosis as a context for understanding the spectrum of their behaviors and challenges. McGregor suggests that “How the person comes to understand and make sense of FASD is an important factor that facilitates change over the life course” (p. 105).

Exploring how adults with FASD come to understand and make sense of their lives requires a thorough understanding of the concept of identity. To this end specific theoretical perspectives of identity were reviewed, evaluated and coupled with current literature related to the experiences of persons with FASD. This analysis will conceptualize the theoretical framework needed for understanding the identity of adults with FASD who were identified in adulthood. This framework will be used to guide the research design and methodology of this qualitative study.

### **Identity and FASD**

The development of identity principally seeks to answer the question, “Who am I?” Answering this question is a complex process, fashioned in part by family interactions, social context, individual attributes and political factors. Adults living with the effects of FASD are more likely to experience social exchanges and interactions that may pathologize their identity

(Dej, 2011). Dej (2011) further expressed that the socially constructed FASD identity may take the shape of a victim in childhood and as dangerous or irredeemable in adulthood.

The personal stories of those living with FASD illustrate that understanding of self cannot be minimized to a pathologized, socially-constructed identity. Rather, their narratives are multifaceted and a great depth and rich texture of experiences are drawn upon to answer the complicated question of “Who am I?” A synthesis of theoretical frameworks and constructs lends insight into this complex question. To elucidate identity in the context of adults with FASD, this study will link several theoretical perspectives: (1) traditional psychodynamic concepts of identity (Erikson, 1968/1994); (2) models of narrative identity; (3) perspectives on identity and disability; and (4) medical and social models of disability.

This section will begin with a review of traditional psychodynamic models of identity development. The review of narrative identity will highlight the narrative process of identity development and the authoring of a life story across the lifespan. The social understanding of FASD will be considered from both a medical and social model of disability. The summary of identity and disability will explore disability models of identity and the influence of social stigma.

**Traditional psychodynamic identity development.** Erikson (1968/1994) theorized that human development passes through eight key stages. Each of these stages poses challenges that must be achieved. According to Erikson (1968/1994), the major achievement of late adolescence and early adulthood is answering questions of identity, such as “Who am I?” and “How do I fit in the world?” He identified this fifth stage as the identity vs. role confusion stage (Erikson, 1968/1994).

Material that informs identity is collected during infancy and throughout childhood.

Though it is not until late adolescence and the identity crisis, i.e., a turning point, that a person begins to have an understanding of self (Erikson, 1968/1994). This process takes a relatively unstable set of personal ideas and history and moves toward a more formal identity-driven set of goals, values and beliefs (Waterman, 1988).

During the identity vs. role confusion stage, the demands of maturation cause a person to begin to internally arrange personal habits and traits. This process includes questioning and integrating social and cultural perceptions and expectations into individual understanding. Social and historical contexts will greatly influence identity formation and what content the identity is committed to (Waterman, 1988).

Schwartz (2001) reflected that Erikson's psychodynamic perspective conceptually balanced an intra-psychic and an environmental focus on identity development. This balance can be inferred from Erikson's writing about identity.

The young person, in order to experience wholeness, must feel a progressive continuity between that which he has come to be during the long years of childhood and that which he promises to become in the anticipated future; between that which he conceives himself to be and that which he perceives others to see in him and to expect of him. Individually speaking, identity includes, but is more than, the sum of all the successive identifications of those earlier years when the child wanted to be, and often was forced to become, like the people he depended on. Identity is a unique product, which now meets a crisis to be solved only in new identifications with age mates and with leader figures outside the family (Erikson, 1968/1994, p. 87).

Waterman (1988) reflects on the function of identity from Erikson's perspective.

For Erikson, identity is a subjective sense of wholeness, both conscious and unconscious,

comprised of synthesized identifications that represent the person's psychosocial stimulus value both for himself or herself and for significant others in the community. The functions of identity stressed include inner coherence, continuity over time, and self-preservation.

(p. 188)

The development of this sense of wholeness requires the review of personal characteristics and traits, ideological and religious beliefs. Thenceforth, an individual commits to a self-definition and personal actions that live up to those traits. It is through this process that a purposive sense of identity begins to take form.

Erikson identified three linked levels of identity: the ego identity, personal identity and social identity (Kroger, 2003). Ego identity refers to the silent innermost, unconscious processes underlying the formation of identity (Schwartz, 2005). Personal goals, values and beliefs are included in the definition of personal identity (Schwartz, 2005). "Social identity refers to group identifications and to one's assigned and chosen place in the social world, as well as to processes by which one negotiates one's way through the social world" (Schwartz, 2005, p 295).

Identity from a psychodynamic perspective can be broadly viewed as a property that organizes experiences. Identity can be defined as the synthesis of one's traits, attitudes and personal values or the integration of values from ascribed social groups into a personal ideology and the subsequent actions and behaviors that one presents to the world. This semblance provides a life that has a degree of unity, sense of purpose and harmony in relation to others (Stevens, 2002, 26).

***FASD and traditional identity theory limitations.*** Erikson's rich description of identity and the process of identity development are limited by a focus on Western cultural values (Markus & Kitayama, 1991), the original understanding of female identity (Gardiner, 1981) and

the limited application of different ethnicities and nationalities (Schwartz, 2005). The scope of FASD crosses gender, culture, race and economic status; but the limitations of traditional psychodynamic models akin to the effects of FASD are of particular concern to this study.

From a traditional identity theory perspective, common characteristics of FASD such as dysmaturity, cognitive delays and poor social skills may make successfully achieving stages of identity challenging. Since the effects of FASD are potentially a lifelong reality, typical identity development maybe especially difficult. Schultz and Liptak (1998) state that cognitive impairments may impose barriers to successfully meeting psychosocial challenges. If unresolved, Erikson posits that a person will continue to recreate crisis events until the psychosocial stage work is completed (Erikson, 1968/1994). A lack of stage resolution could make it more difficult to resolve the identity vs. role confusion stage (Erikson, 1968/1994). Saladino and Bellus (2000) reflect on the confliction that persons with mild mental retardation may experience when resolving the identity vs. role confusion stage.

Continued emotional dependence upon the family conflicts with the need for separation...Successful resolutions lead to interdependence with family and with self-chosen friends and confidants (141).

The consequences of unsuccessful navigation of this stage can cause a person to become uncertain of who they are and have difficulty emotionally connecting with others (Erikson, 1968/1994). Erikson (1959) also concluded that gaining family independence is important to successful identity development. Yet, individuals with FASD often require some type of supports across the lifespan, further hindering the development of an independent identity, from this perspective.

Behaviorally, adults with FASD often have long lasting difficulties with trust and may be viewed as having poor initiative. Whether this is the function of a brain-based disability, impacts of trauma, ineffective supports, the lack of psychological stage resolution or a combination of the three is unclear. While an interesting exercise, viewing the challenges of adults with FASD as unresolved psychological stages is not within the scope of this review. However, understanding the effects of neurological impairment on personal behavior could help individuals psychologically address previously unresolved stages.

Many behaviors and actions exhibited by persons with FASD are defined as symptoms of a neurological disability. Accepting that behaviors can be symptoms and influenced by personal ideology further complicates the understanding of identity through a traditional psychodynamic perspective. A dichotomous appreciation that behavior and action can be both symptom and identity-based is required.

Behavioral actions resulting from symptoms of vulnerability or impulsiveness cannot be defined as representative of identity. The internalization of the reflexive meaning assigned to the action can be defined as representative of identity. For a person with FASD who was identified as an adult, behaviors may have been assigned meaning that did not account for a brain-based disability.

**Narrative, the life story and identity.** From a narrative perspective, the process of identity formation has a literary or storied quality and is influenced by a lifespan developmental approach. This perspective assumes that placing events into stories which organize, arrange and express meaning support the ongoing development of cohesive identity across the lifespan (McAdams, 2001; Mishler, 1986). The lifespan developmental approach presumes that development and behavior change can occur across the life course (Baltes, Staudinger &



Lindenberger, 1999). It is through the dynamic process of telling personal stories to others, incorporating feedback and reviewing the stories that people begin to understand who they are and shape their identity (Reissman, 1993).

The cornerstone of this narrative process is the development of a life story. The life story integrates past, present and future understandings of self into a consistent and comprehensive life account (McAdams & Cox, 2010). New experiences, situational events, the feedback from others and larger cultural and social narratives continue to be incorporated into the life story throughout a person's life (McAdams, 2012 and 2001). Events included in the life story begin to explain changes or developments in an individual (Bluck & Habermas, 2000).

The life story is more than recalling and reporting memories. The raw materials for the life story are relevant and important life experiences that are shaped through autobiographical reasoning. Autobiographical reasoning is the process of connecting past events and decisions to the current functioning and understanding of self. It is the knowledge that past events and experiences influence current decision making (McLean & Fournier, 2008).

Autobiographical memories are the product of this process and are stories that embody the connections between our experiences and the influences on choices and behavior (Conway & Pleydell-Pearce, 2000). Over time these stories can change as new information is gathered and events are reinterpreted and understood.

Through the process of emplotment, memories and events are arranged into a life story with a plot. Meaningfully arranging fragmented experiences into a story with a unified plot provides a sense of congruency. In this sense, the past, present and future understanding of self all become part of a person's true identity. This concurrent insight into who we were, are and want to be is a guiding force when navigating new life events (Crossley, 2000).

Present, meaningful events potentially can cause a person to change his or her long-term goals, strengthen an individual belief system (Pillemer, 2001) or change one's representation of himself or herself. A turning point is an example of one such meaningful event. Turning points are key episodes in a person's life that cause one to undergo some type of substantial change (McAdams, 1993) or understand something new about himself or herself. The process of making sense of the event and the construction of the information into the life story may be more important than the actual event itself (Bruner, 1994).

In addition to direct personal experiences, socio-cultural stories such as those related to gender, sexual orientation or disability also shape and influence the life story. A person is born into larger societal and cultural stories, all of which influence identity. Each person draws upon, adapts and applies larger social and cultural stories in everyday social interaction (Smith & Sparkes, 2007). The interplay between person, society and culture results in an identity that is embedded in and resonates within a social and cultural context (McAdams, 1999). Simply stated, the stories that we hear about ourselves from others, as well as larger social narratives, can greatly influence our identity (McAdams, 1993, 2006).

***Life story model of identity.*** McAdams (1993) connected Erikson's concept of identity to a narrative perspective and proposed the Life Story Model of Identity. The cornerstone of the Life Story Model of Identity is that identity is largely built by constructing a life story in late adolescence or early adulthood. McAdams (2006) states that "by the time a person reaches adulthood they will have a wealth of psychological material with which to construct narrative identity" (p. 87). This life story is composed so that individuals can understand who they are and how they came to be the person they are today (McAdams, 2011). In this model, the life story is more than the vehicle that holds the identity. The constructed life story *is* a person's identity

(McAdams, 1987). While largely theoretical, many narrative identity researchers adhere to this assertion (Singer, 2004).

McAdams's (2001) posit that identity is the third level of a three-level hierarchy to understanding human personality. The first is non-unique flexible personality traits and the second is patterns of behaviors and values that can be shared by others. The third level is the unique identity that explains personal development within the context of personal past. In this domain, McAdams (2001) uses the term narrative identity. This term specifically is used to acknowledge that narrative is utilized to make sense of events and understand self and experiences.

Singer (2004) summarizes the essence of the narrative identity as written in McAdams, Reynolds, Lewis, Patten & Bowman (2001).

(Identity) That is, individuals' ongoing sense of self in contemporary Western society coheres around a narrative structure, which casts the individual as a protagonist in a lifelong journey, marked by mutual challenges, characters, turning points, and varying outcomes of redemption or contamination.

Secondly, they do not see this work of building a narrative identity as adhering to a particular stage or phase of life. To do research in narrative identity is to embrace a lifespan developmental perspective on personality. Biological and cognitive changes, role demands of particular life stages, historical and cohort influences all conspire to make any individual's narrative a fluid and evolving work in progress. Third, they do indeed believe in the word that I just used, "progress." These researchers see the potential, though it is certainly not realized in every case, for individuals to learn and grow from the stories they construct out of their life experiences. (p. 445)

***FASD and narrative identity theory limitations.*** The narrative perspective and The Life Story Model of Identity have strengths and limitations when applied to understanding the identity of adults with FASD. These models provide an understanding of the dynamic process that is undertaken when developing personal identity. One can begin to understand how adults with FASD began to develop their understanding of self. This perspective provides guidance regarding how larger cultural and social stories can influence a person with FASD and his/her identity significantly. This includes societal and political views about FASD itself. This could also include the interventions, stories and responses from their family and support systems ie. *if the stories I hear about myself change, I too may change.*

From a narrative perspective, development occurs across the lifespan. This addresses a specific concern related to FASD. Namely, people with FASD may not adhere to a stage theory of psychosocial development due to cognitive delays or dysmaturity. They may not have resolved previous stages of psychosocial development.

Understanding identity within the three-level hierarchy of personal traits addresses the concern that behavioral symptoms of FASD may become confused with identity. Shared patterns of behaviors, such as the ones those with FASD struggle with, are not included within the definition of identity. Rather, identity explains the development of a person within the context of their past. The Life Story Model of Identity provides a dual appreciation that shared patterns of behaviors can influence understanding but do not define a person's identity.

Some persons with FASD may have trouble with verbal language. At first glance, a weakness of a narrative perspective could be the assumption that telling a life story is an oral endeavor. Since the life story itself is an internal construct, it can be uniquely internalized and stored by the individual. Smith (2000, p. 328) reflected that most narrative researchers would

suggest narrative is mainly an oral, written or filmed account told to others and it is not exclusively verbal material. This allows for the interpretation that the life story could be internalized and told to others in written accounts or moving pictures.

**Identity and disability.** For those with a disability, their identity has been suppressed and influenced by a society that has devalued and stigmatized their experience. Persons with disabilities generally have not had their identities acknowledged as valuable, experience a lack of personal integrity and their “problems” merely become objects of study (Booth, 1995, p. 238). The social and medical models of disability will be reviewed to further illuminate disability and identity. Additionally, Gibson’s (2006) and Rodis’s (2001) models of identity development specific to persons with disabilities will be considered.

**Models of disability.** The social model of disability assumes that a physical condition is distinctly different from impairment. The disability or impairment is caused by chronic social exclusion or disadvantage due to a number of social and political factors. From this perspective, social and political interventions are needed to change the impairment or disability (Zarb, 1995). Lennard Davis aptly summarizes the social model of disability. “The problem is not the person with disabilities; the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled person” (1997, p.3).

A medical model of disability asserts that disability is the impaired physical condition and a deficit that impairs an individual’s ability to function in society. This model both devalues difference and implies that the individual experiencing the disability must be fixed or changed. Interventions from this perspective focus on preventing or curing the impaired physical condition (Zarb, 1995).

**Models of identity development and disability.** Two theories of identity development

specific to persons with disabilities will be discussed. Gibson's (2006) perspective is a three-stage theory focused on incorporating disability into identity. Rodis's (2001) perspective is an seven-stage theory that seeks to understand identity and disability as both physically impairing and socially constructed.

Gibson (2005) developed her three-stage perspective to provide practitioners an understanding of the identity development in their clients who were experiencing disability. Gibson identified three stages a person would move back and forth through, as sequential movement is not necessary. These three stages are a passive awareness, realization and acceptance. The final acceptance stage focuses on seeing oneself as having a disability and then shifts the focus from feeling different to embracing self and understanding the social construct of disability.

The book *Learning disabilities and life stories* (2001), edited by Rodis, Garrod and Boscardin, contains a model of identity development in persons with learning disabilities (LD). Through reviewing the life stories of persons with LDs, Rodis identified seven stages of identity development. While not every person with a LD will move through each step, common stages of identify formation appear to apply to persons with LDs. This stage theory begins with diagnosis and initiating an inquiry of how the LD fits into identity. Following identification, individuals go through a process of alienation and/or try to conceal the LD from others. This will often cause a life crisis as the result of denying the LD. After re-confronting the LD it becomes a central part of the identity and is used to understand the self across pragmatic, intra-psychic and political-ideological dimensions. Eventually, one will transcend the LD because they feel it has led to important life discoveries.

The current models of identity and disability are limited in scope, mainly since it is

assumed that adding disability to identity is a primary and needed achievement when understanding the self. To understand the development of identity in FASD, these disability models could serve to supplement other more comprehensive perspectives of identity. Solely using a disability identity perspective to understand the identity of those living with the effects of FASD may serve to further disenfranchise these individuals.

**Narrative and disability.** Narrative gives individuals the ability to accurately present their identity—who they are according to who they wish to be and how they wish to engage with their community (Sharf & Vanderford, 2003, p. 21).

[Narratives] give voice to the concerns of people who are usually not heard because of the stigma of their spoiled identities...Our society privileges those with undamaged bodies and minds to speak with a stronger voice than the voice of others. (Geist-Martin, Ray, & Sharf, 2003, p. 42)

In writing about their experience, individuals reveal the stories they wish to, those with significance to them and frame life stories in a personal manner. (Couser, 2002).

Reviewing these meaningful narratives has provided insight into how persons with a disability have answered the question “Who Am I?” Causton-Theoharis, Ashby and Cosier (2009) reviewed 20 previously published autobiographical texts written by persons with autism and reported on seven of these texts. These seven narrative texts illustrated individuals’ desire for social interaction while having a keen awareness of feeling isolated and lonely (Causton-Theoharis, Ashby & Cosier, 2009). Punshon, Skirrow and Murphy (2000) completed a phenomenological study of the experiences of 10 people diagnosed with Asperger’s Syndrome during adulthood. Commonly reported themes included the characterization of themselves as “outsiders” or “loners” (Punshon, Skirrow & Murphy, 2009).

Receiving a diagnosis was a key life turning point identified in the narratives of adults with Asperger's Syndrome (Punshon et al., 2009). These personal accounts detail how the diagnosis allowed them to find greater understanding of their life experience, the remembered past and the imagined future. For those given a diagnosis related to a lifelong chronic issue, it may take a year to incorporate this new information into the life story (Punshon et al., 2009).

Steve Neafcy, a man diagnosed with a FASD as an adult, published a personal account of his experiences titled *The long way to simple: 50 years of living, loving, and laughing as a person with FASD* (2008). He also identified diagnosis as a key turning point in his life. "I was 43 years of age and finally able to start a new second half of my life armed with the reasons I behaved the way I did" (Neafcy, 2008, p. 8). On its website, The Asante Centre, a support center for adults with FASD, informally reported on the personal stories of adults with FASD. The Centre stated that receiving insight into a diagnosis of FASD in adulthood could help adults understand themselves and the challenges they have faced (Asante Centre, 2012).

In many narratives, the disability itself was not viewed as an important component of the identity. In an analysis of six adulthood life stories with Trisomy 21 (Brown, et al., 2009, p. 220) and a narrative study of 24 persons with an unspecified lifelong disability, for many the disability was not associated with informants' identity (Watson, 2002). The participants in Watson's study "do not claim an identity based on their impairment" (Watson, 2002, p.524). Their identities are constructed in a way that countermands impairment as part of identity. Analysis of participant narratives suggests that the impairment is normal or a fact of life and as such is unimportant (Watson, 2002).

While listening to and reviewing narratives, one still needs to think critically and place life stories in a social and cultural context. Narrative plots found in the stories of persons with



disabilities can be culturally validated. The influence of larger, negative, societal narratives related to disability can cause people with a disability to incorporate negative stories into their life story and in turn their identity.

Counter narratives, which are narratives that challenge and oppose widely-accepted accounts, often are present in the life stories of those with a disability. They are created and unfold in the life story to counteract the effects of socially and culturally preferred or validated stories. These socially-validated stories may disenfranchise a vulnerable population.

Counter-narratives “repair the damage inflicted on identity by abusive power systems” (Lindemann-Nelson, 2001, p. xiii) and in doing so, provide an alternate way to understand disability or impairment. In this context, a narrative can evolve from a suppressed or silenced story to one that is individualized and strengths-focused (Cardillo, 2010).

***Strengths and limitations.*** A narrative understanding of identity in persons with FASD can give individuals the ability to accurately present their identity. This can be accomplished in part through understanding how FASD is dually a medical and socially constructed impairment. Individually, the social and medical models of disability are not adequate to understand the role of FASD in relation to identity. A dual acceptance of both models may be necessary to adequately understand FASD and identity. The following quote is an apt description for those living with the effects of FASD.

The medical model offers the solution of “fixing” disabled people or re- making them. Our experience with FAS/FAE confirms the futility of any medical “fixing”, but we remain committed to the possibility of healing. For us healing is not based on evading fate or fixing but on accepting and integrating. (Gere & Gere, 1998, p. 408)

The social model places value in diverse experiences and supports. This model promotes

the understanding that many of the characteristics associated with FASD are socially constructed and can be addressed through appropriate social supports. Though, prevention of future cases of FASD is part of the mission of many FASD advocacy groups. When applied to identity, reconciling the medical and social understanding of FASD could prove a demanding and necessary identity achievement to promote healing. This is the acceptance that while FASD is a preventable, neurological condition, there is value in the strengths, difference and the diversity of experiences of those living with the effects.

### **Defining Identity in Context of FASD**

Identity and identity development for adults with FASD is complex. Traditional psychodynamic concepts of identity, narrative identity, identity and disability and models of understanding disability were reviewed. This review provides a theoretical scaffolding for understanding the identity of adults with FASD who were identified as adults.

From the standpoint of traditional psychodynamic theory, a sense of self is formed during late adolescence/early adulthood. During this period, one internally arranges personal traits, beliefs and social and cultural perceptions into a self-definition from which personal actions are influenced. This can also include the interventions, stories and supports provided by their family and other support systems. A narrative perspective states this process has a storied quality as one begins to develop one's life story. This life story holds flexible personality traits, patterns of behavior and the identity. From a lifespan developmental approach, personal development and behaviors can change across the lifespan as new information is added to the life story. Additionally, if the stories reflected back to one begin to change, this may in turn change one's understanding of self.

Participants in this study began to negotiate the process of identity development prior to

learning of their FASD. Though they have experienced the effects of FASD, their reflexive understanding of self, held in the personal life story, evolved across the lifespan as new experiences were reviewed and used to guide future actions. Identity is the reciprocal understanding of self, the use of actions and the decision making based on that understanding. Common behavioral symptoms of FASD may influence the understanding of self but are not truly reflective of identity. “A fetal alcohol spectrum disorder may be part of who a person is, but it is not the person’s entire identity. Someone can ‘have fetal alcohol syndrome (FAS)’ but nobody ‘is FAS.’ (SAMHSA, undated, competency 3).” There is often a social stigma attached to FASD, this could influence the understanding of self. How individuals were supported through the very personal process of learning about and understanding FASD could impact how the new FASD information influences understanding of self. Finding personal meaning and not incorporating possible societal stigma could involve the deft support of family members and other support persons.

Individual adults with FASD are likely to be more/less successful when negotiating the process of identity development. This is due to varying degrees of cognitive or social skills impairments. Their ability to reconcile FASD and how it fits (or does not) into their understanding of themselves may have long-lasting implications. This could be due to how the FASD diagnosis is presented and how an individual is walked through the diagnostic and post-diagnostic process. The resolution of this could help individuals address previously unresolved stages.

### **Review of Empirical Evidence**

With a few exceptions, the information reported in this literature review derived from those who became aware of their FASD prior to adulthood. There are people who are affected and

remain unidentified because they were born before the sequelae of gestational alcohol exposure were understood and well documented (Massey, 2011). Many adults and children with FASD have not benefited from early recognition and may not present associated distinctive physical features or a known history of maternal alcohol consumption (Chudley, et. al, 2007; Lockhart, 2001). This group faces the biggest barrier of FASD, that of having an unidentified, invisible brain-based disability that is difficult for others to understand (Kyffin, et al., undated). The scope of the primary and secondary effects could cause adults with FASD to access services in multiple systems (Chudley, et al., 2007); although, there is little known about subjective experiences and personal identity of adults living with FASD.

Current empirical data focus on the experiences of people living with FASD and the challenges they experience in school, employment and life. These reports are largely written from a disability or deficit perspective which cannot account for life's complexities. There is a lack of inquiry into the experiences and identity of those living with FASD who became aware of that neurological condition during adulthood. While research suggests that those living with FASD are more likely to have experienced negative early childhood events and adverse life outcomes, the ways that life experiences are incorporated into a life story and, in turn, identity, are largely unknown. For people who became aware of their FASD in adulthood, it is unknown if their new knowledge of having FASD was incorporated into the life story or influenced the understanding and conceptualization of themselves. People with FASD are more likely to have heard social and cultural stories that are advanced by a deficit-based system that pathologizes symptoms and disability. We do not know how these larger societal narratives influenced the life stories of adults with FASD or what counter narratives arose because of their experiences. The socialized narrative themes may have led those with FASD to characterize themselves as being,

rather than having, a problem (Malbin, 2008).

Erin Dej (2011) hypothesizes that by the time persons with FASD have reached adulthood, society may view them as “deviant, dangerous and unsalvageable” (p. 138). Since it is suggested that a diagnosis is insufficient to provide appropriate supports (Hannigan & Berman, 2000), it is necessary to know how the lived story is situated in society and culture and how adults with FASD understand who they are in order to inform social support services. Researching the identity development in adults with FASD is essential to combating discriminatory societal characterizations through understanding the individual experience.

In the past several years, scholarly articles have recommended this as an area of research. The Public Health Agency of Canada published a manual titled *Assessment and diagnosis of FASD among adults* (2011). In this publication, research recommendations emphasize a need for literature that focuses on quality of life and insight into improving quality of life. Additionally, more information is needed about the perspectives of students with FASD (Ryan & Ferguson, 2006), social and cultural influences on services (Ryan & Ferguson, 2006) and understanding the psychosocial implications of living with FASD (Public Health Agency of Canada, 2011).

### **Research Questions**

This study seeks to explore the identity of adults living with the effects of FASD, in particular those who learned about this during adulthood. The aim of this study is to highlight the subjective experiences of adults with FASD. This study will explore the stories of adults who have potentially struggled their entire lives with the effects of FASD but remained unidentified until adulthood. Not acknowledging these lives and experiences can potentially add to the ongoing marginalization of an already vulnerable population.

Three research questions directed the development of the scope of the research and development of the interview guide.

- What themes of identity arise in the life stories of adults living with FASD?
- What social and cultural factors have influenced the themes?
- Does having FASD figure into the identity of adults living with FASD and if so how?

### **Chapter Three: Methodology**

The purpose of this research is to explore the life stories of adults with FASD in order to understand their personal experiences and uncover themes of identity. To this end, I designed and conducted a qualitative study. This methodology made possible a rich description of the experiences and identity of a population whose voice and experiences are rarely heard.

I specifically employed a narrative methodology for both its conceptual and procedural process. A case study design was used, as this research focuses on examining the experiences of a specific group. Underpinning concepts related to qualitative research, narrative methodology and case study design will be introduced. Specifics related to development, data collection, interpretation and trustworthiness will be reviewed. Additionally, I will discuss the measures employed to specifically address FASD and the needs of a potentially vulnerable population.

Throughout this process, there was an aim to remain faithful to the initial line of questioning, which focused on listening to and learning from adults who became aware of their FASD in adulthood. The participants were eager to tell their stories both as a way to advocate for prevention and also to educate others regarding their experience. While the words research and data are used often in this report, what cannot be lost is that these are people's stories about their lives. Each participant was generous in sharing her or his story for the study.

#### **Research Approach**

Qualitative research principally explores phenomena about which little is known (Strauss & Corbin, 1990) and sheds light onto an individual's or group's understanding of such phenomena (Creswell, 2007). Generally, the underlying question for qualitative research is, "What was a particular experience like for a specific group?" (Merriam, 2002). In the work *Qualitative research in practice: Examples for discussion and analysis*, Merriam (2002) outlines

four general qualities of qualitative research (p. 4-6). These characteristics include:

- being concerned with the search for meaning,
- regarding the researcher as interpreter,
- being an inductive process and
- having a descriptive end product.

The goal is to develop an acute understanding of the meaning that people assign to their lives. This includes exploring how personal meaning is constructed through a reciprocal relationship between an individual and his or her surrounding world. As a research instrument, the researcher is immersed in understanding this meaning through data collection, data analysis, interpretation and summarization. Concepts, themes, hypotheses and theories are developed through this inductive process. The final result is the creation of a richly descriptive analysis that is developed from quotes, interviews, documents and other sources (Merriam, 2002).

Qualitative research conducted from a narrative perspective allows the researcher to collect knowledge through the analysis of personal narratives. Throughout the narrative research process a researcher will take the perspective of a story analyst (Smith & Sparkes, 2008, p. 21) working within a context of discovery (Reichenbach, 1938 as cited in McAdams, 2012). The perspective of a story analyst is one of exploration of knowledge held within the story (Smith & Sparkes, 2008, p. 21). Narrative inquiry, within the context of discovery, is an inductive process that naturally extracts knowledge from the textual data (Merriam, 2002, p. 9).

The unit of analysis in narrative inquiry is the story that can be explored through a thematic, structural, dialogic or performative methodology (Reissman, 2008). Narrative inquiry from a thematic perspective seeks reflexivity of life stories, as well as how they are situated in society and culture. Specifically, a thematic approach mines the life story for themes that connect



identity with associated socio-cultural influences (Reissman, 2008).

A case study design is most commonly used when conducting narrative research (Wells, 2011, p. 130), as it focuses on a specific case or examines a singular group of people (Rubin & Babbie, 2011, p. 443). Within this framework, a case study design can be both descriptive and explanatory when investigating the experiences of a particular group.

Since the methodology assumes the position of the researcher as a story analyst, a case study design situates itself within the context of the research, allowing for proper explanation and description of the phenomenon being researched. While semi-structured interviews are the primary method of data collection, additional data sources can include previously published autobiographical accounts, documentaries and observation (Merriam, 2002). Supplementing the primary interview data can enrich and increase diversity of the research findings.

Researchers and those living with FASD view the use of narrative or storytelling research methods positively. In the report *Toward inclusion: Involving people with FASD in research* (undated), Kyfin, et. al. found that young people with FASD desire to have their stories heard and prefer to do this through a relaxed conversation during which their needs are being met and they feel comfortable and supported. In the study *Adults living with FAS/E: Experiences and support issues in British Columbia* (2002), Rutman, LaBerge, & Wheway interviewed more than 30 individuals with FAS or FAE. Numerous themes were identified through the analysis of personal narratives. These themes provided insight into the daily realities of those living with FASD. Additionally, two Master's theses and one doctoral dissertation used the method of gathering and analyzing narratives and stories in order to understand the experiences of those living with FASD (Chatterley-Gonzalez, A., 2010; Knorr, 2011; McGregor, 2009).

### **Data sources**

In keeping with a qualitative narrative approach, I gathered the life stories of 4 adults with FASD through the use of in depth interviews. These in depth interviews were conducted via telephone. In addition, previously published autobiographical accounts were collected and used as secondary sources of data.

### **Interview sampling criteria**

My goal was to interview adults with FASD who learned of their diagnosis or neurological condition in adulthood. I made multiple attempts to gather rich, descriptive and diverse life stories. During the process of recruitment, it became apparent that the identified sample was a subset of an already small population. This contributed to the small sample size.

To participate in this project each participant was expected to:

- have a self-reported diagnosis related to FASD after the age of 18 or be in the process of evaluation for a diagnosis related to FASD (If there is no diagnosis, then they must have knowledge/confirmation of maternal drinking);
- be at least 22 years of age, i.e., born after 1990;
- be currently involved in some type of support service (formal or informal), including but not limited to case management, therapeutic counseling, support groups, active family support, etc.
- be at least 12 months post diagnosis or knowledge of diagnosis or knowledge of FASD.

Exclusion criteria included:

- having a reported diagnosis of Mental Retardation (MR) or Intellectual Deficiency/Disability;

- having a diagnosis related to one of the many genetic causes that needs to be ruled out by the differential diagnostic process such as: Fanconi anaemia, Smith-Lemli-Opitz Syndrome, Stickler Syndrome, Turner Syndrome and Kabuki Syndrome
- currently using alcohol, illegal substances or prescription drugs (for non-prescribed effects) during the interview;
- having a reported diagnosis of schizophrenia or a personality disorder; and
- being currently on probation or parole.

### **Recruitment**

Recruitment material was distributed to local, regional and national agencies that provide FASD resources and supports. Organizations located in Pennsylvania and New Jersey posted recruitment material. I spoke with multiple regional and national FASD advocacy groups and circulated an informational flyer. I distributed IRB approved recruitment material and used an IRB approved recruitment script (Appendix A; Appendix B; Appendix C). Individuals and groups reposted the informational flyers on FASD associated websites, Facebook pages and weekly advocacy e-mail blasts. Each participant or his or her personal representative made initial contact through e-mail. I used e-mail communications and phone calls to gather additional information and clarification as to suitability for the study. The response from prospective participants and their community supports was enthusiastic. In all, approximately 20 people from the United States, Europe and Canada made contact regarding the study. Five of the approximately 20 respondents met the criteria and participated in the interviews.

The roughly 15 prospective respondents who did not participate in the study were excluded for differing reasons. Two adults, who met all study criteria, were assessed as being unable to

provide informed consent. This determination was based on multiple dialogues with both the adult with FASD and their personal advocate. The personal representatives of two adults currently incarcerated inquired about the study. These two adults were unable to participate due to being incarcerated. I communicated with the personal representatives of the remaining prospective respondents. These potential respondents were excluded because they were adolescents or diagnosed/became aware of their FASD as children or adolescents.

After receiving additional information and clarification, five adults participated in the interviews. Four interviews will be reported in this study. One interview was not reported. The participant did not respond to communication attempts to approve of personal quotes/themes. Recruitment lasted approximately seven months.

### **Description of Participants**

The narratives of two women and two men who have a range of backgrounds are reported. They were between the ages of 22-43. Three were previously identified as having a diagnosis under the umbrella term Fetal Alcohol Spectrum Disorder (FASD) and one has a self reported FASD and knowledge of maternal drinking. It should be noted that a formal diagnosis was not required to participate in the study. Participants lived in diverse communities across the United States and were of Latin, African-American and Caucasian birth. Two participants were adopted and two were raised by their birth families.

Figure 1.

#### *Demographics*

Participant Pseudonym	Identified Gender	Education	Age	Type of Diagnosis	Ethnicity	Age at Diagnosis	Interview Dates
Mitchell	Male	High school graduate	Early 20s	FAS	Caucasian	18	3/24/2013 4/13/2013 4/27/2013
Andrew	Male	High	Mid	FASD w/	African-	Early 30s	4/11/13

		school graduate with some college	30s	confirmed maternal drinking	American		4/19/13
Marie	Female	High school graduate with Post secondary trade school	Early 40s	FAS	Caucasian	Early 30s	4/27/13
Kathy	Female	High school graduate with Post secondary trade school and some college courses	Early 20s	FAS	Latina	18	4/12/13 4/18/13

### **Statement of Human Rights Protection**

Each participant was required to sign a consent form that clearly detailed the potential risks and benefits of participation in the study. The consent also reviewed the measures taken to protect the confidentiality of the participants, including use of pseudonyms (Appendix D). I provided my contact information should ongoing support services be needed and followed up with the participants at regular intervals following the interview. The University of Pennsylvania Institutional Review Board approved this project prior to data collection.

Personal representatives of three out of four of the interview participants reviewed the research project, participant criteria and the interview process. The personal representatives reported that each participant was appropriate for and had the ability to take part in this study. No interview participant was identified as having a below average intellectual capacity. During the interview process, several participants identified specific intellectual/cognitive disabilities such as difficulty with learning, attention, memory and executive functioning, which were consistent

with those identified in FASD literature. Additional safeguards intended to address these issues comprised: the inclusion of personal representatives; the inclusion of personal representatives in the informed consent process, pre-interview screening process, interview design, follow-up protocol, involvement of representatives in thematic review process; and additional interviewing precautions to address potential vulnerabilities.

For those respondents with personal representatives, I initially reviewed the project, inclusion criteria and consent form with an identified supporter. Respondents and representatives report they reviewed this information together before the respondent contacted me. I presented the project information to the respondent and reviewed the specifics related to consent. Participants stated they co-reviewed the consent form with their personal representative. Respondents and personal representatives report they co-reviewed and approved the included themes and quotes. This was in an effort to ensure respondents were comfortable with the inclusion of personal quotes and agreed with the identified themes.

As the primary researcher, I felt confident that the participants and their personal representatives understood the research process. Additionally, each participant was in some way active in the FASD community either through work in advocacy and education. Each participant had shared elements of his or her personal story in other forums such as conferences, trainings or for parent groups; but participants' life stories had not previously been collected and reviewed to cull specific information related to personal identity.

Prior to the interviews, I screened the participants for consent competency through a series of questions related to understanding, appreciation, reasoning and choice. The specific questions discussed are listed in figure number 2 below. Dunn, et al. (2006) stated that experts generally include at least four components when assessing decisional capacity: understanding the

information, appreciating the information, using the information in reasoning and expressing a consistent choice. The MacArthur Competence Assessment Tool for Clinical Research (Applebaum & Grisso, 2001) was reviewed to assist in developing the pre-interview consent screening questions.

Figure 2

*Pre-Interview Consent Screening Questions*

<u>Component</u>	<u>Screening Questions</u>
Understanding	<ol style="list-style-type: none"> <li>1. What am I asking you to do?</li> <li>2. What will we be talking about?</li> <li>3. What can you do if you decide you do not want to talk to me anymore?</li> <li>4. After I do the write up what will I ask you to do?</li> </ol>
Appreciation/Reasoning	<ol style="list-style-type: none"> <li>1. Are there good/bad things about talking to me?</li> </ol>
Choice	<ol style="list-style-type: none"> <li>1. Do you want to participate?</li> </ol>

The consent form was sent to the participant prior to the interview and each participant reviewed the form. They legally were able to provide their own consent. Prior to participating in the interview, three participants reviewed the consent form with a friend or family member. The personal representatives communicated that each participant had the capacity and associated qualifications to participate in this study. I also reviewed the consent form with the participants prior to the interview in order to answer any questions and/or to provide clarification. Upon consent, each participant was notified of the opportunity to withdraw from the study at any point without repercussion.

### **Data Collection Process**

The Life Story Interview (McAdams, 2008) was modified for the use as an interview guide to collect participants' life stories (Appendix E). This interview guide has also been used to gather the life stories of mid-life American adults and to understand generativity in the elderly

population. While The Life Story Interview has not been tested with the population living with FASD, it is rooted in a theoretical narrative construction of identity which I applied earlier to the evolution of identity in adults with FASD. Dan McAdams was contacted on January 24, 2012 via email and provided the appropriate permission for me to use the Life Story Interview with any modifications that would be deemed necessary. The Life Story Interview has been modified to accommodate an adult with FASD.

An adult living with FASD and his or her support person provided me with written feedback on the interview questions and procedures. Their recommendations included:

- making sure the interview was conducted in a relaxed and conversational manner;
- providing appropriate wait time after each question to ensure that participants understood the question, had enough time to process it and provided their entire answers.
- ensuring that the researcher asked a single question at a time.

### **The Interview Process**

I provided the interview questions to each participant several days prior to the interview. Most of the participants reported that they reviewed the questions and answers with a support person prior to the interview. The total interview time was between 1-2 hours, conducted over several phone calls. Individual phone calls lasted between 20-45 minutes. Interviews were conducted in March and April 2013.

I relied on an interview guide to capture the stories of the participants. During most of the interviews, the questions were used as a guide, and the stories flowed in a relaxed and conversational manner. During the interviews I asked questions for clarification, both to build the relationship and to ensure that participants were comfortable and not emotionally upset by the line of questioning. Toward the end of the interview, I reviewed the interview guide to ensure



no questions were missed.

**Telephone interviews.** Interviews were conducted via telephone. This section will discuss study-specific telephone interview considerations relative to methodology. Additional discussion is included in the Limitations section.

Creswell (2007) notes that telephone interviews can be appropriate when a researcher does not otherwise have access to a participant. Since all of the participants lived a considerable distance from the designated research location, the interviews were conducted over the phone. The participants consented to and stated they were comfortable with this process. One participant's personal representative independently reflected that he/she would do well with a phone interview. Another participant had a personal representative present via conference call during the interview. The use of telephone interviews required that I was more aware of the need to: build rapport with participants; ensure respondents comprehended the study questions; monitor affect and present myself as actively engaged in the interview. I found telephone interviews were appropriate because: interviews could be easily rescheduled; potential anxiety caused by attending a scheduled interview was reduced and imposition on respondents was minimized.

Rapport was built by engaging in introductory, non-recorded phone calls and small talk prior to the interview. Building rapport in this manner is cited as appropriate for telephone interviews (Burnard, 1994). These occasions allowed for the analysis and assessment of the participant's speech pattern, vocal cadence, cognitive processing and general affect. Non-verbal body language could not be assessed. I assessed confusion or misunderstanding by how participants answered a question or used silence. Tausig and Freeman (1988) found that "careful listening enabled the telephone interviewer to hear affect that was conveyed with the content

without the benefit of visual access” (p. 424).

During the introductory conversations, I learned that after posing a question an extra breath or two of wait time allowed me to avoid interrupting a respondent’s story. This guaranteed I really listened and did not prematurely end a participant’s story.

This approach is well illustrated by my interactions with one study participant. After posing a question, I would internally meter my response time by counting my breaths. This allowed for extra participant processing time and therefore a richer response. Over-prompting or prematurely checking for comprehension could have led the participant to become disengaged or frustrated. Additionally, slight ‘vocal jumpiness’ was observed when a break was needed or when a question needed to be clarified. The interview was promptly and appropriately closed if a break was required, and was easily rescheduled for another day or another time later same day.

Miller (1995) noted that a researcher’s vocal responses were needed to communicate ongoing attention to the respondent when non-verbal gestures were unavailable. Chapple (1999) calls this aspect of the telephone interview as *sounding* interested. During the interview, I actively sounded interested without talking over or interrupting the participant. I used vocal encouragers such as ‘hmm-hmm, yeah, etc.’

Additional measures to ensure participants understanding of questions include: one participant having a family member participate via conference call; prior to the interview one participant wrote notes to refer to and two participants stated they reviewed the questions before the phone calls.

Telephone interviews allowed flexibility with scheduling, interviews were easily rescheduled if necessary and text message reminders could be sent prior to the scheduled interview time. Since life, at times, can be unpredictable, the ability to reschedule an interview

was particularly appropriate and necessary. While not common, respondents rescheduled interviews because: they worked late, had a difficult day or simply felt it was not a good time. This allowed participants to have greater agency and control over the interview process. Phone interviews may have minimized the stress of trying to access an interview location. Additionally, participants did not witness the interviewer taking notes or referring to my questionnaire, potentially leading to a less clinical and more comfortable conversation.

Most people are accustomed to communicating by telephone (Gillham, 2005) and due to email, social networking and the telephone, it is not uncommon for many people to have limited face-to-face interaction during the day (Trier-Bieniek, 2012). Respondents were especially adept with social networking, texting and using personal cell phones.

Methodologically, every effort was made to ensure that participants were comfortable and engaged in the process, had their needs met, and understood and comprehended the questions. Nevertheless, telephone interviews can be viewed as a limitation (Irvine, 2011), this limitation will be addressed in the limitation section.

All interviews were audio recorded with participant's consent using a Olympus digital voice recorder model V405171SU000. The researcher transcribed the interviews verbatim and the original digital recordings were erased.

### **Participant Compensation**

Participants were compensated \$50.00 for each interview and \$50.00 to review the final report and return the report with comments. Upon initial consideration, this may seem a significant compensation. The compensation protocol was developed to compensate for travel expenses. Since the interviews were completed over the phone, the additional monies could be helpful with defraying the cost of phone calls and text messaging. The researcher paid for all

needed postage. One participant requested that the monetary compensation be donated to charity. Per this request I anonymously donated the financial compensation to a non-profit FASD advocacy group.

### **Specific Interview Considerations**

During the course of the data collection, I took specific steps to customize the interview process in terms of the preferences and needs of each participant. Personal representatives were involved in reviewing the interview process and research questions with participants. I aspired to conduct each interview in a relaxed and friendly manner. One question was asked at a time and participants were never pressured to answer within a certain time limit. If necessary, I restated questions to ensure clarity for the participants.

Several of the participants preferred taking part in multiple interview segments that were shorter in time. This process allowed them to focus on the interview without becoming overly tired, distracted or disengaged. One participant chose to have a family member present at the interview.

### **Non-Interview Obtained Data**

Additional narrative data were gathered from previously published autobiographical accounts. These data sources included:

- one participant-published electronic book,
- two personal accounts published in book chapters,
- two personal accounts included in a published dissertation
- three personal accounts published in newspapers and/or magazines

The search engines used to collect these data included Google Scholar, Google Alerts, EBSCO Megafire, Lexis Nexis, JStore and Psyc Info. The search terms used included fetal alcohol, fetal

alcohol and story and adult, fetal alcohol and life story, pre-natal alcohol and story and adult, pre-natal alcohol and life story. These terms yielded valuable and rich sources of information that served to supplement the stories collected through interviews.

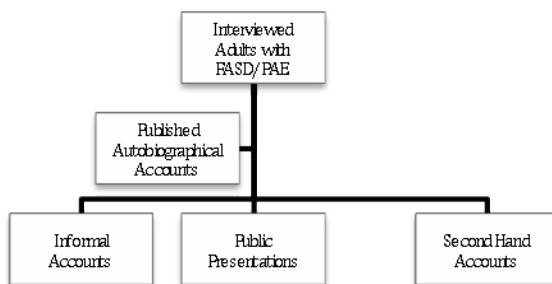
Many informal narratives that appear in web-based form were important to this research, including personal accounts on blogs, advocacy websites and informational websites. Additionally, attending a conference that included a panel discussion offered by adults with FASD, two of whom learned about their FASD as adults, provided a valuable perspective on the overall project. From each of these methods of informational gathering, I took copious notes which I reflected upon during both the primary and secondary research processes. Since these autobiographies were not published, they were not included as formal data. Nevertheless, due to their similarities, these accounts add an additional level of trustworthiness to the reporting.

### **Summary of Research Procedures**

A modified Life Story Interview was used to collect the narratives of adults living with FASD. The four interview participants were recruited from the FASD community and able to provide informed consent regarding the research process. Three of four participants consulted with and involved a support person in the consent and interview process. Three types of data were collected: (1) the primary data from the interview process and (2) secondary data from published autobiographical accounts, as well as (3) web-published personal experiences, other informally-posted accounts, public presentations by adults with FASD and published second-hand accounts.

Figure 3

*Hierarchy of Data Collection*



## Data Management

I transcribed each interview verbatim, and the voice recording was destroyed by being digitally erased. The interviews were typed and securely stored on a password protected electronic file. I then number coded the interviews, and the respondent's name was not attached to the transcribed interview. The consent forms and any associated identifying documents were also number coded and kept separate from the transcribed interviews. The printed interviews and all forms were safely secured in a locked, 26-1/2 inch, commercial vertical file cabinet located in the researcher's home office. A pseudonym was assigned to each participant in order to further ensure anonymity.

## Data Analysis

I began to analyze the interviews during the transcription process by noting initial thoughts and potential follow-up questions. During the course of several months, I reviewed and analyzed the interviews and other data sources, taking extensive notes and recording voice memos. Initially, recurring themes, ideas and quotes were cut and pasted on notecards as a form of visual organization, but I found this quickly became unmanageable. The second method of data analysis and organization was more successful. I used Microsoft Excel to organize the stories and associated themes that emerged from the initial review of the interviews and autobiographical accounts. Each person was assigned a specific color as the narratives were being analyzed and thoughts combined.

I then wrote specific notes, interpretations and follow-up questions in the second column. In the third column, I compared the similarities and differences among the interviews and how each of the stories fit into the larger narrative. The fourth column represents the identified theme. This process was chosen because the respondents' stories were dynamic. I found that an intuitive and personal data analysis process was necessary to respect the life stories and people interviewed.

Upon analysis of the data, certain themes and similarities in the participant life stories paralleled psycho-social variables reported in previous studies and support strategies outlined in journals/books, as well as informal reports of strengths. These findings will be reported and discussed.

Figure 4

*Example of Data Analysis Process*

<u>Participant Interview Date</u>	<u>The Story</u>	<u>Initial Thoughts</u>	<u>Processing Similarities/Differences</u>	<u>Theme</u>
Andrew	(Learning about my FASD earlier) It would have helped me out by knowing that was what was wrong, instead of me speculating and worrying.  Like I said it gave me a better understanding of myself.	Helpful to receive knowledge of FASD. It was a normalizing experience.	Learning about the FASD was beneficial and a relief- it was 'sense making'	Identification, Naming and meaning making: A turning point

### **Methods to Ensure Trustworthiness**

To support the trustworthiness of this research project, the widely used criteria related to credibility, confirmability, dependability and transferability outlined by Drs. Yvonna Lincoln and Egon Guba (1985) were utilized. Issues of trustworthiness specific to narrative research were

addressed through criteria outlined by Dr. Catherine Reissman (2008) and Dr. Atkinson (2001).

**Credibility.** The credibility or believability of this proposed research project was supported through documentation, subject corroboration, negative case analysis and independent peer review (Lincoln & Guba, 1985). The concept of ensuring honest responses from participants as proposed by Shenton (2004) was also addressed. Throughout the interview and analysis process, I documented the data analysis process through detailed field notes and voice memos. These notes were reviewed after each interview and slight modifications to the interview style were made following post interview reflections. I also referenced the notes and memos during the data analysis process. Each interview was transcribed verbatim. The use of the slow playback feature on the Olympus voice recorder eased the transcription process. I then reviewed the transcription against the audio recording three times and identified and corrected transcription errors during this process.

During data analysis, I noted similarities between the life stories and previously reported psychosocial variables, support strategies and strengths. These findings will be reported and discussed. I also made attempts to acquire previously published accounts that met the inclusion criteria though reported different outcomes.

I engaged in the process of independent peer review through providing interviews and autobiographical accounts to two independent reviewers. Each of the reviewers had doctoral-level training in the evaluation of qualitative interview data. Each reviewer completed a protection of human subjects training course through the Collaborative Institutional Training Initiative (CITI). Following their review, a debriefing session was held and a scholarly discussion ensued. Debriefing sessions were conducted via telephone and copious notes were taken. Debriefing sessions occurred in November, 2013.



During this process, one theme was discarded. Because neither of the reviewers had independently identified the particular theme, it lacked credibility. The themes included in the final dissertation had 100 percent inter-rater agreement. Through the peer review process an additional area of further study was identified. One reviewer advised that an important area of study would be the understanding of the lives of some adults with FASD through the context of literature reporting the experiences of adult children of alcoholics.

After data analysis, participants were mailed a write-up of the discovered themes and asked to provide feedback. Each participant was provided with the specific quotes targeted for use in the dissertation. Three out of four participants stated they reviewed the quotes and themes with a personal representative. Three out of four participants reviewed and returned the cover sheet confirming the findings. One of the participants reviewed the materials and responded by e-mail that “everything looked good.”

***Ensuring honesty.*** Rapport was established with each participant through “getting to know you phone calls” that were friendly in nature and not used for research purposes. During each interview, participants were reminded that the answers were neither right nor wrong and any question could be skipped. Given the researcher’s professional experience, there was cognizance of the fact that people with FASD can be susceptible to suggestion and may include suggestions in their stories to please others (Brown, Gudjonsson, Conner, 2011). The article: *A fetal alcohol behavior scale* by Streissguth, Bookstein, Barr, Press, and Sampson (1998) reported that persons with FASD may:

- enjoy talking, but the act of talking maybe more important than the content;
- like to talk about unrealistic subjects; and
- try hard and desire to please others.

I addressed these concerns through a heightened awareness during the interview process, making the interview as relaxed as possible, soliciting feedback on the identified themes and speaking with personal representatives. If a participant stated, “I don’t know” or “I can’t remember,” I moved to another question. In a follow-up interview, the skipped question was restated in a more concrete manner. I also monitored for changes in vocal tone and pitch were monitored while asking follow-up questions as a safeguard so that participants did not feel pressured. Additionally, the narratives were reviewed for internal consistency, ensuring that the told individual stories fit within the larger life story.

**Confirmability and dependability.** Confirmability and dependability refer to techniques that ensure the consistency of findings in repeated interviews. These techniques assure that results reflect the experiences of participants and not the desire of the researcher (Shenton, 2004). Shenton (2004) also recommends recognizing the shortcomings of the study and the study design. Lincoln and Guba (1985) state confirmability and dependability should be addressed through:

- inclusion of themes,
- having an audit trail,
- inclusion of original quoted material in the final document and
- admission of the researcher’s beliefs and assumptions.

After the identification of initial themes, the interviews, autobiographical accounts and informal accounts were reread to ensure the credibility and dependability of the data. Direct quotations are included throughout the dissertation to support interpreted concepts and themes. An example of the process of data interpretation and theme development was included as an example of the audit trail. Notes and voice memos were used to document and reflect upon

challenges and research turning points.

A reflexivity statement is included. The reflexivity statement will clearly outline how my interaction with the data analysis process informed the findings. The process of reflexivity was helpful in setting aside potential research bias.

**Reflexivity statement.** My personal and professional experiences supporting adults living with FASD and IDD cannot be discounted as part of this research. For ethical reasons, the adults with whom I have worked were not included in this study, though their life experiences have provided me with a wealth of knowledge.

This study stemmed from my personal and professional interest in FASD. Learning of clients' previously unacknowledged FASD provided me with a new path toward understanding their experiences and behaviors. This led me to question if learning of their FASD in adulthood also provided clients with new insight into challenges, life experiences and a new understanding of self. I was also troubled by the possibility that many adults struggle with the effects of FASD that often go unidentified. Would the identification and naming of FASD provide them with greater insight into their own experiences?

As a social worker, I practice a largely eclectic therapeutic modality. A significant component of my practice is to address environmental, sensory, social, political and familial factors that may hinder or influence individual change or growth. I use my skills to support those with intellectual and developmental disabilities (IDD) to live successfully within their communities. This group includes adults with FASD who are identified and those who meet criteria and do not have a formal diagnosis.

The adults with FASD whom I support have been identified as having below average intellect. Thus, they qualify for certain residential and vocational supports and supports

coordination. Most have experienced significant trauma, institutionalized living and trouble with the law. Though they have not faced active drug/alcohol addictions, homelessness and other life experiences that are commonly reported by those with FASD. Additionally, they often rely on paid professionals and have limited, natural family or community supports. These experiences no doubt have influenced my perspective.

My strengths as a social worker were engaged almost immediately during the recruitment process. In order to move past the gatekeepers at advocacy agencies and support groups I needed to prove myself as a reliable person who actually understood FASD. Part of this included delicately balancing the need of support persons to interview me while ensuring they did not disclose the confidential personal information of potential participants. Prior to the interviews, I conducted phone calls that built a rapport with the participants. These were light conversations and required a small amount of self disclosure of personal information. These disclosures were simple and made me a “real person.” This was important since the interviews were conducted over the phone and I could not use my physical presence and facial expressions to convey additional emotion.

Due to the initial enthusiasm of participants, most of the interviews were conducted within a small window of time causing some emotional fatigue due to the tight interview timeline and maintaining my full time employment. This resulted in me feeling stressed and emotionally taxed. I subsequently removed myself from the collected data and writing process for a period of time. In hindsight, I should have carefully planned for self-care, which may have allowed for the dissertation to be completed in a more timely manner.

My strengths also came into play during the interview process. I needed to balance the art of patience and prompting in order to uncover the life story. During an initial interview, I made

the mistake of asking a participant for details regarding a specific time period when an important family event occurred. I heard a minor increase of anxiety in his/her voice and was immediately aware of my error. I quickly acknowledged my mistake to the participant and withdrew the question. Then I diverted attention from this question by returning to a highly-preferred topic we previously discussed. This appeared to quickly diffuse anxiety. I followed up with the participant to ensure there were no lingering issues because of this mistake. Following the interview, I reflected on this error and made adjustments in forthcoming interviews.

As a community based social worker, I process and assess multiple types of information in order to make informed clinical decisions. This includes reviewing case files, family reports, personal reports and assessments of a larger environment. I used these skills during the data analysis process. Since I often process substantial amounts of data, I was able to manage discretely the gathered data and identify broad themes of identity and similarities across narratives.

**Narrative consistency.** There are some important concepts that need to be addressed regarding internal and external narrative consistency. Internal narrative consistency ensures that the story being told is not contradictory across time and that it presents a consistent representation of the past, present and future (Atkinson, 2001, p. 131). External consistency is the expectation that the personal narrative would correlate with the socially known story (Atkinson, 2001).

For the purpose of this research, I placed greater emphasis on presenting a stable and trustworthy internal narrative than in a factually true narrative. The stories people tell as part of the life narrative are important and reflective of who they are and want to be even if the facts are not 100 percent accurate (Atkinson, 2001, p. 134). The message and beliefs are more important

to the purpose of the study and the proposed research questions than the specific details of the account (Rubin and Rubin, 1995).

I used techniques related to ensuring participant honesty, fact checking and clarification during the interview process. Each interview was examined for consistency during the interview, transcription and analysis processes. If an answer appeared to be conflicting or contradictory, then further clarification would have been requested. In this process, I did not identify stories that were inconsistent with the larger narrative. As an additional safeguard, the developed themes and associated quotes were provided to each participant for review.

I did not intend to compare the participant's life story to previously reported demographics, psychosocial variables and life experiences. Yet through the process of data analysis it became clear that the participants did struggle with similar issues and utilized supports that had been reported in corresponding literature. To provide a more balanced view of the realities faced by many people living with FASD, I remained faithful to a focus on strengths, personal achievements and examined larger, possibly oppressive, narratives that may have influenced the personal narrative.

**Addressing any concerns of unintentional exploitation.** During the interview process, the needs of the participants were put first and foremost to provide them with a level of control over the interview process. Accommodations were made to address potential neurological functioning differences. This report takes into consideration a strengths-based perspective and reports on themes that might not fit into more commonly heard deficit-based narratives.

One participant did not respond to the request to review the findings. I did not have the opportunity to review the identified personal quotes and themes with the participant. Due to this and the sensitive nature of the topic, I chose not to include this particular interview in the final

report.

Precautions were taken to ensure that each participant or their representative independently contacted the researcher. Initially, several agencies were in contact and stated they could actively target and recruit adults with FASD who would meet the criteria. After speaking with agency representatives, I decided that agency recruiting for this particular project would not be appropriate. The study was designed so that participants would independently contact the researcher. Deviation from that design would be outside of the approved protocol and potentially cause a coercive situation.

### **Sensitive/trauma-informed research**

Conducting research from a sensitive or trauma-informed perspective required monitoring of the emotional and social well-being of participants. This occurred both in the interview and as part of the follow-up process. When reflecting upon sensitive research techniques, Melrose (2002) stated, "Researchers have a duty to ensure that no harm comes to their subjects, as a result of their lives, we must ensure, at least, that our scrutiny of them does not leave them worse off" (p. 343).

A risk-benefit analysis was conducted and the implications were included in the consent form. While participants did not directly benefit from participating in the interview process, they reported that being an advocate for prevention, supports and education was rewarding.

Barnard reported that, when conducting discomfoting research, researchers must "balance the interests of the research with those of the respondents in deciding when and when not to push for a fuller or less inconsistent account" (2005, p. 14). This concept was particularly relevant when participants spoke of their difficult times, especially those situations involving alcohol use. To be sensitive to their feelings while also ensuring objectivity and accurate information, I

encouraged participants to tell their story but did not push for specific details, such as when or where specific events occurred.

### **Summary**

This study stemmed from my personal and professional interest in FASD particularly how learning of previously unrecognized FASD could potentially alter one's understanding of himself or herself and various life experiences. To that end a narrative methodology was employed for both its conceptual and procedural process.

The following three findings chapters will highlight the personal experiences of the research participants, detail the commonalities, and identify themes of identity found across narratives and life stories.

### **Organization of Findings**

The purpose of this qualitative inquiry was to uncover the identity and personal experiences of those who live with the effects of FASD but not identified until adulthood. To this end, in-depth interviews were conducted and additional data sources were reviewed. The findings from this data analysis will be presented in a systematic manner. *Findings One* will report the interview participants' life stories and analyze similar traits, behaviors and characteristics. *Findings Two* will report the narratives gleaned from previously published accounts and analyze the behavioral and trait commonalities of the non-interview obtained data. *Findings Three* will report the common themes of identity established upon the analysis of both the participant interviews and previously published data sources.



## **Chapter Four: Findings I**

### **Life Stories of Interview Subjects Living with FASD**

This chapter reports the life stories from which the themes of identity emerge. The personal narratives included in the following chapter are reflective of each participant's understanding of his or her and particular life experiences. Caution must be taken when interpreting these experiences. These narratives should not be generalized to understand a larger population living with FASD. This caveat is especially critical when considering the relationship between FASD and unique issues of cultural diversity, individual experiences, nationality and access to appropriate support systems.

Some may dispute the objectivity of the stories participants shared or the factual accuracy of the events they remembered. Others may question whether or not the life stories are truly reflective of the individual's life experiences since many people with FASD undergo dramatic life changes across their life span depending upon their symptoms and level of support (Rutman, La Berge & Wheway, 2005).

The narrative methodological perspective was chosen as a way to address these issues. From this perspective, it is not merely about the facts or the objective reality of what happened; rather, it is how that information is subjectively organized into a larger narrative and the meaning made from that material. Identity and self-understanding develop through telling stories about ourselves and hearing the stories others tell about us. These stories are told and retold, tried on and discarded, until a cohesive narrative is developed regarding who we are (McAdams, 2001). Due to this fluidity, a snapshot of self-understanding, who we were, are and desire to be, can be examined at any given point. The stories shared become personal truths and constitute the scaffolding for identity.

## **Description of Life Stories**

The following biographical sketches are summaries of the narratives shared by each of the participants. It should be noted that names, locations and other identifying information have been changed or generalized, and the stories are presented in no particular order. These are only snapshots. The complexities of these individual lives and identities will continue to unfold during the following chapters.

**Mitchell.** Mitchell was in his early 20s and living at his place of employment at the time of the interview. He was diagnosed with FAS after high school. Mitchell was adopted from an eastern European nation as a toddler and spent much of his childhood living in the Midwest and West Coast regions of the United States. He was raised by his adoptive mother in a supportive and loving household and spoke fondly of his grandparents, a foreign exchange student with whom he is close, other family friends, teachers, and coaches. He viewed this trusted group of family and friends as essential in helping to support him in making more positive life choices. Mitchell stated that as a child he had difficulty connecting with his adoptive family because he could not understand why his birth parents gave him up for adoption. One of Mitchell's narratives, alludes to the possibility of strong and persisting issues with attachment. Nevertheless, as an adult, he identifies being adopted as one of the best things that happened to him.

Mitchell discussed experiencing difficulty with schoolwork, hopping from school to school and struggling to remember school test questions from one day to the next. He said it was hard on everyone "not knowing what was going on-if he had FAS or if he was acting out." He is very proud that he received his high school diploma while at military school.

Mitchell talked about a time when he was “doing all my bad habits.” This is a time after high school when he was living on the streets, partying excessively, couch surfing and using drugs and alcohol. Mitchell remembers being beat up, his so-called friends stealing his iPad or talking him into borrowing money to purchase a car and being jumped on the streets. He says the last incident is what really pushed him to get off of his bad path and is thankful that his family was there to support him through this difficult time.

Mitchell also spoke of the good times, those fun times of traveling internationally, hiking, fishing and playing tennis. He is very proud of his current job at a residential school for troubled youth. He takes great satisfaction in being able to connect with these youngsters and says he can understand them better than most other counselors. Mitchell’s goals are to get his CDL license and to help his mom start a residential support program for young adults with FASD.

**Marie.** Marie is a woman in her early 40s who was diagnosed with FAS in her 30s. She lives in the Middle Atlantic region of the United States and works part time at a local drug store. Currently, Marie lives with an elderly friend and is partially responsible for her friend’s ongoing care. Marie also has multiple health issues, which she says are unrelated to prenatal alcohol exposure.

Prior to diagnosis, Marie discussed the potential of having FAS with a local advocate for persons with disabilities. Marie felt that a confirmation of FAS would allow her to access additional supports and services. She reports going for FAS testing at a regional clinic and that multiple appointments were required. She was scared during this process but was able to get through it with the help of her friends, 12-step program and her 12-step program sponsor. She was supported and counseled through this process by the clinic director with whom she remains

in contact. In order to make sense of the new FAS information, Marie worked with a community-based therapist.

The youngest of four children, Marie says she was born premature and tiny. She talked in depth about the effects of living with a mother who was an alcoholic and who died when Marie was a child. She tells several stories of early childhood guilt, misunderstanding, fear and shame, all of which she continues to process with the help of a therapist and a 12-step support group.

Marie also had several happy childhood stories of going to the shore with her brother and sister-in-law, being an aunt and learning how to drive. Marie enjoys journaling, drawing and practicing sign language in her spare time.

Like several of the other participants, Marie had a difficult time with high school, especially mathematics. After high school, she struggled with the idea of what to do next. She briefly attended a business college and held a variety of clerical-type jobs. In time, Marie found a job that works for her and she enjoys. In the past, she has been promoted but struggled with the associated challenges. Marie also attempted to increase her income by renting extra rooms in a home she had inherited. This venture was short-lived as she felt she was vulnerable and being taken advantage of by her tenants.

Marie also briefly spoke about difficult times in her life, which included alcohol abuse, as well as trying to manage symptoms of an eating disorder, anxiety and depression. Discovering what works for her and having the support of her friends and that of her 12-step group have been instrumental in her success.

Marie states that she has settled nicely into her current life and feels more calm and at peace. She is actively involved in a 12-step program and feels connected with and supports teenagers living in families who struggle with alcoholism. She is proud to present at conferences

regarding her experiences with FASD and actively advocates for FASD prevention.

Additionally, in 2009, she authored an e-book titled “*Story of surviving with fetal alcohol syndrome.*” Marie provided the publication for use in this research.

**Kathy.** Kathy is in her early 20s and was diagnosed with FAS when she turned 18. She was adopted from a South American country as an infant and was raised in the Midwest by her adoptive father, mother and older brother. As a child, Kathy traveled internationally with her family and remembers the wonderful feeling of swimming with dolphins.

Kathy reported a laundry list of misdiagnoses during her teenage years while her family was trying to find ways to support her. She has found attending FAS groups to be helpful in understanding the FAS diagnosis, working through potential stigma and understanding why her birthmother may have drank. Kathy also told stories of having difficulty at school and going to boarding school for what she called an attitude adjustment. She is very proud of her time at the boarding school, which subsequently led to 30 hours of collegiate work. Kathy spoke of a period in her life when she was drinking, fighting, partaking in destructive behavior and having a difficult time maintaining employment.

Currently, Kathy lives with her boyfriend of six years and works part time as an administrative assistant. While she is happy at her current employment, she did express that when she is “overwhelmed she may be too blunt and come off a little bit nasty.”

Kathy says that in the past she has taken her family on a roller coaster ride. She attributes her current success to choosing to work on herself, the support of her family, her boyfriend and God. Kathy speaks to local support groups and finds great reward in helping others.

**Andrew.** Andrew is a man in his mid-thirties from the North Central part of the United States. He learned of his FASD from his mother when he was in his early 30s. Andrew was

raised by his birth mother, who was a single parent to him and his six siblings. Andrew said he was unaware of his FASD condition growing up. When speaking about his schooling experience, he stated he always had an odd feeling that he was different because he had a difficult time “grasping onto things.”

Andrew reminisced about junior high school as a positive time in his life when he was an honor roll student, involved in engineering classes and was a student helper. Andrew is very connected to his community and talks with great pride about his neighbors who play in the NBA.

Andrew is a jack of all trades, does landscaping and is a heavy-equipment operator. He wants people to know that, even though he is a big guy, he is a really nice person. Andrew is very involved in the FASD community. He and his fiancé regularly attend FASD conferences and advocate for FASD prevention and appropriate supports and services. Andrew attributes most of his current success to his family, his fiancé, his soon to be in-laws and God.

These are distilled summaries of the stories told by each participant. While each person may have experienced significant positive or negative life changes following the interviews, these narratives are reflective of their identity at a specific point in time. Each personal narrative reflects individual understanding and personal influences during her or his lifespan.

### **Commonalities Across Narratives**

The adults interviewed told familiar stories of learning difficulties and obstacles related to the education system and employment. The stories included here are those which are embedded in personality such as common behavioral characteristics or descriptors of personality. While these experiences may influence a person’s self understanding they do not independently speak to identity. Some respondents may have experienced other effects associated with FASD but did not include them in the life stories they shared as part of the interview process. Perhaps

those stories were omitted out of personal preference or lack of a specific related question. Participants might also be re-authoring their narratives from a deficit and/or challenged-based perspective to one emphasizing strength.

Excerpts from the narratives that speak to primary effects of FASD will be presented first. Stories associated familial supports and strengths will be presented second. Accounts that address the associated secondary and tertiary effects of FASD will be presented third. Comparing the shared life stories with known psychosocial data is not the sole purpose of this dissertation but has been included as an additional layer of validity and reliability. While the sample is too small for statistical comparison, the similarities between current literature and the shared stories of this adult group are worth noting.

**Primary symptom.** There are many primary neurological effects associated with FASD, effects outlined as part of the literature review in Chapter 2. The study participants spoke about several of these primary issues including their challenges with learning, attention and memory and executive functioning.

Figure 5

*Reported Primary Symptom*

<u>Primary Symptom</u>	<u>Number of Participants who Reported Symptom</u>
Difficulty with learning, attention, and memory	4/4
Executive function challenges	3/4

Primary difficulties with learning, attention and memory were reported by all of the participants. Andrew mentioned his difficulty with attention and learning several times during the interview stating, “I remember thinking how hard it was to focus all the time” and “Well, I always felt (like) so weird cause (like) in school I was a good student, but I had a hard time

grasping onto things and why do I feel this way?” Andrew again elaborated by stating the following:

Unfortunately, I have a short attention span. I get bored easily-this is like a curse...it is very trying for me to pay attention to one thing. If someone is telling me a story, I find myself getting over anxious-like go get to the point already

Mitchell mirrored these sentiments about memory and learning when he spoke about his own school experiences. “What was hard? Actually, all the stuff. Sometimes, I would remember and then in the morning it would be gone and sometimes I would really do well on something and then the next test I would bomb.” He elaborated further by stating:

Wow-school. School was actually really hard. You know it took a lot of effort for me to learn things. For an average kid, it would take for some of the homework 20 minutes to a half an hour and for me it would take two or three hours.

Marie also briefly mentioned her difficulty with attention during school. “School was very hard for me, I remember thinking how hard I had to focus all the time.” While reflecting on her childhood experiences, Kathy spoke of some of her challenges with memory. “I won’t remember stuff that was told to me today but I remember stuff from far away.”

Executive functioning refers to specific cognitive processes such as planning and reasoning, cognitive flexibility and response inhibition (Elliott, 2003). Deficits with executive functioning manifest in difficulty with planning ahead, understanding consequences, experiencing impulsivity and having poor judgment (Mattson, 1999; Niccols, 2007).

While respondents did not speak to specific cognitive processes, they did relay their personal challenges with everyday situations related to executive functioning impairments. Three out of four participants told stories that reflected difficulty with executive function. Marie



included in the following narrative about planning for what to do after high school in an e-book she authored.

I remember when I finished high school. Everyone was talking about where they were going and what they were doing next. I didn't have all those plans. I spent all of high school trying to survive every day. I didn't think about planning ahead. At my graduation, I suddenly thought, "Oh my God, what do I do now?" (*Story of surviving with fetal alcohol syndrome*, August, 2009)

Mitchell told an extended story about his challenges with planning ahead, understanding cause and effect, judgment and vulnerability.

Well, when I was out on the street I had this so-called friend and we were tired of taking the bus so we were like let's go in and get a loan and buy a car. So he introduced me to another friend who had a car for sale and, of course, not fully checking it out. It was a piece of crap, but we went and got a loan and we didn't have any intention of really working on the loan or anything. I wasn't really making any money working security and spending all (my) money on drugs and alcohol and all that other stuff. Later on, I figured out it had a broken seal on the drive shaft. My other friend thought it would be good to get a nice sound system in it and I said I will do this, but you will have to help me pay it off.

So I was taking a friend to a doctor's appointment. I was going about 65-70 miles per hour and the seal totally snapped and the tire popped off and the rear end drops. Then the tire came off and was moving faster than car. It is a good thing I didn't roll or anything and was able to control the car. The axle broke and then I decided to get it towed to the used car place. (I) left it there because I didn't know what to do and didn't

have any money. It was sitting there and my so-called friends broke into the truck to steal the radio.

Mitchell's story also has the aura of an attachment narrative. Persons with FASD could be especially vulnerable to attachment related issues (Ehrman, 2014).

Kathy spoke of her challenges with impulsivity at the work place and interacting with a co-worker.

The other day I was not feeling well and I told her to leave me alone because I was trying to do my work and she was talking to me. I don't know... I guess I am sometimes a little bit more blunt than I need to be and this is one of my challenges (trying to not be as blunt with people). You know, when I am overwhelmed I may come off as a little nasty.

Additionally, this narrative illustrates Kathy's strength of desiring to complete tasks required by her employer. Kathy's co-worker should appreciate and respect that in order for Kathy to be successful, she should not be distracted while working.

**Birth mothers.** Kathy and Marie were sensitive to the complexities of alcohol use when speaking about their birth mothers. Kathy's statement shows how she is beginning to resolve and understand her birth mother's alcohol use.

How do we know if our parents didn't know that they were pregnant? And after they got done drinking, (they are like) Oh, I am pregnant. I didn't know. And the fetus was already exposed to alcohol in the early days.

Kathy states she disagrees when other adults say 'I want my mom to go to jail or we should have our parents arrested.'" Though she does acknowledge that FAS can carry a stigma stating that when she tells others about her FAS 'they treat you differently.'

Marie discussed her mother's disease of alcoholism and how society was unaware of the harmful effects of prenatal alcohol exposure in the 1960s. Marie's words communicate regret over not really knowing her mother: "It wasn't her; it was the drinking. I never really got to see the real her. I only remember the drinking part of her so it's sad."

**Familial supports.** Each of the interview participants reported living in a stable, nurturing home for most of their lives. All of the participants acknowledged their family members and other trusted supporters as being instrumental in the successes they experienced as adults.

Kathy's story of her childhood experiences of traveling with her family brings to life the protective factor of a nurturing family and a happy childhood.

We went all over the place like Mexico, the Dominican Republic, Montego Bay and like a lot of places in the States too, and we're just like a traveling Brady Bunch. (My brother and I) sat in the back seat watching the radio that had a TV on it and watching movies in the front and singing Broadway show tunes.

Marie spoke at length about her mother's untimely death from alcoholism and the stability and nurturing she later found with her sister-in-law and older brother.

Participants alluded to benefiting from their own personal advocacy and that of their family members. Such advocacy could have helped the participants experience greater success finishing high school, maintaining employment and avoiding severe legal entanglements.

**Strengths.** It is important to explore participants' strengths in order to have a balanced understanding of each person. The strengths that were identified by participants included being able to connect with others, being skilled with their hands and being considered artistic or creative. Individuals took great personal pride in their ability to connect with people, and this

quality has brought some level of meaning and purpose to their lives. The two men who were interviewed identified working with their hands as a strength. Those who identified creative and artistic pursuits as strengths also reported that they use this strength as a coping mechanism, a way to calm themselves and to find joy.

When asked about his strengths, Mitchell was quick to state, “Well, I am a people person. I can actually talk to people and really understand where they are coming from.” Kathy also identified connecting with others as a special gift expressing:

I think I am able to put myself in other people’s positions. There is a kid when I was young and they always used to make fun of him because he was handicapped. He always invited me to his birthday party because nobody else was nice and they used to make fun of him. I would play with him at recess. I always am trying to go above and beyond...because I did not want anyone to feel left out or bullied.

Marie spoke of the joy and calm space she finds when writing and drawing.

I like to write. I enjoy that. I do a lot of writing for myself. I like to draw. I do pencil drawing. I think I like it because I can get into my own world and my own space and that is when I do my best, in my own space when I draw. When I draw it just takes me away into my own quiet place and I enjoy it.

Mitchell spoke of not only being skilled with his hands, but also learning more quickly through hands-on experiences. “I am actually really good with my hands. I can build stuff, not easily, but I can learn really quickly about how to build stuff with my hands”. Andrew also reported that his strengths include hands-on skills. “I am kind of like a jack of all trades, I do carpentry, I cut hair, I am a gardener, and I do landscaping.”

When asked the question “Tell me a story from being a kid or a teenager”, Andrew told two stories from his time in junior high when his teachers and supporters helped him build upon his identified strengths as a people person and his skills with hands-on trades. Andrew identified junior high school as a successful time that provided some of his best memories of being a kid or a teenager.

I got to pick an hour out of school that I got to do errands for the office and in seventh grade I was actually working with our vice principal. But in eighth grade I did more gopher stuff like go drop off mail to classrooms to teachers. Another thing was about math class and motorized Legos. They (the school) also took us to a (technical college) and that was my first opportunity to actually weld and that was awesome. I was captivated by that.

Andrew told these stories from when he was a child/teenager, narratives of what worked and what helped him be successful.

**Secondary/tertiary effects.** The common but not inherent effects of FASD that arose in the stories of those interviewed include disrupted school experiences, problems with employment and drug and alcohol issues. While specific individuals spoke vaguely about challenges with anxiety and depression, which could be considered a primary effect, as well as obstacles with stable housing, specific stories and quotes were too few to report. Additionally, other tertiary effects, such as difficulty with the law, were not reported in this group. It should be noted that, due to issues with vulnerability, those who were currently incarcerated or on probation were not included as participants.

The tertiary issue of disrupted school experiences of all four participants and employment problems reported by three of the participants can be understood as the combined effect of

primary challenges with learning, memory and attention with inadequate or inappropriate support services. These difficulties appeared in the most commonly told stories of this group's narratives.

Mitchell spoke about his disrupted schooling experiences stating, "I constantly kept hopping from school to school." and that he attended private, public and military schools. Kathy also reflects on her school experience stating, "I was getting sent away to a boarding school to better my grades and go there for therapy and fix my attitude because it definitely needed an adjustment." Kathy also relayed challenges with stable employment, quickly moving from positions as a certified nursing assistant, administrative assistant and working at a school for children with disabilities.

Marie's short narrative in her self published e-book illustrates that when expectations and abilities do not match they can lead to problems with employment.

I've always had trouble with keeping jobs, but I had that first job for six years. A good friend of my dad's hired me as a file clerk at an insurance company. It was good until they started promoting me. When they made me a typist, I hit another wall because I couldn't spell and there was a lot of pressure. I quit before I was fired. (*Story of surviving with fetal alcohol syndrome*, August, 2009)

Three participants spoke of drug or alcohol related challenges. Mitchell spoke about a time in his life when he was using drugs and alcohol and reported difficulty with social relationships: "Actually, I really didn't connect with a lot of people and if I did connect with people it was with the wrong crowd-drugs and all that other kind of stuff."

He further elaborated on this part of his life which also included a brief period of homelessness.

I guess a real difficult time would be when I was doing all my bad habits and living out on the streets for a few months. Yeah, you know I was on the streets for a while hopping from party to party, friend's house to friend's house.

Marie wrote about how her feelings of difference led her to use alcohol. "I had no idea about the FAS. I just knew something was different, something was wrong with me. At this point, I started to drink (*Story of surviving with fetal alcohol syndrome*, August, 2009).

**Positive life outcomes.** While there is not a researched list of positive life outcomes experienced by adults with FASD, there are common, positive life outcomes that this group reported. These are valued experiences that could be considered positive for all adults, including living independently/interdependently and connections with friends and family. These positive outcomes are likely the combined net effect of strengths, advocacy, supports and other unidentified factors. This is a subjective list of outcomes that has been extrapolated from the told narratives and is being reported to provide a balanced view of the lives of the adults interviewed. Kathy spoke affectionately about her relationship with her boyfriend:

I always dance around the house and my boyfriend is always laughing at me. He says I always have so much energy and you are always dancing everywhere. He says I like that about you and I said well that is nice.

When asked about the special people in her life, she was quick to reply,

My mom, my dad, my brother, my Bubbie, my grandmother who passed away who I told you I was really, really close to. She never judged me no matter how many times I fell and did something wrong in her eyes. I really attribute my success to my parents. I would like to give them a shout out. They helped me and my brother even (helped me). Though, I brought the family on an up and down roller coaster, they never gave up on me. And my

boyfriend, he has been with me for 6 years and I am an interesting person to be with at times and I attribute it (my successes) to him too.

Andrew also spoke warmly about the people in his life:

I have been blessed to meet a lot of good people right now. My best friend is my fiancé/girlfriend, it is her and my family, and my soon to be in laws and my extended family like my church.

Mitchell spoke of his family in earnest:

I did have fun and good times. I had a family that really loved me and cared for me. We had good times and did a lot of traveling and did a lot of fun stuff. A highlight of my life would be going to Europe and so many different places, I would say going fishing with my brother at Glacier National Park, flying to several places with my mom.

Marie spoke fondly of her relationship with her sister-in-law and the friends that she shares her life with now.

Other than my brothers and sisters, it was sister-in-law; she was my angel. She was like a big sister to me and when she got engaged to my brother and when they got married she took me under her wing...Really she was a blessing in my life and she made me part of her life...

I share with my friends every milestone that I do today. I get a lot of support, there is no words for it, except for that there is a lot of love. They show love to me and accept me for who I am and they love me for who I am and that is all I need.

I've rented a room in the home of an 85 year-old woman, who is an angel; she is like a grandma to me. We have really gotten to love each other; I'm there for her and she's there for me.



**What works for me.** Several times during the interview, Marie made the comment, “And that is what works for me.” Upon further reflection, many of the participants shared strategies of what works for them either by using the strategy, as an answer to the question ‘what advice do you have for others’ or through the natural course of the interview.

The specific strategies that the interview participants mentioned or used during the interviews included reducing distracting stimuli, establishing structure and consistency, taking it one step at a time, teaching coping skills, designating a mentor and accepting alternative communication methods. Two participants also mentioned the importance of personal faith.

People with FASD can become overloaded by sensory input and distracted by environmental stimuli. Reducing distracting stimuli refers to techniques such as reducing noise level, changing lighting, removing unnecessary wall hangings or posters and reducing other types of stimulation. Marie mentioned how she feels overwhelmed in overly stimulating environments and now she avoids them. “I learned over the years to stay away from crowded places, from loud places, people go too fast.” Kathy echoed these sentiments when she spoke about finding success at her current place of employment. “Taking it slow was helpful-it has to be on the quiet side.”

While each person is unique, many people with FASD can become overwhelmed when expected to process multiple directions or excessive information at one time. Marie spoke of how she feels when she is given too many directions, what she needs from her employer in order to be successful and what coping skills she employs. This story also illustrates how Marie has been personally empowered to be an advocate for herself while at work. These accommodations are necessary for Marie to be successful at work. The employer also has a responsibility to ensure that Marie’s work based needs are met.

I talked to manager and said sometimes if you come at me too fast, including him, I said I am not going to get it. It is going over my head or I am going to explode. So he knows, and when things get that crazy and I feel a lot of anxiety coming up, things are happening too fast, I tell them I need to take a 15.

In this world everything is going at 200 miles per hour, so sort of looking to pace myself, sometimes, I just need to tell people slow down over here.

Modeling structure and consistency refers to techniques that lend to predictable environments, including establishing a predictable schedule, expectations, policies and practices. (Grant, et al., 2013). Kathy spoke briefly about the importance of structure in order to be more successfully employed. “Yeah-(work) that’s how it needs to be-structured you know.”

Marie spoke again about identifying when she is becoming overwhelmed and the coping mechanisms that she utilizes, noting that she “can recognize my limitations”.

I call someone up and tell them I need to take a 15 and I step out, I go in the back, go to the ladies, go outside, go to a chair, I just take a breath, a breather, make a phone call if I have to, then regroup and I can go back in.

Designating a mentor or others to provide external executive function refers to gathering a group of trusted advisors to assist with decision making, provide feedback and guidance and act as an advocate. The concept of an external executive function is often referred to within FASD literature, and several participants mentioned this as being crucial for success.

Mitchell spoke of this concept when asked what advice he would give to other people with FASD. “Make sure you find someone you trust (to help you).” He reiterated this idea when asked a follow-up question regarding how he avoids trouble or what he would do if he was confused about a difficult situation. “Also, it helps to talk to your family about it and find out.”

Marie's advice to others echoed this sentiment. "I would encourage people in my situation to find safe people to talk about it."

Finding alternative yet equally acceptable methods of communication can be vitally important when supporting adults with FASD. The use of digital communication, especially text messaging and email were incredibly useful during the process of coordinating interviews and answering questions. Texting was a quick, immediate and non-intrusive way to remind participants about upcoming interviews, check in and alert them that compensation and follow-up reviews had been mailed. Using digital communication allowed participants to refer to written reminders instead of having to rely on remembering verbal instructions.

Andrew spoke of the importance of his church and faith and how they sustain him.

I go to church every Sunday and Bible Study every Tuesday. I attend church because, it's like church is a hospital for the soul. You go there when you feel under the weather. You don't have to have the flu or anything, maybe just a bug but you still need to go and get checked out at the hospital.

Kathy also felt that prayer was an important part of her life, stating: "I always feel refreshed after I pray. When I don't pray, that is when things go wrong."

### **Chapter Summary**

This chapter reported summaries of the interview participants' life stories. This chapter also spoke to the strengths and challenges reported by the individuals interviewed and incorporated their life stories into the larger body of research. The stories shared were akin to previously reported findings related to primary challenges, familial supports, as well as secondary and tertiary effects. Furthermore, this chapter highlighted individual strengths and

positive life outcomes to provide a more balanced understanding of those adults who are living with FASD.

This chapter continues to set the stage and provide a context for how participants developed their life stories and constructed their identity. As these narratives are examined, personal identity, the influences on the development of that identity and what gives meaning and purpose to each individual's life will be explored further.

## Chapter Five: Findings II

### Review of Non-Interview Obtained Data

This chapter will introduce the published biographies used as secondary sources of data. The narratives included are summaries of those published biographies and express an individual's understanding of his or her particular life experience. Following the narrative summary, there will be a review of the common personal traits, behaviors and characteristics identified within the writings.

#### Description of Life Stories

The following narrative summaries were developed from previously published accounts. These previously published stories are not as rich in personal detail and cultural and regional nuances as the narratives of interview participants. Each narrative snapshot will reference only material contained in the original source. The life stories are presented in no particular order.

**Francis P.** In the article, "My Life with FASD" (Perry, 2006), Francis P. reported his personal experiences of living with FASD. Francis is a Mi'Kmaq First Nations man and wrote his account at the age of 32. Francis was adopted at age three and diagnosed with FAS at the age of 19.

During his elementary school years, he was often tormented by his classmates. He attributed the torment to his lack of social skills and hyperactivity, which caused him to be excluded from school activities. Transitioning to high school and community college was equally difficult, as Francis felt ill-prepared for the increased expectations in these settings.

At varying times in his life, Francis reported trouble with the law, experienced homelessness and had thoughts of suicide. Francis expressed that he often felt like a failure during these low points in his life. By interpreting his life events through the lens of FAS,

Francis now understands that being vulnerable and easily manipulated, common characteristics of those with FAS, led to some of these outcomes. This knowledge unburdened Francis, knowing he was not a problem but had a problem.

Francis expressed that he found hope while living in a religious commune. While at the commune he learned to mediate, a practice that taught him patience. After leaving the commune, Francis moved to Nova Scotia in an effort to locate his birth family. It was during his time in Nova Scotia that Francis learned about FASD. At The Friendship Centre in Halifax, Francis was walked through the process of receiving and making sense of his diagnosis of FAS. Following his formal diagnosis of FAS, Francis felt that he was finally able to understand the reason behind his challenges. This was like a weight being lifted off of his shoulders and he was able to let go of long held bitterness. Armed with the knowledge of FAS, Francis has made adjustments to his life routine in order to be more successful.

At the time his story was published, Francis was a speaker for the Mi'kmaq First Nations Healing Society. He shares his story in the hope that others will begin to heal and gain knowledge of FASD. Francis continues to learn about himself. Knowledge of his FAS has helped put some of his life experiences into perspective.

**Tanya.** The article “Invisible disability” (Pennel, 2013) reports the story of Tanya. While reading about experiences of other adopted children identified with FAS, Tanya began to recognize similarities to her own life story. At the age of 25, Tanya identified herself as having an FASD and recently received formal confirmation of her FASD at the age of 36.

With three college degrees, Tanya states she does not initially present as someone who struggles with the effects of FASD. It takes a closer look to notice her challenges are the result of a non-neuro typical brain. Tanya was adopted by a loving and caring family. Her family did their

best to support her but were often at a loss as to the cause of many of her behaviors. In her teenage years, she struggled with school, alcohol use and would run away from home. Tanya has had difficulty with stable employment and felt she was often behind her peers developmentally. Understanding her FASD has helped her to identify and harness her strengths. She now shares her story at conferences to educate and inspire others.

**Val B.** Val B.'s story, "The Journey to Overcome FASD" (Busch, 2013), was published by the Northern News Service. She is a First Nations woman who grew up in Edmonton, Canada. At 54, Val has spent her life managing the effects of FASD, a condition not identified until her 50<sup>th</sup> birthday. She was in and out of the foster care system as a child, had great difficulty in school and eventually dropped out in the 10<sup>th</sup> grade. Val reports that teachers classified her as a bad kid and when she was unable to meet the expectations of others, she was accused of not trying hard enough.

Eventually, she joined the Canadian military, married and had two children. Val struggled with alcoholism and parenting responsibilities, causing her to leave her children and husband. She feels great remorse and regret regarding this period of her life.

Upon learning of her FASD, Val was initially very upset and angry. Through her work with a support person, she has started to move past this initial reaction and understand how FASD affects her life. Val routinely speaks at schools in order to raise awareness of the myriad of effects associated with FASD.

**Stef P.** Stef P. wrote a chapter for the book *Fantastic Antoine grows up: Adults and adolescents with Fetal Alcohol Syndrome* (2002). Her chapter, "How I grew up with FASD" details some of her life experience. Stef was raised by her birth family and has a younger sister with FAS. Stef was identified as having Fetal Alcohol Effects (FAE) at either the end of or

slightly after completing high school. During high school, teachers told her she was lazy and not working up to her potential, though she excelled in art and architecture classes. As a teenager, she often felt angry and made suicide attempts. Eventually, Stef was diagnosed with bipolar disorder and felt that psychiatric medications helped her manage her mood.

Following high school, Stef attempted to attend community college but realized she was ill equipped for the social challenges that awaited her. She began to work part-time and moved into her own apartment. Independent living skills such as organizing daily tasks and managing money were challenging for her and eventually Stef enlisted in the Navy. Stef found that the Navy's structure and constant motivation provided her with the ability to be more successful. It was during this time that Stef learned many skills that since have transferred into her post-military life.

At some point during her enlistment in the armed forces, Stef stopped taking her psychiatric medications. This induced a self-described breakdown. Soon thereafter, she became pregnant and requested to be discharged from military service.

Currently, Stef is married and raising a young child. She successfully manages these responsibilities by working in the moment instead of worrying about the future. Stef attributes her current success to an appropriate medication regime and the advice of her church group.

**Robyn.** Robyn's brief narrative was published in McGregor's dissertation *Never say never: Struggle and determination in the lives of young adults with FASD* (2009). At the time of her interview she was 21. Robyn was diagnosed with FAS just prior to her 18<sup>th</sup> birthday. Robyn is caring for two young sons and lives with her fiancé.

Robyn lived with her birth mother until she was nine years old and then became part of the foster care system. During her life, Robyn reports that school was a sanctuary that protected



her from physical and sexual abuse. Robyn has struggled with self-harm behaviors, accessed multiple treatment programs and attended behavioral or learning support classrooms during her school years. She reports that learning of her FAS helped to put her life and challenges into perspective.

**Dax.** Dax, age 25, also was interviewed as part of McGregor's dissertation *Never say never: Struggle and determination in the lives of young adults with FASD* (2009). At the time, he was not diagnosed with a FASD and was waiting for a formal assessment. His adoptive parents informally researched and identified him as having an FASD several years prior. Dax emphasized that he had a typical early childhood and only began to have difficulty in his mid-teens. He reports being bullied in school, necessitating a transfer to a private school. Dax reflected he began to drink in mid-adolescence, which led to a serious alcohol addiction by the age of 20. Dax has a great desire to get his life on the right path. He feels that his struggles with alcoholism have caused him many more problems than those associated with FASD.

**Steve N.** In his book *A long way to simple: 50 years of living, loving and laughing as a person with FASD* (2008), Steve Neafcy recounts his life struggles and accomplishments. Steve and his siblings were raised in Pennsylvania by their birth mother and father. While he often struggled with school and expressing his feelings, he found music helped him cope. Steve states he dropped out of school prior to graduation and had difficulty finding stable employment. When Steve was a young adult, his father committed suicide, an event Steve still struggles to reconcile.

Eventually, Steve moved to Nevada where he married, had two children and then divorced. Throughout his 20s and 30s he struggled with mental health problems, the law and obtaining stable employment. Today he recognizes that many of these troubles are characteristic of FASD. Steve reports he always found helpful support from his family and his friends.

At the age of 43, Steve was formally diagnosed with Fetal Alcohol Effects (FAE). This diagnosis provided him with additional insight into his experiences. Steve now uses this insight and knowledge to guide his life choices. He meditates and prays in order to manage his mood and mental health. Steve is happily remarried and helps others research and understand the effects of FASD.

These are summaries of the published accounts of those who experienced effects of FASD but were not identified until adulthood. Each person may have experienced significant life changes following the publication of their narratives, but the stories remain a reflection of their identity at a particular point in time.

### **Commonalities Across Narratives**

Unfortunately, many of the published narratives lack details that reflects the narrator's individual strengths, unique gifts and talents. The published accounts contain common stories of challenges with alcohol and experiences with the foster care system. Most of the narratives contain painful, in-depth stories of unfortunate experiences with the education system. The stories presented below reflect personal behavioral characteristics and descriptors of personality. While each may affect identity, they are not representative of a complete understanding of self. Reported primary symptoms associated with FASD will be presented first and followed by reports of risk/protective factors. This will be followed by stories which report associated secondary and tertiary effects.

**Primary symptoms.** The many neurological and physical symptoms of FASD are reported in the literature review. Most of the published biographies report secondary and tertiary effects, from which the underlying primary symptoms can be inferred. Specific primary

symptoms of physical/facial features, neurological differences, challenges with executive functioning and mood dysregulation were reported in the previously published accounts.

Val B.'s narrative was the only one that specifically referenced the facial features of FAS. When she was born she had "several of the physical markers of FASD, including a lack of a fissure on her top lip, a flat nose and a thin upper lip" (para. 6). She also reports having hearing difficulties, a common physical symptom of FAS. Val was born at a time when physicians would not have associated these collected features with a specific medical diagnosis, since FAS was not formally identified until almost a decade after her birth.

Tanya believes her mind needs to work much harder than an average brain in order to get through the day. At the end of the day, Tanya feels drained, exhausted and has little energy to interact with friends, family or engage in activities she enjoys. "When I'd work an eight-hour day, I'd come home and I'd lay on my bed. I'd want to go out and do things and enjoy my evening, but I couldn't" (Pennel, 2013, para 7). Developmentally, Tanya also reports that she is in some ways behind her same-aged peers. "I noticed as I got older I wasn't in the same stage of development ... as most adults my age" (Pennel, 2013, para 13).

Stef attributed some of her life decisions to poor executive functioning, specifically struggling with cause and effect reasoning and the ability to structure her time. When speaking of her early sexual experimentation Stef states, "I followed a destructive path of sleeping with guys I dated-no matter how long I had known them. I never thought about the consequences. The only thing that mattered was that they liked me" (Pummel, 2002, p. 111). Stef's comments also illustrate problematic sexual behaviors, a common but not inherent associated characteristic of FASD. Problematic sexual behaviors can develop when normal sexual development is combined with delayed social development. While Stef now identifies joining the United States Navy as a

positive experience, she did not clearly understand the ramifications of enlistment. “Without stopping to think about the consequences, I became a member of the United States Navy” (Pummel, 2002, p. 111). Stef reflects that her employment and college career were both negatively affected by the inability to structure her time. She describes this challenge by stating she was “fired from a job as a nanny because I could not structure my time (Pummel, 2002, p.111)” and (in her second semester of college) “because of lack of structure, my grades slid downhill” (Pummel, 2002, p.111).

Stef is particularly perceptive as she describes how her body feels when she is angry. She describes this mood change as often coming out of nowhere and for no apparent reason. She now is taking medication that aids in managing her mood.

Anger was physically painful. I felt adrenaline running through my blood, and my arms and hands would tingle with it. When that happened, I had to either yell and scream or sob uncontrollably. The cause could be anything from a car that didn't signal when it turned to watching the news on television. (Pummel, 2002, pg. 212)

**Familial factors.** Involvement in the foster care system was detailed in the narratives of Robyn and Val. Val's brief report illustrates a common risk factor of being involved in the foster care system. “(Val's) mother was institutionalized when she was three years old so (Val) and her two brothers went into foster care. She lived in three different homes. One in which Val said she suffered *every kind of abuse*” (Busch, 2013, para 6).

However, in most of the reviewed biographies narrators speak of caring family members who were bewildered by their child's behaviors and did not know how to intervene. Francis spoke of how his extended family worked collaboratively to try and support him. “Part of the disability was that I was so hyperactive my parents could not believe it, and wondered how to

turn me off. I was so hyper my aunt had to take me to the beach to run off extra energy so my mom could get some rest” (Perry, 2006, p. 27).

Steve N. also expressed how he found strength in the support of friends and family. Throughout his book, *A long way to simple: 50 years of living, loving and laughing as a person with FASD* (2008), Steve included original poetry. This excerpt speaks to his families support.

MY FAMILY-

Thank you for hanging in there  
with me and  
understanding  
my inabilities  
and always caring for me.

(Neafcy, 2008, p.14)

**Secondary/tertiary effects.** Specific narratives that speak to difficulty with school, employment, the law and drug and alcohol use appeared in the reviewed biographies. The narratives voice painful experiences of being labeled a problem, a bad child or someone who does not try hard enough.

Val’s story reflects this pain, as she mentioned dropping out in 10<sup>th</sup> grade. She also had a short temper and would often act out, which made teachers and those around her classify Val as *a bad child*. She stated that "Everybody was expecting her to do better than she was but no one was helping her do better. They would say things like 'You're not trying hard enough.'” (Busch, 2013, para). Francis’ narrative eloquently describes his early school experience.

School came and was a complete nightmare for my teachers and myself. Because I was so hyper, I was a distraction for the class, not realizing that they were just as a big

distraction for me. I was punished and soon they built a three-sided box to help me be less of a distraction to the class. But what ended up happening was that I could not interact with my classmates. How do you think I interacted outside of the class? I was tormented, spit on, humiliated and teased.. (Perry, 2008, p. 27)

Steve's account mirrored many of these sentiments.

I dreaded school and learning was almost impossible. My handwriting was so illegible even I couldn't understand it. I was held back about every other year and never retained what I was taught from the previous grade. It was a very hard time for me, and for my parents who naturally wanted me to succeed. (Neafcy, 2008, p. 5)

Francis goes on to describe his high school experience.

I had moved on to high school, which I was not ready for. In high school we had to change classes for every subject, going to our lockers, grabbing books and finding the right classroom was hard. Trying to figure out where to go, the constant movement and the noise of the hall really threw me off. This was overwhelming for me, for I couldn't think. I was often in trouble with teachers. (Perry, 2008, p. 27).

Steve's extended narrative speaks of how vulnerability, impulsivity and cognition can lead to workplace predicaments.

I dropped out (of school) and got a job at Sears Roebuck....A fellow employee...he started to become friendly with me. One day he told me he needed my help to move some things into his truck. Of course I said yes and helped him load the items. A few days later he told me I had helped him steal merchandise from Sears and suggested I try it myself since it was so easy...

I went down to the record and tape department with my Sears name badge on and found Abbey Road on cassette tape and put it in my pocket. As I went up the escalator, I felt a hand pulling the tape out of my pocket and somebody said, “What’s this?” I lost my job. I was shocked when I saw the man who put this idea into my head being congratulated. He was a security person placed undercover to find weak people (Neafcy, 2008, p. 6-7).

Tanya also has had great difficulty finding and maintaining long-term employment. She states that “for most of my life I’ve been in and out of jobs” (Pennell, 2013, para. 5).

For Francis, vulnerability, impulsivity and cognitive issues also lead to involvement with law enforcement.

One night my friends and I broke into a canteen and stole pop, chips, bars and cigarettes. Well I am not the brightest criminal. I left a trail of candy bar wrappers all the way to my door from the canteen, which the police followed. (Perry, 2008, pg. 27).

The secondary and tertiary issues of drug and alcohol use were woven into many of the stories. Tanya reports that as a teenager she “ran away from home, dropped out of school, drank and did drugs” (Pennell, 2013, para 11). Robyn partied a lot and experimented with alcohol, drugs and sexual behavior (McGregor, 2008). Alcohol and, subsequently, the effects of alcoholism have influenced much of Dax’s short life.

In his mid-adolescence, Dax’s life was a very long and desperate struggle with alcoholism. He had been kicked out of home on many occasions, lost friends, alienated his extend family and found himself in countless physical fights or other high-risk situations related to his drinking behavior. He thought he would be dead by age 20 (McGregor, 2008, p. 89).

The adverse outcomes and tertiary effects reported in the published biographies are similar to those in participant narratives and reported in other literature. Unfortunately, all-too-common stories of painful school experiences, unstable employment, legal problems and drug and alcohol issues continue to be present well into adulthood. These experiences may shape a person's understanding of himself/herself in adulthood.

**What works for me.** Similar to interview participants, many of the biographies share the personal day-to-day strategies individuals use to manage primary symptoms. These include meditation, faith practices, harnessing strengths, staying in the moment, and general daily living strategies.

Meditation, faith and prayer were practices commonly reported in the narratives. Individuals employed these skills to cope with stressful situations and the experienced healing powers. For Francis this meant learning to meditate. As a child Steve used music to cope with the unpleasant school experience.

At a very young age I developed a love for music, and music expressed my feelings. Each day after school I felt like a failure, but once in my cocoon (my room), I felt success through my music. When I opened my bedroom door, it was back to reality again- my world of disappointing everyone (Neafcy, 2008, p. 4).

In adulthood, Steve continues to seek out the meditative powers of music to re-center himself. He also speaks about the importance of his faith. "Jesus comforts me, calms me, teaches me and heals me. (Neafcy, 2008, p.14)".

Stef feels that being held accountable to God, her family and her church family has been instrumental in her current success. Stef's church family also acts as an external executive function that provides her guidance and will help with decision making.



I need to be accountable for my life and that's why I attend the church I do. Not only am I accountable to God but to God's family as well. At church I receive advice, the support and the friendships I need (Pummel, 2002, 110).

Francis has learned that to successfully live independently he must employ specific techniques.

Although most of the time my struggles cannot be seen, they are still there. Telling time, counting money, math, grocery shopping, cooking and laundry are a few of the areas that I have trouble with. I have a poor memory and can't remember phone numbers or names, so I have a watch that has a date book, an alarm and a calculator to use when I go shopping for groceries. I go shopping late at night because there are less people at the store and I can think clearer. (Perry, 2008, p. 27).

Stef discloses a technique she uses when learning new concepts. "(I found that) If I could picture the concept in my head, create a mental image, I got it just fine. I always did well on the labs because I could touch the concepts and put them into practice" (Pummel, 2002, p. 112). Stef also has found taking it one step at a time is helpful for her to stay focused. "Tomorrow is an abstract idea, whereas today is something I can work with" (Pummel, 2002, p. 113).

### **Chapter Summary**

This chapter described the narratives held in previously published biographies. It is limited by a lack of detail in each biography. This limits reflection on strengths, positive life outcomes and the nuances of social and cultural influences. The stories held in these writings were analogous to previously reported findings and the narrative accounts of interview participants. The authors' traits and behaviors, while not specific to identity, may have

influenced their individual understanding of self. It is through the reflexive understanding of experiences, traits and behaviors that identity is formed.

## Chapter Six: Findings Three

### Uncovered Themes of Identity

To achieve the goal of this study, the researcher used a narrative approach to organize and analyze the results of four in depth interviews and six published autobiographical accounts. Various themes connected with identity arose through extensive narrative analysis.

The uncovered themes include:

- experiencing unidentified, unnamed FASD;
- identification, naming and meaning making: a turning point and
- making a difference: contribution and advocacy.

Figure 6 includes simple working definitions of the identified themes, descriptive examples and the proportion of personal narratives that expressed those themes. The three themes are inextricably tied together. Each builds upon the previous, and the knowledge and emotions held within those themes are closely linked. Participants experienced a range of thoughts and emotions through their journeys, including confusion with regard to life challenges, making sense of and incorporating new information and harnessing this new information to create greater life purpose and direction.

A main way in which we learn about ourselves is through the stories that we tell others and those that we hear from others (McAdams, 2006). It is through this dynamic process that self-defining memories are arranged and a life story is constructed (McAdams, 2006). The memory of our experiences, the raw material from which the life story is constructed, is arranged in a way to make sense of those experiences. In this way, included stories are more about personal meaning than objective fact (McAdams, 2006). The life story itself is a malleable chronicle that can change dependent on the audience, as new information is added and

illuminated by the inclusion of current perspectives and beliefs (McAdams, 2006). By studying the life story, we can begin to understand how people view and understand themselves, a key aspect of their identity. This chapter will present the raw themes identified in participants' life stories. Discussion, possible implications of these findings and directions for future research will be reported in the subsequent chapter.

Figure 6

*Definitions of Themes*

<u>Theme</u>	<u>Definition</u>	<u>Example</u>	<u>Reported by Interview Participants</u>	<u>Report in All Narratives</u>
Experiencing 'unidentified-unnamed FASD'	Narratives of experiencing the effects of FASD, prior to identification	"I had no idea about the FAS. I just knew something was different, something was wrong	4/4	9/11
Identification, naming and meaning making: a turning point	Using and integrating the named FASD in order to make sense of life experiences	"I was 43 years of age and finally able to start a new second half of my life armed with reasons why I behaved the way I did." "I had Brain Damage"	3/4	8/11
Making a difference: contribution and advocacy	Harnessing new information and creating greater life purpose	"I tell myself all I need to do is be who I am. Share my experiences, strengths, and hope. I always tell myself, if this is what I am asked to do, I will do it knowing that if it can help others, it is worth it."	4/4	8/11

**Experiencing 'unidentified-unnamed FASD'**

Though the individuals were not identified as having FASD until adulthood, they have spent their lives living with its effects. Interview participant Marie, addressed this issue stating, "That was the one thing when I grew up, nobody knew, nobody understood." The written

account of Francis Perry (2006), reflects a similar experience. “In 1975 when I was adopted at the age of three, FAS was just a label, and no one understood this invisible disability” (p. 27).

Prior to identification, many individuals experienced deep-seated feelings of difference, as if something was wrong with them, and a sense of confusion which, at the time, had no identified origin. They did not understand why they experienced difficulties with learning, actions and some behaviors. A few discussed how their families or support systems also struggled to find a reason behind certain behaviors. Upon reflection, the participants and the authors of written accounts attribute many of these difficulties to living with the unidentified effects of prenatal alcohol exposure.

**Struggling to understand challenges.** All of the interview participant narratives recount experiencing challenges consistent with FASD. Many of the participants described how they and their support systems struggled to understand the cause of these challenges.

Mitchell spoke about how not understanding the cause of his challenges was difficult for him and his family. “It was pretty hard, you know, for everyone, really not knowing what was going on- if I had FAS or if I was acting out. I knew they did not know what was going on and it was just hard.” Andrew also used the word hard when he questioned why he had more difficulty in school than his peers. “I always had an odd feeling [and asked myself], ‘Is life this hard for everybody?’ ”

Reported written accounts by several non-participants reflect similar experiences. Stef, a woman who was diagnosed with Fetal Alcohol Effects (FAE) as a senior in high school, reflected on how others viewed the challenges she experienced in high school and stated, “I wasn’t diagnosed with FAE until I graduated from high school, so everyone assumed that I was smart but lazy” (p. 109). Steve Neafcy (2008) wrote about how he struggled to understand his

challenges. “I just did not get it, I could not understand, why I was so stupid” (p. 4). Similarly, Tanya, a woman whose FASD was confirmed at the age of 36, spoke of her challenges: “I did kind of wonder why I couldn’t handle full-time employment like everyone else. I noticed as I got older I wasn’t in the same stage of development... as most adults my age” (Pennell, 2013, para. 13). Francis also spoke of this type of confusion, saying, “I never understood how or why I was the one that ended up getting blamed for starting it (trouble) and getting into trouble” (Perry, 2006, p. 27). He wrote about how the lack of understanding of his challenges by the education system inadvertently caused additional social stigmatization. Val, a woman who was identified with an FASD at the age of 50, relayed some of her experiences. Through a support person she recalled the following: Teachers would classify her as a “bad child”, and everybody was expecting her to do better than she was, but no one was helping her do better. They would say things like, “You’re not trying hard enough” (Busch, 2013, para. 8-9).

Study participants echoed their accounts. Kathy remembers how she was often misdiagnosed and stated, “For the longest time I was bounced around from different medicines they were saying first she may have ADD and then she might have a personality disorder and then bi-polar.” When speaking about the difficulties she experienced, Kathy was also quick to note that, despite her challenges and behavioral struggles, she was and still is a good person.

**Feelings of difference or wrongness.** During her interview, Marie openly voiced how she felt different and that something was wrong with her. “I had no idea about the FAS. I just knew something was different, something was wrong.” She describes this time as being very lonely, and that even today she tends to isolate herself. She elaborated further stating, “I didn’t know what was wrong” and “I remember feeling so alone, feeling so different, thinking I was out

there all by myself.” Marie also was frustrated when trying to find support, simply voicing that she didn’t know where to go for help.

Andrew spoke of these feelings several times during the interview, expressing “Why do I feel this way?” and “I wasn’t alone, but I always felt like I was alone.” Andrew’s simple yet powerful statement, “I always felt it was just me or something, but I had no idea I had FASD” reflects the feelings of many of those with FASD, whether or not identified, who describe themselves as “being a problem.”

These narrative excerpts relate the experiences of those with primary and other associated effects of FASD who did not have appropriate information to attribute these challenges to the underlying neurological cause. In some cases this led to feelings of difference, confusion and frustration. Others wrestled to understand why they had more difficulties in life than their peers. Since neurological differences were invisible, family members, teachers and other supporters were not able to fully comprehend why they acted in a certain way or had difficulty learning.

Some narratives recount the damaging and hurtful words said by others. The participants and their surrounding community did not have all of the information to discern the underlying neurological cause of many of their actions and the associated poor fit between need and intervention. Thus, being a “problem, bad, lazy, or stupid” became part of their personal understanding at a particular point in time. For many, even into adulthood, these words remain a very real part of their life story.

### **Identification, naming and meaning making: A turning point**

Telling others the stories of what we have learned about ourselves is an important element of our being. Most of the participants indicated that the identification, naming and

associated meaning-making of knowing about their FASD was a critical piece of information. This new information changed how they understood themselves and their experiences.

They incorporated this new material into their life narratives and it provided them a better understanding of their past, present and future. This illustrates an important concept in the narrative framework—what is most important is that information is used to further understand and explain our experiences, as well as make decisions for our future (McClellan & Pratt, 2006).

Identification, naming and meaning-making constituted a complex process for the participants. Initially, some rejected the information as unhelpful, incorrect or not pertinent to their lives or experiences. Feelings of upset and alarm were found in most of the stories. For some, adding the information to their life stories took time as they learned about FASD and began to integrate this information to better understand their personal experiences. For others, the identification and naming was an almost immediate relief and turning point. The identification also came with an additional layer of societal shame or guilt. A partner, family member or support system was instrumental in assisting most participants to be identified with FASD and providing initial support in understanding their challenges.

During his interview, Andrew mentioned the naming of FASD several times and what it meant to him. He described learning about his FASD at the age of 33 as having a great burden lifted off his shoulders and that it gave him a better understanding of himself. When asked the follow-up question of, “Would it have helped to know earlier?” he stated, “It would have helped me out by knowing what was wrong instead of me speculating and worrying; it certainly would have helped.”

Francis (Perry, 2006), a non-participant, also equated being diagnosed as an unburdening, as removing a weight from his shoulders in his written report. He begins to explain how he



understands himself in relation to the new information. The naming of FASD and knowing he had an underlying neurological condition was empowering for Francis.

Getting diagnosed was like a weight off my shoulders. Now I know that I have a problem and that I am not the problem. Before I was diagnosed I had nothing to work with. I didn't know how to express what I was feeling or how I even felt. I was quick to react to a problem before I thought things out. I had no ability to comprehend the consequences of my actions. All I had were feelings of hatred, anger, bitterness, resentment and fear...I now have something to work with. I know what my limitations are (Perry, 2006, p.27).

In her written account, Tanya also reports that she felt unburdened after she received confirmation of her FASD at age 36. "It was a huge load of bricks off my shoulders. (Pennel, 2013, para. 18)." Once diagnosed, she reports that she found a greater understanding of her strengths and where she needed more support. Similarly, Robin, in a written account (McGregor, 2009), stated that she was diagnosed just prior to her 18<sup>th</sup> birthday. She felt that the naming of FASD helped to put her life into perspective.

In her study interview, Kathy reflected on her own experience of learning about FAS and her initial rejection of the diagnosis, followed by connecting the new information to previous actions.

When I turned 18, (they said) she has FAS. We get it now, and I am like, yeah whatever, I don't really believe (it). I was having destructive behavior and was fighting, and then I realized that maybe I do have it and maybe why I have so much trouble in school was because of that.

Mitchell's first reaction also was initial rejection, and he continues to be uncomfortable knowing about what he describes as a disability. Mitchell said the word disability with considerable force. His reaction leads this researcher to assume he did not want to be seen as a person with a disability. At the time of the interview, it seems that Mitchell was still wrestling with the decision of how this new information would become part of his life story and how he understood himself. Mitchell stated:

When I learned that I had it, everybody, I think the first instinct in their mind is that I don't have it. Anyone could say that such and such could be diagnosed with a disability. I still wasn't comfortable knowing that I had this disability.

Similarly, Val B. (Busch, 2013), according to a written report by a support person, reported that she was "alarmed and upset and angry and all of those things. But as time went on, she realized it helped explain some of the things she had been going through, and realized it was not her fault" (para. 18).

Participant Marie spoke about the apprehension that she felt during the process of getting diagnosed.

I remember when I first started to look to be diagnosed. I thought, no I am too afraid to do this, but I knew. Something in the back of my head said I needed to be medically diagnosed. I remember how scared I was. [They] just kept telling me that I was going to be okay and it was going to happen and sure enough it all fell into place.

For Marie, while this process was helpful, it was also bittersweet.

There are so many things that I would be doing today if I had the confidence and the skills. I would be doing so much more, but it is okay. I tell myself I am right where I need to be, so I am blessed to have a job, a place to live, a family and friends. I am okay.

Hers is a message of resilience and strength.

Steve N. (2008) in his book *A long way to simple: 50 years of living, loving and laughing as a person with FASD*, wrote extensively about his experience of learning about and incorporating the new information into his life story.

Not knowing the reasons for my actions was frustrating...I could not understand what drove me to disappoint those I wanted to be proud of me. I was so lost! It was only after I was diagnosed at 43 years old with Fetal Alcohol Effects (FAE) that I realized my brain was like a fuse box on overload. I didn't have the current flow healthy brains have to give me the chance to think before I acted and make a wise choice. (Neafcy, 2008, p. 13).

He further reflects on how the new information about FASD helped to explain his thought processes and was freeing to him.

First it was important for me to realize the reason I had a short circuit. It was impossible for me to be someone else. I was me, and 'me' had permanent brain damage. With this information I could stop bashing my head against the wall.

This gave me a chance to begin to better my life (Neafcy, 2008, p. 13).

Many of the participants found meaning and a better way of understanding themselves following identification and receiving information regarding FASD. While responses are complex, the understanding of FASD and the incorporation of that understanding into the life story can be more important than an actual diagnosis. Incorporation of FASD into the life story has provided some participants with a type of relief. They are not bad, stupid, a problem or lazy. Rather, they can harness their strengths, identify areas of needed supports and be empowered to ask for those supports.

**Turning point counter examples.** In two narratives, the non-participant reporters offer an alternate view of the experience of identifying and naming their FASD. They did not feel that knowledge of FASD and the associated symptoms were helpful in understanding their experiences. Instead they attributed some of their life challenges to either their mental health symptoms or the effects of alcoholism. Interestingly, these are characteristics often associated with FASD and over time may have developed due to discrepancies between a person's strengths, needs and abilities and the expectations or ineffective supports from their community. A hypothesis cannot be proposed regarding the specific relationship between FASD and the reporter's personal experience with mental health issues and alcoholism as the published autobiographies did not explore these themes in depth.

In her chapter "How I grew up with FAE", which is included in the book *Fantastic Antoine grows up: Adults and adolescents with Fetal Alcohol Syndrome*, Steph P (2002) , at least initially, wrote that the diagnosis did not provide as much insight as she expected. "Because I didn't exhibit the more serious problem of FAS, the doctors could do nothing to help me understand why I did the things I did" (p. 110). Her written narrative asserts that her difficulties were better explained by her specific mental health diagnosis.

Dax, a young man interviewed for *Never say never: Struggle and determination in the lives of young adults with FASD* (2009), learned of his PAE as an adult and was waiting for a more formal assessment. McGregor, the dissertation's author, stated that Dax attributed most of his difficulties to his ongoing issues with alcoholism.

**Social supports.** Some of the participant and written narratives mention that a family member, social worker or a diagnostic team supported them through the diagnostic process. These supports also assisted individuals to understand the diagnosis and discerning how FASD

might personally affect them. Including how to identify and implement individualized accommodations and assist in developing family and community support changes. Marie credits the specialist who assisted during the diagnostic process, her therapist and a support group for help with this process. In his interview, Andrew credits his fiancé and his future in-laws for their guidance as he began to understand FASD. In a written account, Francis P. spoke of a social worker who coached him through the diagnostic and post-diagnostic process (Perry, 2006). A newly published article “My mother, the alcoholic: living with foetal alcohol syndrome”, reports the story of a woman, who as an adult, learned of her FAS diagnosis from her estranged father. She stated that this information killed her inside, that it was a very bad time and the memory of the conversation is still distressing (Gentleman, 2015). This illustrates how receiving the new FASD information without a knowledgeable supporter or mentor could be distressing and have long term implications.

**Societal implications.** Participants Kathy and Marie spoke of how, after diagnosis, that lack of community and societal knowledge about FASD may cause people with FASD to experience guilt or shame. Kathy specifically stated, “I feel that when you tell people that you have FAS they treat you different.” Additionally, they spoke of the need for others who have FASD to take action and begin to speak out regarding their experiences with fetal alcohol. Marie attributed societal shame as a reason that adults with FASD do not openly speak about their condition or advocate for themselves.

There are a lot of people out there who have it, adults, and they are not coming out.

Either they are not coming out or they are afraid or they are ashamed. What I would like to do would be encourage them to not let their fear or their shame stop them because we need to let people know. They can't help us if we don't speak up. They can't help us if

they don't know we are here. There is a lot of shame; a lot of shame and it takes a lot of work to work through it.

Learning about their FASD was a turning point for many of the participants. They found relief in the naming of FASD. This is especially true for those who experienced being labeled or made to feel bad or a problem. By receiving and supported through the process of understanding this new information, they began to break free of those labels instead understanding that they are affected by FASD. Some reflected on the stigma associated with FASD though they did not present this stigma as part of their understanding of self. Stigma and shame needed to be addressed as an obstacle for families, individuals and society. While the responses are complex, adults found greater understanding of themselves and their experiences. Incorporating this new information into the life story, as an explanation for previous struggles and a guide for future choices, has been more powerful than the diagnosis event itself.

### **Making a difference: Contribution and advocacy**

Following a turning point or an event that adds information to a life story, many people begin to reframe their lives in a type of generativity script (McAdams, Diamond, de St. Aubin, & Mansfield, 1997). Generativity is an adult's concern for the well being and development of future generations (McAdams, 2006). This type of script can be found in the narratives of many of the participants and the written accounts. They feel drawn and obligated to use their experiences and knowledge to better society through the areas of FASD education, advocacy and prevention.

As a founding member of an advocacy group, Andrew spoke of how he shares his experiences with others. This sharing represents an effort to make positive change for those living with FASD, stress the need for FASD prevention and make general positive changes in his

community. Andrew also tries to be a role model and live as an example of the capabilities of people living with FASD.

[The organization] is about us being advocates for everything positive. We are against FASD. We are against domestic violence. We are against homelessness. We are against people starving. We are advocates for everything pretty positive. We don't want anyone to think that they are not capable of doing something, so we are just living our lives and showing everyone that they are capable of doing anything that they set their minds to.

When asked the question, "What do you think you will do next?" Andrew expressed that he will continue to be an advocate. "[The organization], we do motivational speaking. We go to conferences, and we just did an expo on FASD. While there, we raised awareness for FASD."

Study participant Mitchell uses his life experiences to connect with and help youth with behavioral issues. Since he has gone through similar challenges he feels "I can actually connect with these kids better than most people because I have gone through it. They can come and talk to me more than anyone else."

Kathy also mentioned speaking at FASD support groups and trying to provide parents with insight into the diagnosis. "Sometimes these parents have questions about why their kids do certain things and I am able to help them." Marie has been on an expert panel at several FASD conferences. At the time of the interview, she was preparing to speak at an upcoming conference. Marie said she gets nervous before speaking at a conference, but she tells herself the following:

You know I am going to be fine. I tell myself all I need to do is be who I am and share my experiences, strengths and hope. I always tell myself, 'If this is what I am asked to do, then I will do it knowing that if it can help others it is worth it.' I want to go out and people to know that this can be something that can change. Things don't have to be this

way. If people listened, they could learn no child has to grow up like I did. Not anymore. There are no excuses any more. There is no reason for it. I was out there all by myself and thank God I found help. You know I am determined to help anybody who wants help. Marie also uses her experience as an adult child of an alcoholic to support and connect with youth who may have similar experiences. She feels she has a reciprocal relationship with this group and has learned much from them.

I am sharing my story and here I am doing meetings with teenagers and younger ones and being able to assure them that there is a better road and there are people that you can call. It is amazing these kids taught me so much.

The non-interview, written accounts also reflect on an obligation to promote FASD awareness and to help others. In a written account, Val B. reports sharing her message of hope at local schools. "If you are born with FASD, you can overcome and still live a happy, productive life (Busch, 2013, para. 1)." Tanya (Pinnell, 2013) also speaks at conferences and has become an FASD educator. Finally, Francis writes of being a guest speaker for the Mi'kmaq First Nation Healing Society. He shares his knowledge at programs for the community organization Empowering Our Communities on FAS/FAE. These programs provide education, training, healing and support to Aboriginal Communities (Perry, 2006, p. 28).

## **Summary**

The themes presented here relay the experiences of several adults living with the effects of FASD who identified during adulthood. A narrative approach was used to organize and analyze those themes. Prior to identification of their FASD, participants experienced confusion regarding life's challenges and associated feelings of difference. Upon learning of their FASD they incorporated this new information into their understanding of themselves which gave them



greater life purpose and direction. Discussion and review of the possible implications of these findings will be reported in the following chapter.

## Chapter Seven: Discussion

### Discussion of Findings

Identity, from a narrative perspective, is the reflexive understanding of self that occurs from telling and receiving feedback on our life stories. The personal narrative that develops helps individuals make sense of who they are and how they developed into the people they are today. This understanding also provides guidance when navigating new experiences and making life decisions. Marie referred to this process as ‘my journey.’

Three specific themes that speak to identity were found in the life stories of adults with FASD, who learned of their condition in adulthood.

- Experiencing unidentified, unnamed FASD
- Identification, naming, and meaning making: A turning point
- Giving back: Contribution and advocacy

Each theme builds upon and seeks understanding from the previous one. This progression is similar to the process individuals use to arrange their experiences and find meaning, i.e., by connecting past experiences to a current understanding of themselves. This chapter will begin with a brief discussion of shared traits, experiences and coping skills and conclude with an in-depth discussion of themes of identity.

**Shared traits, experiences and coping skills.** Each of the interview participants and the authors of written accounts report experiencing a lack of early diagnosis, which Streissguth, et al. (2004) report as “one of the strongest correlates of adverse outcomes” (p. 234). They further suggest that “an early diagnosis allows capable caring families to effectively advocate for their children’s needs” (p. 235). While not diagnosed or identified until adulthood, each study participant had the protective factor of living in a stable, nurturing home and experienced a

positive home life between the ages of eight and 12. Most of the written accounts also report a strong familial structure. Two of the narratives speak to growing up in the foster care system.

The adverse outcomes and tertiary effects described by the interviewed individuals are those that have been commonly reported in other literature. Difficulties with schooling and the education system were commonly heard in the told narratives and written accounts. These effects can be viewed as a poor fit between primary difficulties and available supports and interventions. Instead of learning challenges being accurately attributed to primary FASD symptoms and an unaware or unresponsive system, behavioral symptoms were often assigned attributes that serve to blame and shame. The narratives voice painful experiences of being labeled a “problem”, a “bad child” or someone who does not try hard enough.

When strengths are identified and acknowledged, interventions and focus can be shifted away from trying to fix a person or a problem to enhancing and building upon positive behaviors and characteristics (Tedeschi, & Kilmer 2005). Many of the stories are also strength-focused and relay successes. The collected life stories and written accounts reveal that participants endeavor to be active contributing members of their community. Reported positive outcomes are most likely due to general perseverance, the diligence of their support system, and a strengths-based philosophy.

Participants and many of the written narratives credit family support, advocacy and persistence for their adult accomplishments. The narratives additionally have a tone of resilience and determination, commonly reported strengths of adults with FASD and presumable influences on life outcomes.

There is a wealth of literature based in practitioner wisdom that outlines strategies considered best practices. Participants identified using these strategies to achieve greater life

success. This adds additional confidence in the use of these strategies to support adults with an FASD or with a suspected FASD. Following identification, they were empowered to tell others what they need to be successful. There is also a societal obligation to understand, identify and respect the supports that individuals require in order to be successful. It is not the sole responsibility of persons with FASD and their supporters to advocate for all needed supports. A non-stigmatized societal and systems understanding of neurological difference could provide a platform for greater success. The importance of faith and meditation were also included in many narratives, a factor not included in the reviewed literature.

**Experiencing unidentified, unnamed FASD.** Since collection of material for the life story begins in infancy and continues through childhood (Erikson, 1968), the early experiences of persons living with the effects of FASD can have lifelong implications. Through analyzing the life stories of persons with LD, Rodis (2001) identified “The problem-without a name stage (p. 213),” a point at which people have no definite concept of having a LD, but feel they were in some way different from their peers. Rodis further explained that during this stage, people begin to develop an idea of who they are, taking into account their experiences of failure or of being a misfit and, in turn, developing a hypothesis of the value of their present and future selves (p. 213).

Adults in my study living with the unidentified and unnamed effects of FASD experienced many challenges during their childhood, adolescence and adulthood. It can be inferred that participants experienced a poor fit between their needs, available supports and their surrounding social environment, adding additional material to the life narrative. Of particular concern are the accounts of chronic difficulties with schooling. These challenges are similar to those reported in FASD literature. Since the possible effects of gestational alcohol exposure were

largely unknown until the past half-century, participants spent most of their formative years with little insight into the underlying cause of these challenges. Their families, support teams and advocates, while supportive, were equally baffled regarding their loved ones' struggles. Participants were often misunderstood, misdiagnosed or subjected to character-blaming sentiments. Such descriptors caused significant distress in the lives of some of the participants. Feelings of difference (Stade et al., 2011) and the use by others of damaging and hurtful descriptors (Green, 2007; Morse, 1993) are commonly reported themes in the accounts of persons living with FASD. Many persons living with the effects of FASD also experience significant adverse childhood events including poverty, multiple foster home placements, abuse, trauma and neglect (Streissguth, et al., 2004), which only further complicate the life story elements shaped by early childhood experiences. These factors can be particularly damaging since what we hear about ourselves from others can greatly influence our life story and identity (McAdams, 2006).

An understanding of self usually begins to hatch in adolescence (Erikson, 1968). It is during this time that people typically begin to organize their experiences in a way that communicates their identity. For study participants who struggled with unknown or unidentified neurological impairments well into adulthood, it meant integrating socially constructed stories into their understanding of themselves.

It is well established that persons living with the effects of FASD can experience mental health issues (Burd, et al., 2003) and higher rates of adverse childhood experiences (Streissguth, et al., 2004), predictors of future difficulty (Hellemans, et. al, 2010). Several participants reported confusion and distress because they could not understand their challenges, were subjected to the criticism of others and felt wrong or different. Adults with other neurological

differences attribute some of their challenges with depression and anxiety to the distress following these experiences, specifically when they were not fully able to describe their challenges and when they internalized the criticism of others (Punshon, Skirrow, & Murphy (2009).

Stories of loneliness, well documented in the literature, were also reported in this study. Feeling alone, even while in the company of peers, was a theme also heard in the narratives of children living with the effects of FASD (Stade, et al., 2011). Such peer-related loneliness has been found to predispose children to adolescent depressive symptoms (Qualter, Brown, Munn, & Rotenberg, 2010). A general sense of not belonging can negatively impact one's mental health (Hagerty, Lynch-Sauer, Patusky, Bouwsema, & Collier, 1992). Studies report depressive symptoms up to 10 years following initial reports of loneliness (Cacioppo, Hughes, Waite, Hawkley, & Thisted, 2006; Heikkinen & Kauppinen, 2004; Hagerty & Williams, 1999).

The narratives reported in this study illustrate how a poor fit between needs and interventions can lead to childhood experiences of feeling alone and confused related to personal challenges. This is especially true for those living with the effects of FASD. Contrastingly, a couple of the participants included stories of positive peer relationships.

**Identification, naming, and meaning making: A turning point.** The most significant implication of this study is that late identification can be incredibly powerful and provide insight for those living with the effects of FASD. Turning-point events are meaningful events and experiences that become an impetus for change in a person's life path (Pillemar, 2001). It is during this turning point that resolution of previously compromised psychosocial stages may occur leading to increased well-being and a better understanding of self. Wethington et al. (1997) suggested that gaining new knowledge of the self, such as a new understanding of limitations and

talents, can be a turning point event. This is much like what Rodis (2001), referring to LD, titled the diagnosis stage. Similarly, for those with autism, being able to attribute their difficulties to a diagnosis was a revelation (Cousins, 2001; as cited in Punshon, Skirrow, & Murphy, 2009) a framework for understanding (Punshon, Skirrow, & Murphy 2009) and also a sense-making narrative (Molloy and Vasil, 2004). Nevertheless, as the Center for Disease Control and Prevention highlights, “Diagnosis is never an endpoint for any individual with a developmental disability and his or her family” (CDC, 2004, pg. 1).

Allison Pooley is a program director at Maple Ridge’s Asante Centre, a group leading the field in FASD research and supports. She reflected on the impact of receiving an FASD related diagnosis in adulthood. “A simple diagnosis can be a game-changer for adults. ‘It’s partly the connection to services, and partly being able to understand themselves, and tell people what’s going on with them’ ”(Corbett, 2014, para. 16-17). This statement emphasizes how a diagnosis of FASD can be a catalyst for the potentially complex process of personal understanding and access to services.

The importance of appropriate and suitable supports that shepherd individuals and their support persons through diagnosis and post diagnosis cannot be underestimated. The presentation of a diagnosis of FASD can influence how a person understands her/himself in light of the new information. This is critical since respondents and written narratives reflect that a diagnosis of FASD can be alarming and potentially stigmatizing.

Following diagnosis, ongoing follow up and support is essential. Support networks must: walk with individuals towards a greater understanding of how FASD may impact their daily lives; connect them with appropriate services; potentially facilitate conversations with family, employers and other community agencies and possibly serve as advocates. These actions will

likely influence how an individual makes sense of their FASD. This is crucial since one way individuals learn about themselves is through the stories (interventions and responses) of others. Thus, if support systems' and family members' responses and interactions became FASD informed, an individual's understanding of self will likely be influenced. A turning point in this case is more than individual understanding; it is the understanding of others reflected back to an individual.

This crucial and complex process was not well captured within the told narratives or written accounts. Several narratives indicate that assistance and support was provided during the assessment process. Narratives also suggest that social workers, therapists and support networks were essential during the sense-making process. But there is little specific information about this assistance gathered from their reports. Since participant and written accounts communicate positives associated with learning about FASD, it is likely the diagnostic and post-diagnostic process was one of support and understanding. If this process presented FASD in a way that was stigmatizing or labeling, participants would likely have had a much different reaction.

The narratives and written accounts presented in this study focus on FASD as a tool towards understanding. The new FASD information had much value as an instrument to understand previous experiences and potential support needs, although there is a depth of personal inner understanding that is not part of the stories captured for this thesis. Crucial understanding of the underlying psycho-social aspect of the process of sense-making is a missing from the narratives. There is more to diagnosis than simply *being* a turning point. Missing from the narratives is an understanding of the process of *how* it became that turning point.

The told and written accounts in my study reflect that identifying and finding meaning in their FASD was a turning-point event. Individuals reviewed and reflected upon past experiences



and processed negative memories and stories through the lens of FASD. They used this information to reinterpret their experiences, guide their present lives and understand enduring and current characteristics of themselves. Knowledge and understanding of FASD came with a new set of challenges. For most it not only added to their life stories, but also shook the foundation of how they saw themselves, their experiences and what supports they needed to find success.

Initially, some participants rejected the information as unhelpful, incorrect or not pertinent to their lives or experiences. Others reported that they felt an immediate sense of relief and unburdening. Regardless of the initial reaction, deciding how to incorporate this new knowledge was most likely a gradual process. As a result, personal changes were made regarding how everyday life and future expectations were altered (Rodis, 2001). Several narratives indicate that individuals received assistance navigating the assessment process. Additionally, some individuals report accessing therapeutic supports to process the new FASD information and develop life strategies that take FASD into account.

Participants expressed a better understanding of their challenges with learning, self-regulation and troubling behaviors once they were attributed to the effects of FASD. Connecting school difficulties and other life struggles to the effects of FASD and unresponsive systems, lessened some of the blame they put on themselves. Through this reframing, some accounts report feeling freed from the undue burden of trying to live by the standards of others. Taking into account this new information participants were able to set new life goals and improve their life.

For many, this reinterpretation lifted a weight off their shoulders. Psychologically, they no longer felt that something was intrinsically wrong with them. Rodis (2001) refers to this

transition as the owning and outing stage (p. 219). New information becomes part of one's self image and identity. Through this process, people begin to live consciously and deliberately, taking their disabilities into account. This includes the realization that not acknowledging it could be personally damaging. Participant and written accounts clearly illustrate how using this new information to advocate for supports is necessary for continued success.

It is unlikely that this type of advocacy is solely an autonomous effort. Included in the told and written narratives are references to support networks of family, friends and professionals. Paley and O'Conner (2009) advise that an important aspect of working with individuals with FASD is equipping parents and caregivers with tools to effectively advocate for services. Parents report that advocacy on behalf of their child is needed during high school (Duquette, et al., 2006) and ensuring a successful school experience involves parental advocacy (Duquette & Stodel, 2005). The inclusion of advocacy services and supports during treatment yielded better outcomes for young women (Grant, et al., 2007).

Within the owning and outing stage, Rodis (2001) identified three dimensions when persons with LD utilized their new insight to understand themselves and alter everyday life experiences. These dimensions also well describe how persons with FASD in my study harnessed the new information about themselves. Participant and written accounts report that social workers, therapists, diagnostic teams, friends and family members supported them through the process of harnessing this new information. The dimensions are the following:

- **pragmatic dimension:** "Understanding unique learning styles; pursuing real life goals; accessing legal rights in educational and vocational settings" (p. 220).

- **intrapsychic dimension:** “Admitting to oneself the disability status thus allowing the evolution of a more realistic and accepting self-concept; emphasis on supporting the self in the accomplishment of life’s pursuits” (p. 220).
- **political/ideological dimension:** “Addressing the disability through social, cultural, and political analysis. Recognizing the social construct of disability and/or organizing for political action” (p.220).

In the pragmatic dimension, individuals were able to understand both the areas for needed extra support and their areas of strength. The told and written stories reflect on the practical use of the new FASD information. Including in an employment setting, finding better ways of managing daily tasks or generally being fully armed to face the world. It is likely each individual was coached to become a self-advocate or has a person advocating on his or her behalf.

It is not the sole responsibility of an individual with FASD or their support system to identify and request accommodations or legal rights. There is a societal obligation to acknowledge and respect individual neurological differences, hence the need to assist people with FASD to live productive, meaningful and successful lives. By appearances this obligation often falls short since, persons with FASD are thought to be overrepresented in the correctional system (Burd, Selfridge, Klug & Bakko, 2004) and have difficulty finding and keeping jobs (Spohr, Willms, & Steinhausen, 2007; Streissguth & O'Malley. 2000).

For most, legal entitlements can be difficult to access at best and non-existent for most. Since most people who experience the effects of prenatal alcohol exposure do not have a below average IQ (Mattson, Crocker, & Nguyen, 2001), they do not meet the criteria for a vast number of helpful and much-needed services. Frustration with the available supports for children and

adults with FASD is a common theme in parent driven literature, websites focused on FASD and at conferences and trainings.

The intrapsychic dimension of personally admitting and owning limitations and acknowledging the need for support systems is very complex for adults with FASD. For one participant this meant reconciling that she might not have certain skills to reach previous aspirations. Instead the accounts report the importance of fashioning a more accepting self-concept, taking strengths into account and relying on support teams. Understanding personal strengths has been empowering for many as they are now able to set attainable goals.

Participants and written accounts reflect the dynamic use of FASD in order to understand personal strengths and abilities. Ultimately, individuals did not appear to incorporate a poor self-image, due to the FASD diagnosis, into their identity. While there is often a stigma attached to FASD, these accounts did not report incorporating this into their understanding of themselves. How each individual and their support team walked through the diagnostic and post-diagnostic process, no doubt influenced this understanding.

Within the political/ideological dimension, one participant was especially vocal regarding the need to recast the social construct of FASD. She felt that the association between FASD and shame limits others' access to available services and supports.

While not mentioned specifically in the narratives, many of the challenges associated with FASD are socially constructed. Most obviously is the development of associated but not inherent characteristics of FASD. Issues with drug and alcohol abuse, homelessness and trouble with the law, for example, are associated with but not inherent in FASD. Adverse life conditions develop, in part, due to social environments that do not or cannot recognize or appropriately support those with neurological functioning differences (Malbin, 2008).

A surprising finding was participants' brief discussion of their birth mothers. Two participants commented on their understanding of their birth mothers' use of alcohol. There are also many social implications worth exploring when considering the maternal risk factors associated with FASD. An over-simplified and reductionist viewpoint would describe FASD as currently being 100 percent preventable, especially if considering zero alcohol use during pregnancy as preventing alcohol-exposed pregnancies (Tait, 2001). When one considers the myriad of maternal risk factors, and that 49% of pregnancies in the United States are unplanned (Finer & Henshaw, 2006) viewing FASD as completely preventable, given the current social climate, becomes less obvious. Risk factors, along with barriers to prenatal care (Phillippi, 2009) and treatment services for substance abuse issues (Ashley, Marsden & Brady, 2003), further contradict the premise that given the current social environment, FASD is 100 percent preventable. These complex social and political implications cannot adequately be addressed through a self-sustained, individual effort of maintaining sobriety during pregnancy. Socially and culturally competent prevention strategies will be discussed further.

**Making a difference: Contribution and advocacy.** Following a turning point or an event that adds more information to the life story, such as finding out about their FASD, people sometimes begin to understand their lives in a type of "generativity script" (McAdams, Diamond, de St.Aubin, & Mansfield, 1997). Generativity refers to an adult's concern for the well-being and development of future generations (McAdams, 2006). Generative narratives can be found in the stories of those from late-adolescence through old age (McAdams, 2006). This theme of concern for the well-being of others and future generations can be heard in the life stories of those with FASD.

All study participants and most written accounts report devoting some of their adult life to endeavors that would educate others about FASD, prevent FASD, or advocate for services for people with FASD. One participant specifically stated his desire to be a role model for how to live life with FASD. Two accounts reflect a thread of caring for future generations as a central part of understanding who they are. They feel it is their calling to educate others about the effects of FASD and prevent it from happening to future generations.

It is not surprising the respondents develop an understanding of who they are as being concerned for the well-being of others. A strength reported by study participants and informal reports from families and professionals is that persons with FASD often are naturally inclined to care for others (Community Living British Columbia, 2011; Malbin, 2006). This characteristic could easily develop into a way of personal understanding, given the catalyst of a turning point event such as learning about FASD. Individuals are able to harness the strength of caring for others and direct this energy into what they feel is an obligation of advocacy, education and prevention work.

The preceding discussion reviewed the possible implications of living a large part of life with an invisible, unnamed disability and the associated social implications. Feelings of childhood loneliness and difference were commonly heard in the reported life stories. These early experiences become a part of each person's understanding of themselves. These early experiences have far-reaching consequences as distressing and traumatic childhood events can be a catalyst for mental health issues across the life span. In adulthood, learning of a previously unacknowledged FASD allows for a reinterpretation of life experiences. This reinterpretation can provide a better understanding of self and challenges across the lifespan, possible access to more appropriate supports and a sense of unburdening. The reinterpretation of life experiences

influenced many towards a new life purpose or path. This reinterpretation was likely facilitated by a network of supportive and insightful family, friends and professionals. Gratitude for individual support networks was reported in the narratives and written accounts. Through harnessing a strength of concern for others, these adults have begun to contribute to FASD related causes through advocacy initiatives.

### **Relevance of Findings**

The findings of this study bear witness to the unique and largely unexplored experiences and identity of this predominantly unknown group of individuals. There are few scholarly works that address the identity and experiences of adults with FASD. This study's findings use first person narratives to provide rich accounts of personal traits, behaviors, beliefs and aspects of identity. The findings were informed by current literature but were chiefly developed from the first hand narrative accounts of 4 participants and 7 previously published biographical accounts. The most significant finding is that late identification can still be incredibly powerful and provide greater personal understanding for those living with the effects of FASD. For my participants, the ensuing reinterpretation of past experiences and challenges resolved long-held negative perceptions and understanding of themselves and provided altered life purpose and intention. The participants in this study articulated and had insight into their experiences. For those with FASD who have more significant cognitive challenges and limited insight these findings could also be relevant. Parents and support professionals report that learning about FASD is a pivotal moment (Devries & Waller, 2004). Part of the assessment and diagnostic process should be the development of an effective treatment plan that minimizes risk factors and promotes protective factors across the lifespan (Bertrand, Floyd & Weber, 2005). Astute supporters can implement effective strategies that may lead to better life outcomes regardless of

an individual's full understanding of FASD. However, helping professions in the position to identify and provide supports report deficits in significant knowledge, skill and attitude related to FASD (Wedding, et al., 2007; Diekman, 2000; Abel & Kruger, 1998), deficits that may put many adults living with the unidentified effects of FASD at risk for being unable to experience the benefits described in this study.

### **Construction of Findings**

During the data analysis process, I strove to cast off preconceived beliefs and remain faithful to the themes that emerged from the collected life stories and published narratives. Nevertheless, my personal experiences as social worker supporting those with FASD influenced how I interpreted and uncovered themes within the data. My own professional experience fostered my understanding of FASD both as a neurological condition and as socially constructed by a lack of access to appropriate supports and limited societal knowledge and understanding. My findings depict the social and cultural influences on identity as well as my subjects' personal traits, experiences and support needs. The participants' life stories and the non-interview written accounts provided the raw material for the findings; but I personally identified and organized the themes, resulting in a deeply personal creation.

### **Transferability**

While this study's sample size is small, I have attempted to provide rich and detailed descriptions of identity and highlight personal experiences. The study participants hailed from communities across the United States, illustrating that FASD impacts persons living in many diverse communities. It is likely that their experiences will resonate with other individuals living with FASD, their family members, friends and other informal support structures. On reflection, readers may consider whether or not this information resonates enough with their own



experiences to permit a personal sort of generalization. Hopefully, through this process of naturalistic generalization (Stake & Trumbull, 1982), readers will be able to apply pertinent findings to a personal context.

### **Discussion of Limitations**

This study has several limitations that suggest directions for future research. Limitations include: sampling, diversity, possible bias, use of telephone interviews and initial conceptualization. These limitations were addressed through study design, acknowledgement of limitations and a statement of reflexivity.

**Sampling.** Generalizability and transferability of study findings are limited by the research sample size (Morrow, 2005). Factors that can influence sample size include methodology (Creswell, 2007), aim (Charmez, 2006), a focus on a special interest focus (Ritchie et al., 2003) and the sample size of similar studies.

Qualitative research does not define sample size as simply a number of participants; rather it arrives at knowledge through an in-depth sampling of subjects' experiences (Sandowlski, 1995). The narratives of four interview participants, one participant written biography and six previously published works offer access to such experiences through the rich accounts of the collected life stories. The sample size provided an appropriate number of experiences to answer the research questions. This dissertation sought an appropriate number of participants to ensure a robust and a richly descriptive understanding of experience. This balance is well described by Sandowlski (1995).

An adequate sample size in qualitative research is one that permits-by virtue of not being too large-the deep, case-oriented analysis that is a hallmark of all qualitative inquiry, and

that results in--by virtue of not being too small--a new and richly textured understanding of experience. (p. 183)

In the second edition text, *Qualitative inquiry and research design: Choosing among five approaches*, Creswell (2007) writes the following about sample size and narrative methodology.

The procedures for implementing this research (*narrative*) consist of focusing on studying one or two individuals, gathering data through the collection of their stories, reporting individual experiences and chronologically ordering the meaning of those experiences. (p. 54)

Creswell (2007) further recommends, "Select one or more individuals who have stories or life experiences to tell, and spend considerable time with them gathering their stories through multiple types of information (p.55)." Crouch & McKenzie (2006) suggest that fewer participants are required for methodologies that use multiple in-depth interviews. There were four participant interviews reported in this study. Multiple interviews were conducted with participants to gather in-depth knowledge of their life experiences.

A small sample size is appropriate if a study is not geared at describing a process or theory that would span multiple disciplines (Charmez, 2006). This dissertation's research questions were developed to gather knowledge of an experience, not a process or for theory development. A large sample size is disproportionate to the goal of this study and would not have allowed for rich descriptions, multiple interviews and in-depth analysis.

The targeted group of adults with FASD could be considered a special interest group requiring intense study, a factor affecting sample size (Ritchie et al., 2003). Since this is a small target group, recruitment was more challenging than initially expected. I found that those who learned of their FASD as adults are an unrecognized group representing a largely unknown

disorder. The sample size was small and insufficient for generalization to populations but abundant in valuable descriptors of life experiences.

While small, this dissertation sample is consistent with the sample size of similar dissertations and theses that seek to explore the experiences of persons with FASD. This dissertation is significantly different and contributes to the overall body of research within the field because it confines its focus to experiences of adults with FASD who were identified in adulthood. Other qualitative studies based on small sample sizes include the following: McGregor (2009) explored the collected life stories of five young adults with FASD in her dissertation *Never say never: Struggle and determination in the lives of young adults with FASD*. Knorr (2011) interviewed four adults for her master's thesis entitled *Overcoming adversity: The stories of four resilient adults with Fetal Alcohol Spectrum Disorders*. In her master's thesis, *The experiences and needs of young people with FASD: Silenced voices from youth in care*, Chatterley-Gonzalez (2010) chronicled the experiences of five youth with FASD. Castelli's (2005) dissertation, *Fetal alcohol spectrum disorders across the lifespan: A series of case illustrations with implications for professional psychologists* included an in-depth literature review and five case study illustrations from which implications for professional psychologists were inferred.

Recommendations for future studies aimed at larger samples include: (1) development of interview protocols that target the expertise of family members and other support staff, and (2) working collaboratively with an agency to target research participants, for which an agency-specific recruitment protocol would be developed.

It should be noted that Andrew did not have a diagnosis related to FASD and was not formally assessed or diagnosed. This difference is a limitation. He stated that his mother

provided him with the information about his FASD. Based on self-report he identified as having an FASD. Best practice dictates that following diagnosis individuals should be provided with resources and an individualized treatment plan. Andrew reports great support from his friends and family. He credits others for their guidance; he did not specifically state how they supported or walked him through learning about FASD and the implications of having an FASD. Future sampling should clarify and explore the differences and implications of diagnosis, formal screenings and personal/familial identification of FASD without a diagnosis.

**Diversity.** The effects of FASD are not limited to a specific culture, race or geographic region. Literature addresses the challenges of FASD in Australia, Canada, the United States and Australia (Kyskan & Moore, 2005); South Africa (May, et al., 2000); Russia (Miller, et al., 2006); and Finland (AuttiRämö, et al., 2006).

I employed a purposive and snowball sampling process to identify and recruit participants. Recruitment was limited to those respondents who freely and independently responded to recruitment postings and flyers. The sample included adults of Caucasian, African-American and Latina heritage and ethnicity. The use of previously published accounts adds additional diversity to the findings. The findings are limited, however, by a Euro-Western social and cultural perspective.

The unique voice and perspective of those from Aboriginal and Native American culture and ethnicity are absent from the sample. The historical, social and cultural aspects of alcohol and its use can be significantly different within Aboriginal, Native American and First Nations populations (Tait, 2001). To thoroughly understand and investigate FASD within native cultures, it would be wise to develop research questions and protocols to address and capture their unique life stories. Additionally, such research would require a mentor with first-hand knowledge of

traditions and customs. Given the strong oral story telling tradition of Aboriginal, Native American and First Nations people, using a narrative method to capture the life stories of adults with FASD could foster a more complete understanding of their experience.

My respondents were primarily from urban or suburban areas across several regions of the United States. Those from rural communities were not represented in this sample. In addition to prevalence estimates of FAS by the Institute of Medicine, the prevalence of FASD in subsets of the US population, including those from rural and urban areas, is needed (May & Gossage, 2001). While maternal risk factors such as a lower socio-economic status are present in rural and urban communities, the life stories of these groups could be vastly different. Future studies should be designed to actively recruit those from rural communities. Studies exploring the potential differences in life experiences between those living with FASD in rural vs. urban communities would be helpful when developing and tailoring support services.

My study participants were raised in working class or affluent families; therefore those representing lower socio-economic status were not represented. Given that this status is a maternal risk factor, their absence is a significant limitation of the study. The experiences of those who dually endure both the effects of FASD and lower socio-economic status could be vastly different from those represented in this study.

Additionally, persons with FASD are demographically overrepresented in the foster care and correctional systems. The lack of representation of persons with FASD who reported experiences with the foster care or correctional systems is an additional significant limitation of this study. While my participants may have been cared for in orphanages as infants or experienced homelessness in adulthood, their basic human needs were met for most of their lives.

Due to its inclusion and exclusion criteria, this study may not be reflective of the experiences of the most vulnerable persons with FASD. This is especially relevant when considering those who experience significant secondary and tertiary effects of FASD. Future studies should use protocols that specifically address these vulnerabilities, such as requiring a personal representative to be involved in the consent process; having a personal representative present during the interview; and/or interviewing parents, educators and other support persons.

Participants in this study may have been highly motivated to tell their stories since, to some degree, each was involved in advocacy work. Thus, their experiences may not be reflective of the experience of many people with FASD. Participants also had active support systems. Their support systems may have counseled them regarding how to put their personal life experiences into the context of FASD. These support teams also may have ameliorated possible secondary and tertiary effects, such as legal entanglements, chronic homelessness and prolonged drug and alcohol use. Future studies should actively work to recruit a more inclusive population. This may include working collaboratively with support agencies to target specific populations.

**Respondent bias.** Another limitation to this study is the potential lack of trustworthiness as a result of respondent bias (Bowen, 2005). The influence of social desirability is also a concern, as participants may have responded to the researcher in a way that he or she felt the researcher wanted to hear (Rubin, 2000), a possibility especially likely for adults living with FASD. I attempted to minimize this bias by building rapport with the participants prior to the interview and having participants review and comment on the findings. Additionally, I explained to the participants how the provided information would be de-identified and used an interview style that was neither judgmental nor leading. Future research should consider interviewing

family members or personal supporters as an additional method to address this bias. This type of triangulation of data would also address process issues also cited as a limitation.

**Confirmability.** Another limitation of this study was the lack of confirmability, or the degree to which the results can be confirmed by others. This is due to the researcher being the sole research instrument. The interviews and analysis were subjected to researcher bias, as the researcher is emotionally invested in the topic, and had previously read scholarly and informal literature about the topic (Morrow, 2005).

The research followed a semi-structured interview format. All participants were asked the same primary questions. Probes and follow-up questions were used during the interviews and varied dependent on the participant. The researcher also engaged in the process of reflexivity, as noted previously.

**Telephone interviews.** Historically, qualitative interviews conducted via telephone have been considered inferior to in-person interviews (Irvine, 2011). Textbooks note concerns regarding building rapport (Shuy, 2003) and being unable to observe the respondent's nonverbal communication (Creswell, 2007). Contrastingly, researchers also cite the strengths. These include the potential for greater anonymity (Sturges & Hanrahan, 2004), lessening the intrusion on respondents (Holt, 2010), allowing participants to remain on "their own turf" (McCoyd and Kerson 2006, p. 399), and increased participant control (Stephens, 2007). Multiple disciplines have used telephone interviews to conduct qualitative research (Irvin, Drew & Sainsbury, 2012).

Holt (2010) reflects on the appropriateness of using telephone interviews for qualitative research targeting marginalized/vulnerable populations though not specific to FASD. From an ideological perspective, Holt (2010) states that in-person interviews may expose already marginalized populations to unwanted professional scrutiny. Holt explains:

In such circumstances, the interview experience may not be dissimilar from other experiences where professionals have come into the participants' homes and asked a series of questions about their lives. . . . Thus, the use of the telephone with such participants may at least reduce the intensity of the 'surveillant other' (Walkerdine, 1990, p. 195) by not intruding on the narrator's home, which to some extent, avoids reproducing such 'gazing' practices (p. 115).

Telephone interviews also raise concerns that less rapport is established between researcher and respondent (Shuy, 2002; Stephens, 2007; Sturges & Hanrahan, 2004), though Trier-Bieniek (2012) mentions that rapport during in-person interviews is not guaranteed. Burnard (1994) suggests that, when conducting telephone interviews:

...it is also useful to make some more general enquiries about the interviewee to set him or her at their ease. Many people take a little time to 'warm up' on the phone and such general conversation is equivalent to the initial questions that are asked at the beginning of a face-to-face interview to make the interviewee feel more comfortable (p.70).

During this study, rapport with participants was established through non-recorded introductory telephone calls and small talk prior to the interviews. Upon personal reflection, I felt the conversation was one of ease. If future telephone interviews were to be conducted with any particular interviewee, additional reflection on rapport from the respondent's perspective should be solicited.

The most obvious difference between face-to-face interviews and telephone interviews is the lack of visual observation of the respondent. In this study, I was unable to visually monitor respondents for comprehension or affect change. This is a concern cited by both Rubin and Rubin (2005) and Shuy (2003). Similarly to Tausig and Freeman (1988), I was able to monitor



these concerns through rapport building and careful listening.

Researchers have found that telephone interviews can generate quality data (Sweet, 2002; Stephens, 2007) which challenges the view that telephone interviews are poorly suited for qualitative research (Holt, 2010). Potentially, in-person interviews could have yielded additional data. Due to prohibitions such as location, it is unlikely that the stories reported here would have been captured without telephone interviews. Upon personal reflection, I feel that telephone interviews avoided potentially stressful and intrusive in-person interviews though may have limited rich descriptions of experiences. Future use of telephone interviews should include greater process reflexivity on the part of the participant (Holt, 2010).

**Conceptualization.** Aspects of the initial conceptualization of this dissertation need to be addressed as limitations of this study. Limitations include: understanding the diagnostic and post-diagnostic process; discerning how FASD was presented to individuals and supporters; and unraveling how potentially, socially marginalized individuals can understand themselves in a social context. The lack of family member or support person accounts could also be viewed as a conceptual limitation.

This dissertation did not adequately capture the process of how individuals were diagnosed and understood the personal influence of FASD on identity. I did not adequately appreciate this significant aspect during the initial conceptualization of this dissertation. Thus, the interview guide was not developed to specifically uncover this process. The diagnostic and ensuing support process is briefly mentioned in a few of the participant and written accounts. The captured accounts lack details needed to reveal the contextual complexity of FASD. This fault became apparent during the discussion process following data analysis. Future research should include questions that address:

- the diagnostic process
- supports provided to individuals, families and supporters during and following the diagnostic process
- if the diagnostic process included: development of treatment plans and strategies to access appropriate services and supports.

From the inception of this project, I was interested in learning from and reporting on themes that emerged, first hand, from the narratives of adults with FASD. I felt that information gleaned from supporters would be an interpretation about a person and his or her experience. Following prolonged initial reflection, I concluded that only adults with FASD could provide relevant data to answer the research questions. This view was reinforced when I attended a FASD conference. A panel of adults with FASD spoke about their personal experiences. This panel was noticeably less well attended than those of researchers.

Closing reflection leads me to believe that family member or support person interviews would have yielded greater procedural details and information. Including a greater understanding of system and family supports. Within the case study design, this would not have compromised the integrity of the narratives of adults with FASD. Inclusion of family member or support person interviews would also have addressed issues of bias.

After receiving feedback, I considered how adults with FASD could understand themselves in a social context. Often those with FASD are ostracized from society. The small sample of narratives contained in this study report the importance of individual contribution to society.

As a community based social worker, I felt that this was an important theme. From personal experience, individuals with FASD and intellectual and developmental disabilities

(IDD)/intellectual deficiencies who exhibit challenging behavior often have limited access to their community. This restriction occurs regardless if the behavior is the result of unresponsive systems, uninformed supports or being misunderstood. This inhibits their potential to be engaged and productive community members. This limitation often results in apparent poor self-worth.

The following quote from Community Living British Columbia reflects my personal experience:

In most ways, adults with FASD share the same basic needs and desires we all do: To make a difference. To be cared about. To be heard and understood. To contribute to their communities.

If these basic needs are not met, adults with FASD experience frustration, isolation, increased vulnerability, and failure. So too will their families and support persons. We believe that our communities are stronger when all citizens are well supported.

(Community Living British Columbia, 2010, p. 40)

### **Implications for Social Work Education and Practice**

This research highlights the experiences of adults living with FASD who became aware of their condition in adulthood. Due to the chronic under-recognition of FASD, there are presumably a great number of adults who experience the same effects.

Persons with FASD are likely disproportionately represented in organizations where social workers and support workers provide services. These organizations include professionals who work with clients or patients who exhibit mental health issues, struggle with addiction, women of childbearing age or families and children who are at risk. The effects of FASD presumably impact all areas of social work and should not be underestimated.

Implications for social work education and practice gleaned from this research and other writings on FASD include:

- the importance of appropriate and culturally competent prevention and identification strategies
- the need for appropriate supports for adults with FASD and
- the need to address societal and systemic issues related to FASD.

**Advocacy and identification.** Several of the narratives addressed the personal meaning participants found in sharing their experiences with FASD, specifically related to the need for further educating others regarding prevention. While not initially the primary intent of this research, the stories depict the ongoing need for skillfully provided prevention strategies. Those who work with women of childbearing age, regardless of whether or not they evince concerns about alcohol use, should be aware of screening and support strategies that include psychoeducation about the intergenerational aspect of FASD and informing women about the importance of sobriety during pregnancy. Motivational interviewing interventions and techniques have been found to reduce alcohol exposed pregnancies. These preconception intervention strategies can be utilized as an option for preventative care (Ceperich & Ingersoll, 2011; Floyd et al., 2007; Ingersal, et al., 2013). Additionally, screening for alcohol use and brief interventions in prenatal care environments can influence maternal drinking behavior (Change, 2004; O'Connor & Whaley, 2007). The Parent Child Assistance Program through Washington Stated DHS is an evidence-based and effective model of prevention and intervention (Astley & Grant, 2014). Community approaches such as Alberta's Parent Child Assistance Program have been found to reduce alcohol exposed pregnancies in tribal communities. [Cox, (March, 2015). 6<sup>th</sup> *International conference on FASD: Research, results and relevance*. Vancouver, BC., Canada]. The Project CHOICES curriculum United States has also been found to reduce alcohol exposed pregnancies (Center for Disease Control, undated) though modifications for cultural relevance

are necessary [Hanson, Wilton, Langland & Gillen (March, 2015). *6<sup>th</sup> International conference on FASD: Research, results and relevance*. Vancouver, BC., Canada]. Such efforts can become complicated if the expectant mother has a previously unidentified FASD and has difficulty navigating life's challenges as a result, especially if prevention strategies are not FASD informed i.e., those with FASD may have difficulty with motivational interviewing strategies (SAMHSA-FASD Center for Excellence, undated).

In the event that prevention strategies have not been adequate or effective, recognition that clients may have FASD is imperative. The period from birth to two years old is the most dynamic phase of postnatal neurological development and is a sensitive period for neurodevelopmental disorders such as autism (Knickmeyer, et al., 2008). For infants presenting signs of gestational alcohol exposure, being well cared for and stimulated in a stable home environment can be reparative. Such infants and their families profit from early identification and immediate intervention. Such efforts can potentially prevent or minimize the development of secondary or tertiary characteristics, leading to improved outcomes (Bertrand, 2009). Though the process of how infants are identified and how this information is presented to families requires a nimble and educated approach. It is unclear how mandated reporting efforts, such as those recently taken by the state of Pennsylvania, will be addressed. If a child, under the age of 1, is suspected of having FASD mandated reporters are required to alert the appropriate county agency (PA Code, Title 23, Section 6303a), at which time the county will complete a risk assessment. Given the many complexities of FASD, including the intergenerational aspect, further procedural understanding of this possibly traumatic or stigmatizing process is needed. Valid and reliable FASD screening tools are needed to identify children and adolescents in need of a clinical FASD assessment (LaFrance, et al., 2013).

Parent literature reports that an accurate and appropriate diagnosis was the first step in creating effective supports and accessing appropriate services for those living with FASD (Devries & Waller, 2004). The recently published SAMSHA “TIP 58” manual states that knowledge of FASD could prove important when providing effective supports.

For every client that did not return for appointments, seemed non-compliant or resistant with no clear explanation of why, or just didn’t seem to ‘get it,’ a knowledge of FASD could be an extra clue that helps solve that puzzle and enable success for both the client and program (SAMSHA, 2014, p. 18).

The most significant implication of this study is that late identification still can be incredibly powerful and provide insight and hope for those living with the effects of FASD. Study participants reflected that until their FASD was named, they struggled to understand why they experienced many challenges, often leading to feelings of difference. Additionally, prior to identification several participants accessed mental health supports, though their FASD was not recognized until adulthood. Grant, et al. (2013) discuss an option for screening adults, who are currently in drug and alcohol treatment, for FASD. The Washington State FASD Interagency Work Group has developed the *FASD Behavioral Traits Screening Tool*. Service providers who have long- term contact with an individual could use this tool to identify and screen teens and adults who may need further evaluation.

The specific level of knowledge and education that support professionals have of FASD is unknown. Generally, social work education regarding issues of disability is limited, which has implications for the quality of services being provided to persons with disabilities and their families (Lawes et al., 2010). Additionally, family members of those with FASD feel there is a lack of support people who are available and have adequate knowledge and training about

FASD, especially as it relates to availability during crisis situations (Devries & Waller, 2004). A primary barrier to correct identification of an FASD is inconsistent knowledge (Gahagan, et al., 2006). Astute and well-trained support professionals are crucial since they often serve populations where FASD is more prevalent.

This knowledge gap can begin to be addressed through social work education and practitioner continuing education. FASD spans the scope of social work practice and should be incorporated into both Bachelor and Master's level Human Behavior in the Social Environment syllabi. A starting point would be inclusion of the two-hour curriculum infusion package available for both Bachelor and Master's level social work students through the regional FASD training centers ([http://www.frfasd.org/education/soc\\_cip.html](http://www.frfasd.org/education/soc_cip.html)). A focus should be placed on educating front-line social workers about how to identify a person with FASD. Additionally, they need to be aware of how to access appropriate local services and supports. Government and community based agencies should work collaboratively to implement strategies recommended by SAMHSA (SAMHSA, TIP 58, 2014). A mandated two-hour intellectual/developmental disability CEU requirement would benefit such efforts.

Community agencies should also become FASD informed. Being FASD informed includes staff training, implementation of a brief identification assessment and identification of an FASD mentor. Additional strategies are outlined in the recently published SAMSHA "TIP 58" manual (SAMHSA, TIP 58, 214). Universities can also contribute to the prevention, identification and support effort through developing a professional post-graduate certificate in FASD studies. This certificate would be similar to specialized certifications in autism spectrum disorders administered and accredited by The Pennsylvania State University, West Chester University, Temple University and George Washington University. This type of certificate

would certify those with an enhanced specialized knowledge of FASD and increase the knowledge base of community providers. The University of Wisconsin-Madison has a FASD certificate program that other universities should explore and use as a model.

**Developing appropriate supports.** Social workers and other support workers must be able to adapt their perspective when working clinically with people affected by FASD. Implementing appropriate adaptations and modifications across environments may be necessary. Individuals with FASD and all their supporters (ie. social workers, family members, friends) can be instrumental in implementing structural adaptations. A neurobehavioral perspective should inform modifications and adaptations to social work practice, vocational supports and other social situations. See the work of Diane Malbin for a complete review of appropriate modifications and adaptations.

All too often, clinical practice is focused on a treatment perspective to restore full functioning capacity or overcome limitations (Roulstone, 2012) and moving towards recovery and full independence. While mental health issues can be addressed through medications, treatment and adapted supports, for a person with FASD neurological-associated challenges could be lifelong. For example, persons with FASD commonly have difficulty generalizing information across settings. A neuro-typical person may be able to apply learned knowledge from clinical sessions into a variety of new situations, whereas those with FASD many not be able to do so effectively. For the latter group, there is a never-ending cycle of changes and challenges experienced across their lifetime, and support workers benefit from specialized tools and alternative treatment options that respond to the challenges of various developmental stages.

The participants in this study re-authored many parts of their stories and found greater understanding of themselves and their experiences. Such re-authoring has a narrative overtone.



Narrative techniques seek to externalize rather than internalize stories (Carlson, 1997). This process of externalization empowers people to see that “they are not the problem but the problem is the problem” (White & Epston, 1990, p. 39). People then are able to re-author their stories and develop a new understanding of their experiences, increasing their strength and self-worth (Semmler & Williams, 2000).

While persons with FASD may not respond as well to talk-based therapies, narrative techniques can be adapted to appropriately harness the strengths of a person with FASD. Adaptations of traditional talk based narrative therapies can include performance art (El-Nasr, 2007), art (Carlson, 1997), songs, poems and journal writing to facilitate the re-authoring process (Carlson, 1997). Such therapies also are seen as culturally competent techniques (Semmler & Williams, 2000).

Participants in this study state that they have found greater life success due to family, friends and professional supports. Family members and teachers report that many people with FASD benefit from personal advocates (Duquette, et al., 2006). Further exploration into the role personal advocates play in an adult’s life is needed. This could assist in determining ways to educate and support those who are providing informal supports to individuals with FASD.

It is known that underlying neurological differences due to gestational alcohol exposure can impact a person’s social, emotional and behavioral functioning. There is a growing body of research that explores these structural changes and possible dysfunction of the HPA axis. HPA dysfunction can cause a body chemically to over or-under-react to stressful situations.

Understanding this stress response highlights the need for persons with FASD to be supported to learn and employ self-regulating strategies to avoid impulsive or destructive behaviors. Breslin, Zack & McMMain (2002) suggest that mindfulness techniques may decrease

the urgency in an emotion or impulse. Similar relaxation techniques may also be a way to diminish stress and decrease the urge to act on emotions (Chan, Ng, Ho & Chow, 2006). Mindfulness strategies have been found effective in decreasing impulsive behaviors (Stratton, 2009) and are thought to be a beneficial intervention for those with ADHD (Krisanaprakornkit, Ngamjarus, Witoonchart & Piyavhatkul, 2010). Several participants in this study and in other informal accounts mention the positive benefits of prayer, spirituality and meditation in their lives. Adapting and teaching mindfulness strategies could be a great benefit when supporting persons with FASD.

Shame was noted by participants as a possible barrier for people with FASD seeking supports and identification. Social stigma is noted as a barrier for accurate diagnosis of children with FASD (Lupton, Burd & Harwood, 2004) and biologically related family members may feel stigmatized when seeking evaluation and supports for FASD related challenges (Bertrand, Floyd & Weber, 2005). Breene, Cook, Racine and Bell (undated) state that feeling judged by others and the stigma of FASD leads to discrimination. This judgment prevents individuals with FASD and their families from seeking services and interventions and supports, which could increase quality of life (Stewart & Glowatski, 2014).

It is here where social workers and other support professionals have a two-fold duty: the first being working with a person and his or her family to understand the individual social implications; and the second is to address the societal implications related to FASD. Professionals who work with persons who have experienced shame or stigma due to mental health issues recommend addressing the nature of adverse experiences, issues of discrimination and their impact on self image and the implications of social networks when developing

treatment goals (Byrne, 2000). Adopting a model of empowerment as described by Shih (2004) can prove helpful when addressing shame on an individual or family level.

Social workers and other professional support persons have a duty to address FASD at a societal level. The NASW *Code of Ethics* advises social workers

To participate in activities leading toward improved social conditions. They should advocate and work for conditions and resources that give all persons equal access to the services and opportunities required to meet basic needs and to develop to the fullest potential (2008, Section 6.01, p. 8).

There is currently an increasing mainstream presence of vocal grassroots advocacy groups that address multiple aspects of FASD. Groups like the National Organization on Fetal Alcohol Syndrome (NOFAS) are often helmed by family members and those living with the first-hand effects of FASD. Social workers should take a greater role in advocacy, education and promoting contact between the general population and those with FASD. These are all common strategies previously used to promote community knowledge of mental health issues (Corrigan & Penn, 1999). As with any advocacy or education work, the impact of other stereotypes related to minority status should be considered (Corrigan & Penn, 1999).

### **Implications for Social Work Research**

This research supports the recommendations for future research found in works related to FASD, including but not limited to a generally accepted method to identify and diagnosis adults with FASD; a need for evidence-based support techniques; and a way to identify persons with FASD without confirmation of maternal drinking (Assessment and Diagnosis of FASD Among Adults: A National and International Systematic Review, 2011). This study's findings suggest several research priorities, including the need for:

- Continued exploration of the process of FASD identification, diagnosis and post-diagnosis as a ‘turning point.’
- Investigation and development of guiding principles about how to introduce or shepherd adults and their families through the process of FASD identification, diagnosis and ongoing support.
- Further exploration of narrative therapies and meditation as interventions.
- Identification of social workers’ knowledge deficits and exploration of the best ways to provide them with essential information.
- Studies of the many complexities of the adult experience, including the impact of FASD on adult attachment issues.
- Planning for the process of aging and the elderly with FASD.

Further research into the psychological impact of learning of an FASD in adulthood is needed. Mixed method studies designed to quantify the experience of learning about FASD as an adult could lend support to the movement for widespread adult diagnostic criteria and diagnostic/support services. Support professionals, families and those living with FASD should be solicited for studies emphasizing focus on insight to develop guiding principles and best practices on this process. These strategies should be developed into a handbook or manual. The potential use of narrative techniques, faith based supports and meditation practices warrant further research. A research study targeting an FASD manualized intervention based in one of these techniques would begin to provide an evidence base for practice. Additionally, development of specialized aging and geriatric support guidelines is needed. This includes investigation into if persons with FASD could be more susceptible to dementia/or increased age

related cognitive decline. A mixed method study targeting the knowledge level and effective ways to provide social workers/support persons with additional FASD training is critical.

### **Conclusion**

This study explored the narrative identity of adults with FASD who lived with the unidentified characteristics of FASD until adulthood. Common behavioral traits, life experiences and helpful support strategies were identified. The research identified specific themes of identity and several social and cultural factors that influenced identity. Participants commonly experienced early confusion regarding their challenges. This confusion led them to feel different. After learning of their FASD, participants felt they had a greater understanding of themselves and their experiences. They and their supporters also used this information across pragmatic, inter-psyche and political/ideological dimensions. Most participants harnessed this new information to help current and future generations through FASD education and advocacy.

This study added to the research by identifying how living with an unidentified neurological difference can contribute to a person's understanding of themselves. Additionally, it added understanding of how a turning point can be a catalyst for re-authoring experiences and giving back to current and future generations. Findings about how new information was harnessed and used by each person across many life dimensions suggest implications for education and training of support professionals and systems.

For future research, further information is needed regarding appropriate therapeutic methods to introduce and support adults through the FASD identification and post-identification process. Additional understanding of the role and influence of supporter providers during this process is required. Systems need to be educated to understand individuals from a neurobehavioral/neurodevelopmental approach. Finally, future investigation of the impact of

FASD on adult attachment and aging will inform best practices for support of this vulnerable population's strengths and resilience.

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## Appendix A

### Flyer

As you may know, there is not a lot of information about adults who are currently living with a Fetal Alcohol Spectrum Disorder and Prenatal Alcohol Exposure.

I am collecting the life stories of adults with FASD and PAE and am asking adults who are living with FASD and PAE to participate in an interview.

1. Are you at least 22 years old?
2. Does someone help support you like a case manager, counselor, or family member?
3. Were you an adult when you realized you had a Fetal Alcohol Spectrum Disorder and Prenatal Alcohol Exposure?
4. Was it at least 1 year ago you learned about your FASD or PAE?

If the answer to these questions is “yes,” then you may be eligible to be in this study. There are several things that may make you not able to participate such as: being on probation or having other specific mental health or intellectual disability diagnosis. I would be happy to talk with you about the interview to see if you are able to participate.

Here’s what would be involved if you participate.

1. We will talk 1 or 2 times on the phone or through email. This is so we can get to know each other. We would also talk about how we look and act when we are stressed out and ways that we deal with being stressed.
2. We would meet in person. You would be asked 10 questions about your life. These questions can be emailed or mailed to you before the interview. We can meet 1,2, or 3 times to talk about these questions
3. Several months after the interview, when I have had time to review all the information. I will send you a note about my thoughts about the interview. I would ask you to look at those thoughts and let me know what you think.

People who participate in the interviews will be paid for their time.

Please contact me if you are interested in participating and we can talk more!

Anna C. Kann Erb

[akann@sp2.upenn.edu](mailto:akann@sp2.upenn.edu)

## Appendix B

### Introduction Script

Project: A Narrative Exploration into the Identity of Adults With Prenatal Alcohol Exposure

Investigator: Anna C. K. Erb, University of Pennsylvania

Principal Investigator: Jeffrey S. Applegate, Ph.D.

Contact Information: E-mail: [akann@sp2.upenn.edu](mailto:akann@sp2.upenn.edu)

What will I be asked to do?

My name is Anna Erb, and I am contacting you to see if you would be interested in participating in an interview for the purpose of dissertation research. You were chosen to participate because you are a person who has been affected by prenatal alcohol exposure and/or fetal alcohol spectrum disorder. My research will explore your life experiences with PAE and/or FASD, in particular its effect on you during adulthood. By participating in this interview, you can provide me with valuable information that details your life experiences.

These questions may seem somewhat personal. There may be moments when you feel upset because our discussion may remind you of difficult times. You do not need to answer any questions that you feel uncomfortable discussing. You have the right to say that you do not want to answer the question or ask to move on to the next question. You never have to answer a question that you do not want to or answer a question that makes you feel too uncomfortable.

The interview will take between 1-2 hours. We will schedule it at a time and place that is convenient and comfortable for you and me Anna Erb. We can take frequent breaks during the interview, and you can request a break at any time. We can meet a few times to answer the questions. I will record your conversation and your answers will be typed. Then I will combine your answers with the answers of other people. Upon completion of the research, the results will be published for the public to read. I will give you with a copy of your answers so that you can review the interview results, provide approval or make recommendations for change.

You will be paid \$50.00 for the interview and \$ 50.00 to review and return the interview results with your comments.

If you decide to participate, I encourage you to bring a friend or family member to the interview. I will provide you with an interview questions ahead of time so that you can look them over.

You can bring artwork, photos, pictures or poems that will assist in telling your life story. Markers and paper will be available at the interview if you would like to use them.

If you would like to speak on the phone one or two times before the interview so that we can get to know each other then that can be arranged. These conversations are not part of the interview and will not be recorded or used for the research.

If you decide to participate but then change your mind, you can withdraw from this study at any time without any problem to you or without affecting the results of this study.

If you agree to participate, we will go over this information again with an official consent form. I can send you the official consent form for you to review before the interview.

Before we move on do you have any questions?

Do you think you would like to participate? If so, before we go any further I just want to ask you a couple questions about what we just talked to make sure that you have all the information you need.

#### General

- a. Why do you think you are affected by (have) FASD?
- b. About when/how old were you when you learned about this? Were you an adult or a kid?

#### Understanding

- a. What am I asking you to do?
- b. What will we be talking about?
- c. What can you do if you decide that you do not want to talk to me anymore?
- d. After I do the write up, what will I ask you to do?

#### Appreciation

- a. Are there good/bad things about talking to me?

#### Communicating Choice

- a. Do you want to participate?

## Appendix C

### Introduction Form Letter

Dear (Insert Correct Title for Distribution),

As you may know, there is not a lot of information about the lived experiences of adults who are currently living with a Fetal Alcohol Spectrum Disorder and Prenatal Alcohol Exposure.

For my doctoral dissertation, I would like to explore the lived experiences of this group of people through collecting and reviewing their told life stories.

I am currently recruiting adults who are living with Fetal Alcohol Spectrum Disorder and Prenatal Alcohol Exposure to participate in an interview. I am looking for places to post information for recruitment purposes.

Below are details about the study and inclusion criteria. If your agency would be willing to post information for recruitment purposes, to participate or if you have any questions you can reach me at [akann@sp2.upenn.edu](mailto:akann@sp2.upenn.edu). You may also reach the study's principal investigator at:

Thank you! Feel free to pass this along to any and all appropriate parties.

Sincerely, Anna C. Kann Erb

Details about the study:

This is what would be required of the person with FASD

1. We would talk 1 or 2 times by phone or through email. Or We would meet in person.
2. The person with FASD would be asked 10 open ended questions about their life. These questions can be emailed or mailed to them before the interview. We can meet 1,2, or 3 times to talk about these questions
3. Several months after the interview, when I have had time to review all the information. I send a note about my thoughts about the interview. I would ask that the person with FASD would review those thoughts and provide feedback.
4. Each participant would be compensated \$50 for the interview and \$50 for reviewing the thoughts.

Inclusion and Exclusion criteria: There are a few criteria to participate in the study.

1. Are you at least 22 years old?
2. Does someone help to support you like a case manager, counselor, or family member?
3. Were you an adult when you realized you had a Fetal Alcohol Spectrum Disorder and/or Prenatal Alcohol Exposure

4. Was it at least 1 year ago you learned about your FASD or PAE? Additionally, there are a few exclusion criteria.

If the answer to these questions is “yes,” then you may be eligible to be in this study. There are several things that may make you not able to participate such as: being on probation or having other specific mental health or intellectual disability diagnosis. I would be happy to talk with you about the interview to see if you are able to participate.

Please contact me if you are interested in participating and we can talk more!

## Appendix D

### Adult Consent Form

#### Consent Form for Adult Participants

**Project:** A Narrative Exploration into the Identity of Adults with Prenatal Alcohol Exposure

**Investigator:** Anna C. K. Erb, University of Pennsylvania

**Principal Investigator:** Jeffrey S. Applegate, Ph.D.

**Contact Information:** E-mail: akann@sp2.upenn.edu

**Penn IRB Contact Information:** Should you want to contact someone other than the researchers about the project, please contact the Penn IRB at 215-573-2540.

This consent form, a copy of which has been given to you, is only part of the process of informed consent. If you want more details about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this and any accompanying information carefully. The investigator, Anna Erb will also review the information included in this document with you.

This proposal will be submitted to The University of Pennsylvania's Institutional Review Board to assure the protection of human subjects.

#### What is the purpose of the study?

The purpose of this study is to understand who you are as an adult with Prenatal Alcohol Exposure (PAE) or Fetal Alcohol Spectrum Disorder (FASD) and what factors may have influenced that answer. This study may help social workers, parents, teachers, and counselors to develop better skills to support other people with PAE or FASD.

#### What will I be asked to do?

If you decide to participate in this study, you will be asked to participate in an interview. I will be conducting the interview. I will ask for personal information such as your name, birth date, where you grew up and about your life experiences. After the interview I will provide you with a copy of your responses so that you can review the interview results, provide approval or make recommendations for change. You will be compensated \$50.00 for each interview and \$ 50.00 to review and return the interview results with your comments.

#### What will the interview be like?

I will ask you to tell me about your life, I will ask questions about who you are and how you describe your life. I will record your conversation with a digital recorder and then transfer that recording to my computer. You may stop the interview at any time if you feel uncomfortable. If I assess that you are upset or stressed out, I will stop the interview without prior consent. You may refuse any question I ask you or chose to only answer part of a question.

Please put your initials on the line.

I give permission to be audio taped: Yes: \_\_\_ No: \_\_\_

### **Can I bring a support person or friend with me?**

I encourage you to bring a family member or friend with you for support if you decide to participate in the interview. I encourage you to have a support person review this consent form with you. I encourage you to bring artwork, photos, pictures or poems if that will help to tell your life story. Markers and paper will be at the interview, if you would like to use them.

### **How long will I be in the study?**

Before the interview we would talk for about an 1 on the phone, in person or by skype. We would develop a self care plan and talk about where we would plan on meeting for the interview.

The interview will take between 1-2 hours. We will take frequent breaks during the interview, and you can request a break at any time. We can make arrangements to meet a few times to answer the questions. I may get in touch with you again, after the interview, to ask you some more questions or to check with you about your responses. This may take place on the phone, using skype, or may be in-person. The second interview likely may take up to one hour.

After the interview I would follow up with you about 4-5 times to make sure that you are okay. These follow ups would take about 5 minutes.

Once I finish writing everything up, I would ask you to read the report and tell me if it is okay. This would take about 1 hour of your time.

The overall length of the study may take 3 months from the pre interview until I send you the final write up for approval.

What is the best way to contact you (phone, email, address)?

### **Where will the study take place?**

A location that is mutually agreed upon by Anna, the interviewer, and the interviewee. The location will be easily accessible, safe, and free from distractions.

### **Are there risks or benefits if I participate?**

There may be some risks to you if you decide to participate. The interview questions are personal. I will ask you to remember and tell me about life experiences. Some of the questions may cause you to feel upset. I will check in with you to see if you would prefer to not answer that question or to see if you would like to stop.

The research interview will not be a counseling session but if you continue to feel upset after the first interview, I will speak with you at another time for a counseling appointment, if you would like. I will help you to figure out what help you need and I will give you some ideas for things you can do so that you start to feel better. I will refer you to a community organization for more support. There will be no charge for this follow up and all records of these appointments will be kept confidential.



If you tell me any information that makes me worried about the safety of yourself or anyone else, I am legally required to report that information to the authorities. This includes if you tell me that you plan to hurt yourself or someone else, then I need to inform the police. If you give me information that makes me believe you have harmed a child, I need to inform Child Welfare.

### **What happens if I do not choose to join the research study?**

Your participation in this study is voluntary, meaning it is completely your choice to participate or not. You can say no to this right now or you can change your mind at any point during the study. If you say no, or decide to leave the study, nothing will happen as a result. This will not affect any services you are receiving from any community organization or agency you are involved with now or want to be involved with in the future.

### **What happens if I decide to quit the study?**

You may decide to quit the study at any time. If you decide to quit the study this will not affect any services you are receiving from any community organization or agency you are involved with now or want to be involved with in the future. If you decide to quit I will ask you if it is still okay for me to use the information you provided. If you do not want me to use your information, I will destroy the information. If you want me to use your information, I will ask you for your signature saying that it is okay for me to use the information. If you quit the study I will follow up with you in a few days by phone, email, or text to make sure you are okay.

### **How will my privacy be protected and confidentiality ensured?**

The information you provide may be kept for quite a long time, until all the information that is gathered can be written up. When the final report or book is published, the information will be destroyed. I will keep your responses anonymous (no names) and confidential (private) unless you have given permission to use some of your quotes.

Please put a check mark on the line(s). You may quote me using a pseudonym (fake name): Yes: \_\_\_\_\_ No: \_\_\_\_\_

You may use a picture I drew. Yes: \_\_\_\_\_ No: \_\_\_\_\_

You may use part of a poem I wrote: Yes \_\_\_\_\_ No: \_\_\_\_\_

### **Affirmation of Participation Criteria:**

1. Are you at least 22 years old? Yes \_\_\_\_\_ No \_\_\_\_\_ 2.
2. Do you have some type of support system such as a case manager, counselor or therapist, an active family life, etc.? Yes \_\_\_\_\_ No \_\_\_\_\_
3. Do you have Mental Retardation (MR) or an Intellectual Disability (ID)? Yes \_\_\_\_\_ No \_\_\_\_\_
4. Do you have a diagnosis of schizophrenia or personality disorder? Yes \_\_\_\_\_ No \_\_\_\_\_
5. Are you currently on probation or parole? Yes \_\_\_\_\_ No \_\_\_\_\_
6. Do you have a Fetal Alcohol Spectrum Disorder or Prenatal Alcohol Exposure . Yes \_\_\_\_\_ No \_\_\_\_\_

7. Were you an adult when you learned about your FASD or PAE? Yes \_\_\_\_\_ No \_\_\_\_\_
8. Has it been at least 1 year since you learned about your FASD or PAE? Yes \_\_\_\_\_ No \_\_\_\_\_

### **What happens to the information I provide?**

I will analyze your responses and then combine your responses with the responses of other people in this study. The research results will be written into a report and I will send the report for publication. Eventually, this dissertation may become a book or article that will be written to help people who are dealing with the same things you are.

Most of the information will be combined with information from other participants, and I will describe the common themes or concepts that you and other participants discussed. The dissertation might include a brief paragraph or story about something you have reported. I also may want to quote things you say to me. There is a small possibility that someone may recognize your personal comments, so I will ask you to look them over before I write them into the research report.

If you are uncomfortable about anything in these write ups, you can ask me to remove the information or you can tell me you do not want to be quoted at all in the report. You can choose whether or not I use the personal things you have told me in the dissertation.

If you agree, I may hire a helper to assist me and make sure the themes I discovered make sense to another person.

Please put a check mark on the line(s).

I give permission to have my interview reviewed by a hired professional to make sure that the themes Anna Erb discovered make sense to another person: yes \_\_\_\_\_ no \_\_\_\_\_

Signatures (written consent)

Your signature on this form indicates that you 1) understand to your satisfaction the information provided to you about your participation in this research project 2) agree to participate as a research subject and 3) you meet the criteria needed to participate in the study.

In no way does this waive your legal rights nor release the investigators, sponsors or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time. You should feel free to ask for clarification or new information throughout your participation.

Participant's Name (please print) \_\_\_\_\_  
Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Investigator's Name: (please print) \_\_\_\_\_  
Investigator's Signature \_\_\_\_\_ Date: \_\_\_\_\_

Support Person Name (at request of Participant) \_\_\_\_\_ Support  
Person Signature (at request of Participant) \_\_\_\_\_ Date: \_\_\_\_\_

#### Questions/Concerns

If you have any further questions or want clarification regarding this research and/or your participation, please contact: [akann@sp2.upenn.edu](mailto:akann@sp2.upenn.edu) A copy of this consent form has been given to you to keep for your records and reference. Anna has kept a copy of the consent form.

## Appendix E

### Interview Guideline

The Life Story Interview Adapted and Used with Permission The Life Story Interview Dan P. McAdams (2008)

If multiple interviews would be conducted, the reflection piece of the interview will be reviewed at the end of each interview and an assessment of stress/upset would be taken. If needed strategies would be employed.

Hi. I'm Anna we spoke on the phone/email/skype/etc. I am glad to meet you. (Allow for chit chat and getting to know you). Please feel free to help yourself to a snack or drink as we talk. We can take our time and take breaks during the interview. We do not need to rush.

The first thing we need to do is to review the consent and background information. (Review consent for questions/concerns and signatures). I had sent this to you earlier and we are going to review, do you have any questions, ask questions to assess understanding of consent...

*It is preferred that the below would already be introduced to the participant and the following would just be a review.*

I. This is an interview about the story of your life. I am interested in hearing your story, including parts of the past as you remember them and the future as you imagine it. The interview will not ask you about everything that has ever happened to you. Instead, we will focus on a few key things about your life. There are no right or wrong answers to my questions. Instead, simply tell me about some of the most important things that have happened in your life and how you imagine your life developing in the future. We will take frequent breaks during the interview and you can request a break at any time.

II. Please know that the purpose of this interview is not a “therapy session” of some kind. The interview is for research purposes only, and its main goal is simply to hear your story. I am collecting people’s life stories to understand the experience of persons with PAE/FASD. Please know that you can choose not to answer a question, that I will keep your answers private, and when I talk about your answers I will use the fake name that we talked about before. If you have brought any pictures, photos, or writings please feel free to share them at any time. I also have paper, markers, pens, and pencils. If you would like to draw, doodle or write something please feel free to do so. I think you will enjoy the interview. Do you have any questions?

#### Life Story

1. I am going to ask you to tell me a story about three parts of your life; as a kid, teenager, and as an adult. It may help to use the pictures that you brought with you.
  - a. Tell me about being a kid. (Interviewer Listen) Do you have a word or picture that describes being a kid? (Interviewer Listen)
  - b. Tell me about being a teenager (Interviewer Listen) Do you have a word or picture that describes being a teenager? (Interviewer Listen)
  - c. Tell me about being an adult. (Interviewer Listen) Do you have a word or picture that describes being an adult? (Interviewer Listen)

2. Tell me about the best time in your life. What made it so good? • When and where, who was involved, and what were you thinking and feeling? (Listen)
3. Tell me about a time in your life that may stand out as the hardest or most difficult. Even though this event is unpleasant, I would appreciate your providing as much detail as
4. What do you think is going come next for you? (Listen) Is there something you want to accomplish in the future? (Listen)
5. What would your advice be for people who may have had similar experiences as you? (Listen)
6. Is there a special person or several people who have really helped you in your life? (Listen)
7. Has learning about PAE/FASD changed how you understand yourself/see yourself? (Listen)
8. What do you think your special gifts and strengths are? (Listen)
9. What are your biggest challenges? (Listen)
10. Is there anything we have not talked about that you think would be important for me to understand you? (Listen)

### Reflection

Thank you for participating in this interview. Many of the stories you have shared with me are about experiences that stand out from the day-to-day. I am wondering if you might reflect for one last moment about what this interview, here today, has been like for you. What were your thoughts and feelings during the interview?