

QUALITY OF LIFE FOR ALASKAN INDIVIDUALS WITH
FASD AND THEIR FAMILIES

By

Brenda S. Dow, MA

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APPROVED:

Dr. Mary Ehrlander, Committee Chair
Dr. Brandon Boylan, Committee Member
Dr. Sine Anahita, Committee Member
Dr. Inna Rivkin, Committee Member
Dr. Mary Ehrlander
Co-Director, Arctic & Northern Studies
Dr. Brandon Boylan
Co-Director, Arctic & Northern Studies
Dr. Todd L. Sherman,
Dean, College of Liberal Arts
Dr. Michael Castellini, *Dean of Graduate School*

Abstract

Fetal alcohol spectrum disorder (FASD) is a lifelong disability caused by prenatal exposure to alcohol. The effects of FASD include a range of physical, mental, behavioral, and learning disabilities. These disabilities impact quality of life, not only for the affected individual, but for family members. The effects from FASD ripple into schools, the correctional system, and throughout rural and urban communities. Although there are no reliable statistics available on FASD in Alaska, many professionals in the field believe Alaska to have the highest rate of FASD in the United States. This research has explored the ways in which prenatal exposure to alcohol affects quality of life for Alaskan individuals and their families. For this study, I have defined quality of life as the multi-faceted evaluation of the individual's personal experiences and life satisfaction, including health, psychological and social indicators. Since the identification of fetal alcohol syndrome (FAS) and FASD, many studies have analyzed the effects of prenatal alcohol exposure, as well as possible interventions. Few studies have investigated how prenatal alcohol exposure affects the individual's quality of life and even fewer studies have analyzed how raising one or more children with FASD affects the family. To address the gap in the literature, this research applied social constructivist theory and employed a qualitative design, using semi-structured interviews to explore individuals' and parents' life stories and perceptions on how FASD has affected their lives. I interviewed eight individuals with FASD and 14 adoptive or long-term foster parents. Findings indicate that FASD impacts almost every facet of the lives of both the individuals affected and their families. All individuals with FASD interviewed for this project suffered serious adverse childhood experiences in addition to their prenatal exposure to alcohol. All encountered academic and social difficulties at

school. Individuals struggled in their transitions to adulthood, with some individuals needing assistance from parents or social services throughout their lifespan. Parents expressed their ongoing need for structure within the home and the continual need to advocate for suitable services for their children. They described how the ongoing stress of raising their child(ren) with FASD affected their social lives, employment and even their marriages. The perspectives and insight of these individuals with FASD and their parents can provide other family members, service providers and legislators a better understanding of how FASD affects quality of life and assist decision makers in making informed choices on how to best provide expanded or improved supportive services to these individuals and families whose everyday struggles go largely unrecognized by the general public.

Table of Contents

	Page
Title Page	i
Abstract	ii
Table of Contents	iv
List of Figures/Tables	viii
List of Appendices	ix
Definitions of Key Terminology	x
Acknowledgments	xii
CHAPTER I: INTRODUCTION	1
Brief Overview of Study	1
Background and Context	1
Problem Statement	4
Statement of Purpose and Research Questions	4
Research Approach	5
Findings	5
Background of the Researcher	6
Rationale and Significance	7
CHAPTER II: LITERATURE REVIEW	11
Fetal Alcohol Spectrum Disorder	13
Early History of FASD	13
Economic Costs	17
Diagnoses and Difficulties in Developing a Profile for FASD	19

Effects of FASD.....	22
Executive Brain Functioning.....	22
Social Skills and Secondary Disabilities.....	26
Families.....	28
Education.....	33
Criminal Justice System.....	40
Victimization.....	43
Interventions.....	46
FASD in Alaska.....	51
Quality of Life.....	55
Definitions and History.....	55
Measurement of QOL.....	57
QOL for Individuals with FASD.....	62
Conclusion.....	69
CHAPTER III: RESEARCH METHODS AND DESIGN	73
Rationale for Qualitative Research Design.....	73
Methods of Data Collection and Analysis.....	74
Participant Recruitment.....	74
Participants.....	77
Data Collection Instrument.....	80
Method.....	82
Data Analysis.....	84

Ethical Considerations	87
Human subject protection	87
Issues of Trustworthiness.....	89
Credibility	89
Dependability.....	91
Confirmability.....	92
Transferability.....	93
Limitations	94
Conclusion	95
CHAPTER IV: FINDINGS: HOW FASD AFFECTS QUALITY OF LIFE.....	97
Impact of FASD on Quality of Life for Affected Individuals	98
Adverse Childhood Experiences (ACEs).....	98
Health Problems.....	101
Difficulties in School.....	102
Difficulties in the Home.....	109
Mental Health Problems Requiring Treatment.....	113
Difficulties Transitioning to Adulthood.....	114
How Raising Individuals with FASD affects Quality of Life for the Family.....	121
Need for Structure and Routine	122
Continual Stress, Vigilance, and Uncertainty about the Future.....	123
Effects on Siblings.....	125
Impacts on Parents' Relationships and Employment.....	126
Most Helpful Services for the Affected Individual or the Family	130

Forms of Support that would be Helpful	136
Conclusion	140
CHAPTER V: DISCUSSION OF FINDINGS.....	143
How FASD Affects Quality of Life for Affected Individuals	146
How Raising Individuals with FASD Affects Quality of Life for the Family.....	156
Helpful Forms of Support.....	162
Needed Forms of Support.....	166
Conclusion	168
CHAPTER VI: CONCLUSION AND RECOMMENDATIONS.....	171
References	179
Appendices.....	195

List of Figures

	Page
Figure 1. Ethnicity and Diagnoses of Research Cases.....	80

List of Tables

	Page
Table 1. Factors for Quality of Life	64
Table 2. Demographics for Research Participants	79

List of Appendices

	Page
Appendix A.....	195
Appendix B.....	197
Appendix C.....	199
Appendix D.....	200

Definitions of Key Terminology

Alcohol related Neurodevelopmental Disorders (ARND) – a diagnostic term being phased out. The term previously classified individuals who had confirmed prenatal alcohol exposure and central nervous system damage (Astley, S. J., 2004)

Fetal Alcohol Effects (FAE) – term used to describe individuals who had some of the abnormalities seen in FASD but did not meet the full criteria for FAS. This term is seldom used today (Astley, S. J., 2004).

Fetal Alcohol Spectrum Disorder (FASD) – umbrella term for the range of effects that can occur in an individual who is prenatally exposed to alcohol (Astley, S. J., 2004).

Fetal Alcohol Syndrome (FAS) – birth defect caused by maternal alcohol consumption during pregnancy and characterized by growth deficiency, minor facial anomalies, and severe central nervous system (CNS) abnormalities (Astley, S. J., 2004).

Neurobehavioral Disorder/Alcohol Exposed (ND/AE) – confirmed prenatal alcohol exposure with moderate central nervous system (CNS) dysfunction (Astley, S. J., 2004).

Neurobehavioral Disorder-Prenatal Alcohol Exposed (ND-PAE) – new diagnosis under the DSM-5 essentially replacing the term ARND; requires confirmed alcohol exposure (Astley, S. J., 2004).

Partial FAS (pFAS) – a diagnostic classification for individuals with most, but not all, of the growth deficiency and/or facial features of FAS, severe CNS abnormalities, and confirmed prenatal exposure (Astley, S. J., 2004).

Quality of Life – An individual's perceptions of their position in life in the context of their culture and value systems. This includes physical health, family, education, employment and other life aspects of life that are important to the individual (CDC, 2011).

Secondary behavioral characteristics – behaviors that develop over time when there is a poor fit between the individual and his/her environment (Malbin, 2002).

Static encephalopathy/Alcohol Exposed (SE/AE) – a diagnostic classification for individuals with severe CNS abnormalities and confirmed prenatal alcohol exposure (Astley, S. J., 2004).

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My family, friends, and colleagues were all helpful through this journey. I thank my parents, Holland and the late Mary Butler, for giving me an ongoing love for learning and exploring. I thank my friends and colleagues, who continued to encourage me through the many emotional ups and downs of this somewhat lengthy adventure. I especially thank my husband Rolin Dow for being patient and supportive throughout.

Finally, this research is dedicated to the research participants; to the individuals with FASD who were willing to share their life stories with me, and to the adoptive parents and long-term foster parents who work so tirelessly to improve quality of lives for these individuals. My goal is to provide additional understanding on how FASD affects individuals and families so that the supports and services they receive are effective in improving their quality of life.

CHAPTER I: INTRODUCTION

Brief Overview of the Study

Fetal alcohol spectrum disorder (FASD) is a lifelong disability caused by prenatal exposure to alcohol. According to researchers in the field, “fetal alcohol spectrum disorders is a leading cause of intellectual disability in the western world” (Ase et al., 2012, p. 221). Possible effects of FASD include a range of physical, mental, behavioral, and learning disabilities. FASD occurs in all cultures in which individuals drink alcohol. In Alaska, where the 2015 alcohol-abuse related health care costs were \$189.7 million (McDowell Group, 2017, p. 65), fetal alcohol spectrum disorder affects a large enough percentage of the population to be considered a serious problem. This dissertation explores the experiences and perceptions of individuals with FASD and family members to learn how FASD has impacted their quality of life. The information from this research can inform professionals, including educators, service coordinators and decision-makers, on how FASD affects quality of life and assist them in better meeting the needs of these individuals and families. This exploratory study used qualitative in-depth interviews to examine this phenomenon. All participants of the study were a purposely selected group of either Alaskan young adults with FASD or the parents of individuals with FASD. For this study, the term “parents” refers to biological, adoptive, or long-term foster parents.

Background and Context

American researchers Kenneth L. Jones and David W. Smith first reported on the serious life-long consequences of prenatal exposure to alcohol in *The Lancet* in 1973 (Jones & Streissguth, 2010). Eleven unrelated children, who were born to women who drank heavily

throughout their pregnancies, showed similar problems in growth and deficiencies. Follow-up research showed affected individuals had intellectual, educational, and adaptive living skills deficits (Streissguth et al, 2004). Since that time, researchers have learned much more about the effects of alcohol on the developing fetus. Studies show the effects vary greatly according to the amount of alcohol the pregnant woman drinks, the age of the fetus when she drinks, the mother's general health, genetics, and other factors (Malbin, 2002). Other research has shown a range of physical disabilities such as heart defects, deafness, and cleft palate, along with sensory problems and cognitive challenges such as poor executive functioning, impaired memory, and emotional dysregulation (Kulp, 2012).

Residents of Alaska consume alcohol at a higher rate than the national average and exhibit a higher rate of binge drinking. A 2015 report from the Centers for Disease Control and Prevention (CDC, 2015) states that 20% of Alaskans over the age of 18 engage in binge drinking, drinking an average of 7.8 drinks per episode. The Russian fur traders, who drank heavily, first introduced alcohol to Alaska at the beginning of the eighteenth century. Subsequently, whalers, traders, military personnel, seamen, and miners brought alcohol into Alaska, often exhibiting a binge style of drinking, many times drinking until the alcohol was gone. This pattern may have set the stage for the high level of alcohol consumption in Alaska that continues today (Ehrlander, 2010).

In 2015, a report from the Centers for Disease Control and Prevention (CDC, 2015) showed that 53% of Alaskan women of child-bearing age report some use of alcohol and that 21% report binge drinking. Khan, Robinson, Smith, and Dillard (2013) conducted a study at

Southcentral Foundation's Primary Care Center¹ in Anchorage, Alaska asking women in their third trimester to complete a questionnaire concerning their alcohol consumption. Thirty-five percent of the women reported some alcohol use in the first trimester of their pregnancy. Twenty percent reported binge drinking in the first or second trimester. With current knowledge about the prenatal effects of alcohol on the unborn fetus, these statistics are alarming. Although the 2017 McDowell Report prepared for the Alaska Mental Health Trust Authority reported that the incidence of FASD in 2014 was 11.3 per 1000 (p. 65), this figure only included those diagnosed at birth. Other researchers believe the overall incidence of FASD across the United States to be between 20 and 50 per 1000 individuals (May et al., 2009). While no studies document the actual rate, many professionals in the field believe Alaska to have the highest rate of FASD in the United States.

Research shows that serious physical, intellectual, and behavioral challenges caused by prenatal alcohol exposure to alcohol often ripple into families, schools and communities as individuals with FASD struggle with emotional dysregulation, mental health problems, trouble with the law, and struggles with drugs and alcohol (Streissguth et al., 2004). All these difficulties affect quality of life or the health, comfort, and happiness of not only the affected individual, but also the family. Quality of life encompasses physical, social and cultural areas common to all people as well as what is important to the individual (WHO, 1997). Although many studies have observed the prenatal effects of alcohol on children and adults, and examined possible interventions, few studies have investigated how prenatal exposure affects the individual's or family's quality of life. In Alaska, where FASD has been identified as a significant problem, a

¹Southcentral Foundation's Primary Care Center provides primary care services to eligible Alaska Native and Alaska Indian people in the urban and surrounding remote villages of the Anchorage area.

paucity of research exists. There is one study on how FASD affects quality of life, examining the lives of five children (Ryan & Ferguson, 2006). My research gives insight into how 22 lives are impacted by this life-long disability, either by having prenatal exposure to alcohol or by raising a child with FASD. Individuals are given an opportunity to share their lived experiences and perceptions on how it affects them personally and within the family. This research will help fill a void and provide valuable information on how FASD impacts individuals, families, schools and communities.

Problem Statement

Research on prenatal exposure to alcohol has shown permanent detrimental effects on health, executive functioning, motor and sensory development, learning and memory, emotional self-regulation, and the development of social skills. All these conditions and functions impact how affected individuals function within their families, schools, and community. Families are impacted as their children struggle with disabilities, creating stress within the family system and the need for ongoing advocacy. Schools and communities feel the impacts as individuals with FASD often lag developmentally and struggle to maintain appropriate behavior and social skills within these arenas. This study explores the individuals' and families' perspectives, striving to understand their lived experiences and how to best support them.

Statement of Purpose and Research Questions

The purpose of this qualitative study is to explore individual and parent perspectives on how living with FASD affects their quality of life. Individuals with FASD and family members have shared with me their lived experiences, contributing to a holistic understanding of living with FASD, the issues and challenges they face, the availability of resources, and how to best support their unmet needs. Research questions include:

1. How has FASD impacted quality of life for affected individuals?
2. How has raising individuals with FASD affected quality of life for the family?
3. What supports were most helpful to the affected individual or the family?
4. What supports would have been helpful to the individual or family?

Research Approach

Upon receiving approval from the Institutional Review Board (IRB), I conducted 22 in-depth semi-structured interviews with individuals affected by FASD and family members to better understand their lived experiences and perspectives on how FASD has impacted their quality of life. Using a constructivist framework, I chose in-depth semi-structured interviews to give both affected individuals and family members a voice, and to broaden my understanding of their individual experiences and their experiences of life together (Williamson, 2006). The constructivist framework strives to portray the individual and family perspectives on how their lives are impacted by this disability. Part of understanding how FASD impacts quality of life is understanding what is valued by both individual and family members (Verdugo, Schalock, Keith, & Stancliffe, 2005).

The semi-structured interviews formed the basis for the overall findings. I conducted a pilot interview to elicit feedback from one interviewee on the format and interview questions. I gave each interviewee a number to respect confidentiality, and I tape recorded all interviews and then transcribed them verbatim myself. After transcribing the interviews, I followed up with e-mails if I had additional questions. I then added their clarification to the transcripts. I conducted a comprehensive review of relevant literature to assist me with theme development and coding categories. I summarized the prominent findings from my research, comparing the emerging themes with those found in the literature.

Findings

My research findings show that living with FASD or raising a child with FASD seriously impacts most areas of individuals' lives, often creating lifelong difficulties. Individuals with FASD struggle to function at school, find employment, or avoid interactions with the legal system. Parents experience conflict and stress as their child exhibits behavioral problems and learning difficulties. They often need to advocate for individualized services for their children due to a lack of understanding about individual differences within the FASD spectrum. All individuals with FASD in my study experienced multiple Adverse Childhood Experiences (ACEs), in addition to their prenatal alcohol exposure, which will have long term negative impacts on their lives (Felitti et al., 1998). ACEs are stressful or traumatic events experienced by children such as abuse, neglect, or witnessing domestic violence. Individuals and families identified transitional years to adulthood as a particularly challenging time, with both individuals and parents identifying the need for additional supports.

Parents spoke of the crucial need for structure within the household, and the stress this often created for siblings, who might want to attend an unscheduled activity, or for spouses, particularly if the spouse was less attuned to the child's needs. Parents often discussed additional stress when they realized their children would not be independent at 18 years, and possibly not in their lifetime.

Parents and individuals with FASD discussed numerous lifelong consequences of prenatal exposure to alcohol. These findings contribute to the knowledge about FASD and what supports best meet their needs. These findings, if they reach professionals in critical positions, can be helpful in contributing to an improved quality of life for individuals with FASD and their families.

Background of the Researcher

I am a lifelong Alaskan born in Fairbanks. I hold a bachelor's degree in Psychology from Auburn University in Alabama and a Master's degree in Community Psychology from University of Alaska Fairbanks. My professional career includes working in the social services field for over twenty years. Positions include five years at the Office of Children's Services investigating child protection cases, working as an on-going social worker with children and families, writing adoption home studies, and later working as a licensing worker with foster families. I worked for five and a half years as a Public Guardian, which is a state employee who manages the affairs of incapacitated adults. I then worked as a Master's level mental health clinician at Presbyterian Hospitality House for eight and a half years, working with youth in a residential treatment program. Throughout this time I have observed the effects of FASD on individuals, families, schools and communities. I have worked with parents with FASD as they struggle to parent their own children. In a clinical setting, adolescents with FASD have shared with me their frustrations and difficulties as they struggle with serious challenges at home and school, along with the anxiety of being in residential treatment, often outside of their home communities. This professional experience has inspired and informed my research.

Rationale and Significance

This study stems from my desire to better understand how FASD affects quality of life for affected individuals and their families, and the hope that my findings will lead to better supports and services for these individuals and families. The following story illustrates the struggles of some individuals with FASD:

As a mental health clinician I worked with many adolescents with FASD. Jimmy (pseudonym) was one of my clients who visited with me after school one afternoon a week.

Jimmy struggled with expressing himself, but his foster parent helped him to prepare anecdotes that he could relate about a current project on which he was working or an event that occurred at home. He enjoyed building and often brought in a completed project he had made. Providing structure helped Jimmy feel more comfortable with his sessions with me and assisted him in learning how to express himself effectively.

It was a new school year and although Jimmy (pseudonym) was 16 years old, he was only in ninth grade in high school. He came in after school one day for his weekly appointment and I asked him about his day. Jimmy shared that he had some difficulties at school that day. He struggled to explain what happened, but I understood he had been sent to the Vice Principal's office and was relieved that he had not been suspended from school.

I learned that Jimmy had gone to the first day of high school with his new backpack. He was assigned a locker for his coat and backpack, along with the combination to his locker. Rather than putting his coat and backpack in his locker, Jimmy walked around the school with them, which violated school policy. Several teachers reminded Jimmy to put his coat and backpack in his locker, telling him that due to safety concerns, he could be suspended for not following the rule. Jimmy ignored the instructions, walking away from the teachers without responding.

Finally a teacher became upset with Jimmy, who continued to ignore instructions, and walked him to the Vice Principal's office. Fortunately for Jimmy, the Vice Principal took time to establish rapport and learn why Jimmy had not followed instructions.

The Vice Principal discovered that Jimmy could not work the combination lock on his locker but was too embarrassed to ask for help. He preferred risking suspension from school to looking "stupid" to those around him. All turned out well as the Vice Principal took extra time with Jimmy, discovering the source of the problem and finding a positive solution.

This is one of the many stories I heard, as individuals with FASD struggled to be like other more typical students, often feeling ignorant, isolated and lonely. My hope is that this study can shed some light on their struggles and help find better ways to support them and their families.

Fetal alcohol spectrum disorder (FASD) is a lifelong disability that impacts individuals, families, schools, and communities. This exploratory research interviewed individuals with FASD and parents to examine their perspectives on how FASD affects quality of life. This research will provide additional knowledge to professionals on how FASD affects individuals and families, what resources or supports have been helpful to them, and how to better meet their needs.

This dissertation begins with a comprehensive literature review on both fetal alcohol spectrum disorder and quality of life. Next, the research design and methodology chapter examines the rationale for using a qualitative research design, the methodology employed, data analysis, ethical considerations, issues of trustworthiness, and limitations. The findings and discussion chapter incorporates key findings, discussing the findings and comparing them to existing literature. The concluding chapter highlights important findings, along with recommendations based on my research.

CHAPTER II: LITERATURE REVIEW

My research explores how fetal alcohol spectrum disorder (FASD) affects quality of life for individuals with FASD and their families. Fetal Alcohol Spectrum Disorder (FASD) is a spectrum of conditions caused by maternal alcohol use during pregnancy, with a range of diagnoses according to the specific effects of the prenatal alcohol exposure on the individual. Fetal Alcohol Syndrome (FAS) is the medical diagnosis given to an individual who has been prenatally exposed to alcohol and has a combination of growth deficiency, central nervous system damage, and facial dysmorphism (Astley, 2004). Although the criteria for an FAS diagnosis is very specific, there is a broad continuum of effects for individuals with FASD. Because individuals with FASD may have no physical signs of a disability, these individuals often experience more difficulties in their school, home and community than those with FAS. Both FAS and FASD occur in all countries and cultures where individuals drink alcoholic beverages. Diane Malbin (2002) reports there is general agreement in the field that the number of individuals with FASD may be five to ten times more than those with FAS.

Individuals who experience FASD struggle with a wide variety of disorders. Research has shown that the brain is the most sensitive organ to prenatal exposure to alcohol (Malbin, 2002). The effects of alcohol on the brain vary from individual to individual according to the amount of alcohol consumed, the time period of the gestational development, the mother's genetic make-up, nutritional factors, and whether other drugs were used. If large amounts of alcohol are consumed, the child's brain will actually be smaller (Malbin, 2002). Alcohol has numerous effects on the brain including killing off cells, changing the migration of cells, reducing neuronal pathways, altering brain chemistry and reducing the myelin sheath around

pathways (Malbin, 2002). These changes in the brain may cause multiple problems including slower processing speed, problems with executive functioning, trouble determining cause and effect, the ability to generalize, sensitivity problems, and becoming easily distracted. Ongoing problems with executive functioning include difficulties with cognitive flexibility, the ability to strategize, verbal reasoning, aspects of inhibition, working memory, and emotion-related development (Rasmussen, 2005). All of these problems affect quality of life.

The use of alcohol and binge drinking among women of childbearing age in the United States is concerning. For example, a study on drinking patterns conducted by the Centers for Disease Control and Prevention (CDC) from 2011-2013 indicates that about half of non-pregnant women report some alcohol use and about one in five report binge drinking. Among pregnant women, one in ten report alcohol use in the past thirty days with one in 33 reporting binge drinking. Pregnant women with the highest alcohol use were between the ages of 35 and 44 years, were college graduates, and were not married. Pregnant women who reported binge drinking experienced an average of 4.6 episodes in the past thirty days. For this study binge drinking was defined as consuming four or more drinks on one occasion. (CDC, 2015, p. 2).

Since the 1970s, when fetal alcohol syndrome (FAS) was first identified in the United States, much research has been conducted on the disability. This chapter reviews relevant literature on both the full spectrum of fetal alcohol spectrum disorder (FASD) and quality of life (QOL). The review on FASD begins with the history of how the effects of prenatal alcohol exposure on children were first identified, the various diagnoses associated with prenatal alcohol exposure, and its many serious lifelong effects on affected individuals. It includes literature on how FASD impacts families, the educational system, the criminal justice system, and current

interventions used within the field. I also explore existing research and articles on FASD in Alaska, which is where I conducted my research.

Next, I review literature on quality of life, looking specifically for research on how FASD impacts quality of life (QOL). Quality of life (QOL) as defined by the Centers for Disease Control and Prevention (CDC, 2011, p. 1) is “a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life.” QOL includes health, housing, education, job opportunities, culture and other aspects of life individuals may value. I found quality of life studies on individuals with various diseases such as cancer or diabetes, or quality of life studies on individuals with intellectual disabilities, but almost nothing specifically on quality of life for individuals with FASD or how it affects quality of life for their families. The gap in the literature on quality of life for this group of people affirmed my sense, based on my professional experience, of the need for my research study.

Fetal Alcohol Spectrum Disorder

Early History of FASD

Although Fetal Alcohol Syndrome is a relatively new term first identified by Jones, Smith, Ulleland and Streissguth in 1973 at the University of Washington, alcohol has been identified as a possible teratogen or cause of birth defects to the fetus since Biblical times (Warren & Hewitt, 2009). Judges 13:7 states “Behold, you shall conceive and bear a son. Now drink no wine or similar drink...” (Warren & Hewitt, 2009, p. 170). During the London Gin Epidemic in the 1700s, English author Henry Fielding wrote about the social, moral and health problems attributed to excess drinking when he states: “What must become of the infant who is conceived in Gin? With the poisonous distillations of which it is nourished both in the Womb and the Breast” (Warren & Hewitt, 2009, p. 171). Between 1912 and 1920, Charles Stockard of

Cornell University conducted experiments on pregnancy outcomes in guinea pigs, exposing them to alcohol before conception. Stockyard found effects of alcohol on growth and viability in the offspring. After Prohibition in America, earlier studies were ignored and scientists who had been involved in previous research dismissed the research as no longer pertinent. For example, E. Morton Jellinek, who is often regarded as the father of the modern era of alcohol research, did not believe that maternal alcohol use was detrimental to the fetus (Warren & Hewitt, 2009). Jellinek began his research on alcohol in the early 1930's and continued until his death in 1963.

In 1970, Christine Ulleland, a University of Washington medical student, studied children hospitalized for Failure to Thrive² as her thesis project. She reviewed their medical records and recognized that over 41% of the mothers indicated problems with alcohol. After noting that infants of mothers with excessive alcohol use were at high risk for growth deficiencies and developmental failure, she recommended that more attention be given to women struggling with alcohol abuse during their child bearing years (Warren & Hewitt, 2009).

A study by Jones, Smith, Ulleland and Streissguth, as cited in Jones & Streissguth (2010), followed eleven unrelated children in the Washington state area born to women who continued to drink heavily throughout their pregnancy. All the children showed similar problems in growth and deficiencies. Of the eight children they continued to follow, four had microcephaly, short palpebral fissures and a smooth philtrum³. Seven of the eight children were evaluated by a psychologist and showed delayed social and motor performance, fine motor dysfunctions, and delayed gross motor performance. One of the authors, Smith, reviewed his files, looking at hundreds of children who had birth defects he had been unable to diagnose, and

² Failure to Thrive: a condition in infants that indicates insufficient weight gain or inappropriate weight

³ Philtrum is the vertical indentations in the middle area of the upper lip

found two cases similar to the ones he was currently studying. The mother in both cases had a history of alcohol abuse. A correlation between heavy maternal alcohol consumption and serious problems with the fetus was substantiated, and the term “fetal alcohol syndrome” was developed.

Paul Lemoine of Nantes, France had published a similar study in 1968 but his colleagues did not believe him (Jones & Streissguth, 2010). Lemoine identified similar physical and behavioral problems in 127 children in Roubaix, France, whose mothers struggled with alcohol abuse. At that time no one realized that something as common as alcohol use could have such a detrimental effect on the developing fetus.

In 1974, Smith, Jones and Streissguth attended a conference in Washington D.C. to access a data base from the Collaborative Perinatal Project of the National Institute on Neurologic Diseases and Stroke (Jones & Streissguth, 2010). Although the doctors had not previously made a connection between alcohol consumption and fetal impairment, records that noted alcoholic mothers were pulled and became the focus of their study. The physicians examined the pediatric and psychological records for the children of 23 mothers who abused alcohol. The children were compared to a control group of similar backgrounds whose mothers did not abuse alcohol. They found worse outcomes, with a perinatal mortality of 17% in children with alcoholic mothers, compared to two percent in the control group. Children whose mothers abused alcohol had a 32% rate of FAS compared to none in the control group. At that time the full spectrum of FASD was unknown, so no other statistics were gathered (Jones & Streissguth, 2010).

Findings from France and Seattle were soon replicated in Germany, Northern France and Sweden (Streissguth, 1994). In the late 1970s, the United States initiated two important policies: an official statement by the Surgeon General warning against drinking alcohol during pregnancy

or when planning a pregnancy (Federal Drug Administration, 1981) and labeling of alcoholic beverage containers with a warning about the risk of birth defects associated with drinking while pregnant (Dukes, 1989).

At first, researchers thought that affected babies would resemble those with Down syndrome. During that time clinicians focused on babies and young children, but were reluctant to diagnose adolescents or adults. In ongoing studies, researchers found that the physical features change with age, making it more difficult to diagnose adolescents and adults. They also found that individuals with FAS show a wide variety of intellectual abilities, often getting into trouble with families, schools, and communities (Streissguth, 1994).

Streissguth, Clarren and Jones (1985) conducted a 10-year follow-up study on the first children diagnosed with FAS. Of the original 11 children, two had died, and eight were available for follow-up. Compared to an average range of intelligence being from 90-110, four of the individuals had IQ scores of 20-57 and IQs for the other four ranged between 76 and 86. The four children in the lower IQ group experienced less difficulties at school and their home communities than the four in the low-normal range. One individual dropped out of school at the fifth grade year, moved to another state, and eventually returned to school. One girl dropped out of middle school and had a baby a short time later. The girl with the highest IQ, who was also raised in a stable environment, ran away from home, lived a transient lifestyle, and became an unmarried teenage mother. The fourth individual could not be located during the follow-up.

In 1992, Lemoine published a 30-year follow-up study on Lemoine's original patients from Nantes, France (Streissguth et al., 1994). Many of the individuals were found in state institutions. Among 50 patients with severe FAS, five had died. Severe cardiac problems or anoxia caused four of the individuals to die during childhood. Among the 28 patients with mild

FAS, two had committed suicide as adults, and five others had attempted suicide. Lemoine found that mental health problems were the most significant challenges of FAS in adulthood and that adults often continued to have problems with focus, instability, and difficulty in cooperation.

Since FAS became recognized in the 1970s, many studies have been conducted on how alcohol affects the fetus during development. There is a greater understanding of the long-term effects of prenatal alcohol exposure and the challenges the affected individual will have with relationships, learning at school and developing the skills needed for adulthood. Yet more research and understanding is needed.

Economic Costs

FASD is costly to individuals, families and communities. In economic terms, Goldsmith et al. (2004) report that the estimated cost to society, including a lifetime of medical, special education and welfare services for one child with FAS is one million dollars. The Lupton et al. (2004) study stated that FAS is the most costly defect in the United States. The McDowell Report (2017) on the economic costs of alcohol abuse in Alaska estimated the 2014 cost for the 129 babies born with FASD to be nearly \$3 million dollars (McDowell Group, 2017, p. 65). These costs include medical treatment, education, social services, transportation, and parent-productivity losses. The McDowell Report states that the annual costs were likely underestimated due to additional children being diagnosed with FASD after birth.

Children born with FASD have much higher medical expenses than children born without disabilities. Amendah, Grosse, and Bertrand (2011) conducted a study using data from the MarketScan Medicaid Multi-State Database for years 2003-2005 to assess the medical expenditures of children in the United States with FAS. The study found that a child with FAS incurred a mean medical expenditure of \$16,782 compared with \$1,859 for a child without FAS,

or nine times higher costs. Children with FAS and an intellectual disability incurred a mean expenditure of \$38,873, which was 2.8 times higher than a child with FAS without an intellectual disability. This study focused on the medical costs of children born with FAS, the most severe end of the spectrum and does not show the total impact of medical costs incurred for other children within the FASD spectrum.

Popova, Stade, Bekmuradov, Lange, and Rehm (2011) used multiple electronic bibliographic databases, various web sites, two economic databases, and reviews from major epidemiological journals to assess the economic impact of FASD. FAS/FASD was found to be a serious public health issue with great monetary costs. Of the thirteen studies used, three were from Canada and ten were from the United States. The researchers did not find cost studies in any other countries. A study by Stade et al. (2009) showed an annual cost of FASD at the individual level as \$21,640 and at the population level as \$5.3 billion for persons 0-53 years of age. Harwood (2003) updated his original 1992 study adjusting for changes in health care costs, consumer price index changes for medical services and compensation losses due to lack of productivity and found the total annual cost to the United States for individuals with FASD to be \$4.15 billion in 1998.

The studies reviewed by Popova et al. (2011) used a wide variety of methodologies and costs. Costs included medical care, educational services, social services, and indirect costs such as productivity losses. None of the estimated costs in the Canada or U.S. studies included the child welfare system or law enforcements costs, although it is believed that individuals with FAS or FASD are overrepresented in both systems. The U.S. studies did not include medical services for physical abnormalities, special education, substance abuse, mental health services, or services

for mild physical and learning disabilities. Some studies did not include the full spectrum of FASD.

Individuals, families, schools, and communities are economically impacted by this disability. Both individuals with FASD and families are affected by increased medical costs. Public school systems incur increased education costs to meet the needs of those with FASD. Later studies in this review examine the increased costs in the child welfare and correctional system.

Diagnoses and Difficulties in Developing a Profile for FASD

Disorders and/or effects caused by prenatal exposure to alcohol are classified under the Fetal Alcohol Spectrum Disorder (FASD) umbrella. Fetal Alcohol Syndrome (FAS) is a medical term characterized by specific facial features including small eyes, smooth philtrum, and a thin upper lip. Individuals with FAS have a growth deficiency with their height and weight being under the tenth percentile for national averages. They also have severe central nervous system abnormalities such as brain damage that causes difficulty with coordination, motor control, or in some cases, a smaller brain size. While the IQ for the average individual is 100, the average IQ for an individual with full FAS is 70 with a range between 20 and 130 (Malbin, 2002).

Specialists have developed several other terms to classify various effects of prenatal exposure to alcohol that do not meet the full criteria for an FAS diagnosis but are within the FASD spectrum. Partial FAS (pFAS) is a term given to those individuals who do not meet the full diagnostic criteria for FAS, but who do have the facial features consistent with FAS. The term Fetal Alcohol Effects (FAE) was developed in 1978 for individuals who do not meet the full criteria for FAS (Clarren & Smith, 1978). However, this term is now seldom used.

According to Astley (2004), the diagnosis of alcohol-related neurodevelopmental disorder

(ARND) refers to prenatally alcohol exposed individuals who exhibit neurodevelopmental disorders in the central nervous system (CNS). Alcohol Related Birth Defects (ARBD) is a broad category referring to a range of facial and other physical malformations due to the prenatal alcohol exposure. These may include difficulties with the heart, kidneys, bones, hearing or a combination of these. The term Static Encephalopathy/Alcohol Exposed (SE/AE) is used for individuals who have prenatal alcohol exposure and central nervous system damage with significant functional abnormalities (Astley, 2004).

In 2013, the Diagnostic and Statistical Manual, 5th edition (DSM-5), from the American Psychiatric Association, included a new diagnosis: Neurodevelopmental Disorder associated with Prenatal Alcohol Exposure (ND-PAE). The diagnosis requires confirmed gestational alcohol exposure. Impairments under this diagnosis must include at least one area of neurocognitive impairment, at least one area of impairment in self-regulation, and two or more impairments in adaptive functioning, such as deficits in communication or social skills (Kable et al., 2016).

Those individuals meeting the criteria for FAS or pFAS are generally easy to diagnose if maternal drinking has been confirmed. Other individuals who are prenatally exposed to alcohol but do not exhibit the FAS physical features are much more difficult to diagnose. May et al. (2009) state that individuals with FASD, other than the most severe cases, are “virtually impossible” to diagnose within the first six weeks, with most children not being diagnosable until approximately age three (May et al., 2009, p. 179). Individuals may struggle throughout their lives without understanding the root cause of their ongoing problems. May et al. (2009) conducted a meta-study of previous studies, methods, and rates of FASD. He concluded that the

prevalence of FAS in the United States was at least two to seven per 1000, with the prevalence of FASD being two to five per 100 individuals. This is much higher than previous studies.

Developing a profile based on the neurobehavioral effects of prenatal alcohol exposure would help with early recognition of FASD as the importance of early diagnosis and intervention is well documented (Warren, Hewitt, & Thomas, 2011). Currently, professionals identify individuals with prenatal alcohol exposure through two means: maternal reports of drinking during pregnancy and dysmorphology exams that assess congenital defects. Some medical centers that serve pregnant women have started using a questionnaire on alcohol drinking patterns to help identify women who may be at high-risk for having a baby with prenatal alcohol exposure. Two questionnaires currently being used are the T-ACE or AUDIT-C. Although the subtle nature of some of the dysmorphic features from alcohol exposure makes diagnosis difficult, computer-generated imaging using algorithms for feature detection and stereo photogrammetry are promising tools (Warren, Hewitt, & Thomas, 2011).

Although retrospective maternal reports of alcohol use are the best assessments of alcohol exposure, reliable retrospective maternal reports are often difficult to obtain due to inaccurate reporting (Mattson and Riley (2011)). For example, guilt and shame may inhibit biological mothers from reporting alcohol use. Also, many individuals with heavy prenatal alcohol exposure are in foster and/or adoptive care, so obtaining maternal reports is not possible. A study by Mattson and Riley (2011) reviewed other possible avenues for identifying prenatally alcohol-exposed individuals. One potential method being studied is through the detection of long-lasting alcohol metabolites. At this time the most studied biological marker is the fatty acid ethyl esters (FAEEs) in the meconium of newborns. Limitations for this method of identification include not being useful for detecting exposure during the first trimester; not allowing identification after the

newborn period unless samples are appropriately stored; and FAEE's being a marker of alcohol exposure but in not showing specific effects, the method may be too inclusive. Current research examines the possibility of measuring the FAEEs in maternal hair as a marker of exposure. Of course, these measures would only be effective under limited circumstances (Mattson & Riley (2011).

Researchers are also trying to establish a profile for alcohol-affected individuals to better identify those affected (Mattson & Riley, 2011). Research has suggested that executive functioning and spatial processing are especially sensitive to prenatal alcohol exposure (Rasmussen, 2005). Researchers are comparing alcohol-affected individuals with other groups of people with low IQ scores and those with ADHD (Mattson & Riley, 2000). Some studies have shown that alcohol-affected children are more impaired on measures of externalizing behaviors such as physical aggression, disobeying rules, cheating, stealing, and property destruction. They also have more difficulty with adaptive skills such as home and personal care (Mattson & Riley, 2000).

Effects of FASD

Executive Brain Functioning. Individuals within the FASD spectrum often experience difficulties with executive brain functioning causing problems in academic, social, and emotional functioning. Functional magnetic resonance imaging in individuals with FASD show increased activation in the prefrontal cortex during situations requiring inhibition of action, suggesting that more cognitive energy is required to complete a task. For example, study by Green et al. (2009) measured executive function deficits in children with FASD using the Cambridge Neuropsychological Tests Automated Battery (CANTAB). The study assessed executive functioning in children with FASD compared to age and sex-matched controls, examining the

following domains: attention, planning, strategy use, and spatial working memory. For example, individuals with FASD may have difficulty navigating around a familiar city. Compared to the control group, children with FASD showed deficits in all four domains with the greatest impaired performance in the spatial working memory task. Of the 14 outcome measures analyzed, that related to the four tasks, only one showed a significant difference in performance between the FAS, pFAS, and ARND groups. This finding indicates deficits in executive functioning regardless of whether the child had full FAS.

Rasmussen and Bisanz (2009) studied executive functioning (EF) in children with fetal alcohol spectrum disorders by examining the profile of executive functioning deficits that are displayed on the D-KEFS, a battery of nine different tests of EF, and one of the few EF batteries to measure EF across a variety of domains. The study examined specific areas of weaknesses and areas of strength, along with identifying age-related differences. The 29 children in the study ranged in age from eight years, four months to 16 years, two months. The study showed that children with FASD show difficulty on the EF components of cognitive flexibility, inhibition, some measures of verbal fluency, abstract thinking, deductive reasoning, hypothesis testing, problem solving, and concept formation. They showed relative strength in some visual-spatial EF tasks such as fluency of categorical information, cognitive flexibility, and reasoning in the spatial domain, all of which involve visual-spatial strategies. When assessing age-related differences, older children performed worse, relative to the norm, even when adjusting for IQs. Rasmussen and Bisanz (2009) note that this finding suggests that deficits become more pronounced as individuals age.

Greenbaum, Stevens, Nash, Koren, and Rovet (2009) examined the social cognitive and emotional processing abilities of children with FASD compared with children with Attention

Deficit Hyperactivity Disorder (ADHD). Children with these two disorders are sometimes thought to have similar deficits. Children with undiagnosed FASD are often diagnosed with Attention Deficit Disorders (ADD) or ADHD. The study compared children with FASD and children with ADHD to a typically developing control group on the following measures: behavioral problems and social skills; tasks of social cognition and emotional processing to determine whether aspects of social cognition would predict behavioral problems; and deficits in social skills. Tests showed a high level of rule-breaking, aggressive behavior, and attention problems in children with FASD. The FASD group performed significantly below the ADHD group and the control group on some social cognition and emotional processing tests. Children with FASD had greater difficulty interpreting the mental states of others and recognizing emotions in faces. This challenge has been associated in other studies with increased risk of behavior problems and social difficulties.

Ase et al. (2012) compared children with FASD, children with similar IQ's to those with FASD but with a specific learning disorder (SLD), and children in a typically developing control group (CON), using the Vineland Adaptive Behavioral Scale (VABS). The three groups resembled one another in age and sex, but the typically developing control group differed in IQ. The VABS was used to assess communication (receptive, expressive and written), daily living skills (daily tasks such as eating, dressing, chores), and socialization (interactions with others, use of leisure time, development of coping skills). The composite scores from the VABS showed that the CON group scored better than the SLD group, who scored better than children with FASD. The FASD group consistently performed less well on the adaptive behavior skills than the CON group, and the IQ-matched SLD group. The researchers found significant differences among the groups in all areas except receptive communication. In the SLD group, socialization

skills improved with age and began to approach the typically developing control group. However, in the FASD group, the older group's socialization skills were worse than the younger children's. One significant factor emerged when a very small subgroup of children with FASD and SLD, who lived with their birth families were compared: the developmental gap between the two groups diminished considerably. This suggests that the caregiver environment may be linked to the level of adaptive skills.

Pei, Job, Kully-Martens and Rasmussen (2011) conducted a study looking at executive functioning and memory in children with fetal alcohol spectrum disorder. Primarily, the study evaluated differences in visuospatial abilities, memory and executive functioning (EF) among children with and without FASD. The researchers used the Rey-Osterrieth Complex Figure (ROCF), a neuropsychological assessment tool that requires the individual to first copy a complex geometric design with multiple embedded details, and then re-create the figure from memory. The ROCF requires planning/organization, attention, visual-spatial perception and construction, motor ability and memory encoding, plus storage and retrieval processes. Pei et al. (2011) hypothesized that children with FASD would show greater decay of information over time, show limited organization of design elements which would lead to a more piecemeal reproduction during recall, and have more difficulty with the initial decoding, and that the control group would exhibit greater accuracy, style, and fluency of production than the children with FASD. The study showed that children with FASD had greater difficulty on the initial encoding of information and were significantly less accurate than the control peers. Children with FASD performed significantly below normal limits on all three trials compared to the control group. Difficulties for children with FASD were most notable in organization during initial encoding, accuracy in recalling the structural components of the figure over time, and

placement of design elements. Children with FASD struggled with seeing the complex figure as a whole, often recalling details accurately but not their correct location in the figure. Pei et al. (2011) thought that the findings in this study might help to develop cognitive training strategies and contribute to diagnostic accuracy.

All of these studies show significant difficulties with executive brain functioning which affects individuals' working memory, flexible attention, and inhibitory control. These are important for individuals to be successful in learning, adjusting to changes in the environment and having emotional self-regulation. Two of the studies, Rasmussen and Bisanz (2009) and Ase et al. (2012) showed that the executive functioning skills actually become worse as the child becomes older.

Social skills and secondary disabilities. Prenatal exposure to alcohol also affects the individual's social skills. Rasmussen, Becker, McLennan, Urichuk, and Andrew (2010) studied the social skills of 60 children with and without prenatal alcohol exposure using the Social Skills Rating System (SSRS). Children were chosen from a center-based respite program; all children had significant behavioral problems. Both caregivers and teachers rated the children on problem behaviors which included: externalizing (bad temper and aggression), internalizing (poor self-esteem, anxiety), and hyperactivity (impulsivity, restlessness). Children with FASD scored significantly lower than non-exposed children on scales measuring responsibility, hyperactivity, internalizing problems, and on the social skills total. The study showed that alcohol-exposed girls tended to exhibit more social skills problems than alcohol-exposed boys. Alcohol-exposed girls were diagnosed as having more internalizing problems and problem behaviors than exposed boys. Caregivers assigned lower scores than respite workers on both groups of children, which may have been the result of the children being in the respite program only one month.

Researchers attributed the differences in social skills impairment between the alcohol exposed and the non-alcohol exposed children to be due to deficits in executive functioning, difficulty with communication, or problems with information processing.

Individuals with FASD may also develop “secondary disabilities,” which are conditions not present at birth that develop as individuals try to manage life with their primary deficits. Secondary disabilities occur less often in those individuals diagnosed with FAS and more frequently in individuals with higher IQs. Streissguth, Barr, Kogan, and Bookstein (1996) studied 415 individuals who had FASD and identified six main secondary disabilities. They discovered that most prevalent secondary disability was mental health problems, which 94% of the full sample experienced. During childhood, 60% of the children with FASD were diagnosed with ADHD. Most adults with FASD experienced clinical depression, with 23% attempting suicide, and 43% threatening to commit suicide. Seventy percent of the adults with FASD had experienced some type of disrupted school experience, including suspension, expulsion, and/or dropping out. Sixty percent of those 12 years and older had encountered some trouble with the law with the most common violations being crimes against persons. Offenses included theft, burglary, assault, murder, domestic violence, child molestation and running away. In this study, confinement emerged as another secondary disability experienced with over 40% of the adults with FASD having been incarcerated, 30% having been confined to a mental institution, and about 20% having been confined for substance abuse treatment. Inappropriate sexual behavior was reported in over half of the individuals 12 years and over, with the most common behaviors including unwanted or inappropriate sexual advances, sexual touching, promiscuity, exposure, compulsions, voyeurism, masturbation in public, incest, sex with animals and making obscene phone calls. Thirty percent of the individuals 12 years and over experienced alcohol and drug

problems. These findings by Streissguth et al. (1996) demonstrated a strong need for further research to better understand these disorders and develop effective interventions to mitigate secondary disabilities.

Research has established that prenatal exposure to alcohol affects the individual in a myriad of ways. The individual has impaired executive functioning, which affects their ability to retain information, make good choices, and regulate emotions and behavior. Due to the lack of emotional self-regulation, individuals often struggle with social skills, impacting their ability to maintain quality relationships. Individuals with varying deficits often develop secondary disabilities when they are unsuccessful in learning how to manage within their environment. Although individual disabilities vary, the effects are life-long and greatly impact their quality of life, as well as quality of life for families.

Families

Families raising children with FASD experience a range of ongoing challenges. Birth parents often experience continual guilt and shame, even if the mother quits drinking once she discovers she is pregnant. Birth and adoptive parents generally struggle with financial strain as children with FASD often have increased medical, educational, and legal needs. Parents also feel frustration at professionals' lack of knowledge; continuing need for advocacy and intervention; stress with the child's behavior problems, especially if the child is involved in the judicial system; and the high time demands that often continue into adulthood.

To date there is little systematically gathered data on how families are impacted by raising a child with FASD. Streissguth et al. (2004) identified five protective factors for children with FASD: living in a stable, nurturing family environment; infrequent changes in their living situation; no exposure to violence; receiving services for disabilities; and being diagnosed before

the age of six years. However, many children with FASD experience “double jeopardy” because they also have unstable living environments, living in neglectful or abusive homes or with parents that abuse alcohol or other drugs. Streissguth et al. (2004) found that children with FASD who were raised in unstable family environments showed increased difficulties in the classroom on measures such as attention, memory and language; developed more signs of oppositional behavior; were more often diagnosed with ADHD; and had increased social problems. Children who had more prenatal alcohol exposure developed more behavioral problems which led to increased maternal stress. Parental stress increased with the increase in externalizing or internalizing behavior problems or the decrease in executive and adaptive functioning. The Paley et al. (2005) study found overall, the child’s level of executive functioning was the strongest predictor of child-related parental stress.

Olson, Oti, Gelo, and Beck (2009) identified two primary needs for parents/caregivers of children with FASD: respite care and an increased knowledge of FASD by all services accessed to serve the child. Studies by Leenaars, Denys, Henneveld, and Rasmussen (2012) and Whitehurst (2012) showed similar needs by caregivers. The Olson et al. (2009) study found the relationship between parental well-being and child stressors to be affected by parental cognitions, parental attitudes, and family resources. The study used data from the Families Moving Forward Program, which is an intervention program for families of children with FASD. The data showed that these children often had other exposures or risks, including neglect, violence towards the child, living with ongoing parental substance abuse, divorce, poverty, or other major traumas. Ninety-two percent of primary caregivers in the program who were parenting children with FASD reported clinically significant child-related stress on their Parenting Stress Index (PSI), a psychological tool used to assess the magnitude of parental stress.

A positive finding in the data from the Child and Adolescent Functional Assessment Scale and the Preschool and Early Childhood Functional Assessment Scale was that most caregivers felt that children with FASD take pride in doing activities independently, participate in family activities, willingly accept routines in the household, and seek and accept help from caregivers. The study also showed that there were critical time periods for children with FASD, in terms of their successful development: second through fourth grade; the transition to middle school; and the transition years to adulthood as they require more time.

In another study, Leenaars, Denys, Henneveld, and Rasmussen (2012) examined the impact of a family intervention program run through Catholic Social Services on families of children with FASD. The Coaching Families (CF) program provided support, education, advocacy and referrals to the families. The program provided each family a mentor. Researchers hypothesized that “there would be a significant overall decrease in families’ needs and an increase in goal achievement from pre- to post-program, and a significant reduction in caregiver stress” (Leenaars et al., 2012, p. 432). The study included 186 biological, adoptive, or foster families. The study showed a significant correlation between the lengths of time in the program and reduced family needs and better achievement of the family’s goals. The greatest reductions from pre- to post-study needs were housing and transportation, family parenting, community development and community resources. Every needs category except mental health issues dropped significantly, suggesting the need to incorporate the assistance of mental health professionals for consultations and development of skills. Overall levels of caregiver stress from pre- to post-program dropped significantly, with 98% of the caregivers reporting satisfaction with the program.

Whitehurst (2012) conducted a study using an interpretive phenomenological approach in which he interviewed both adoptive and birth parents to understand their journeys and the impacts FASD had on their families. The intent of the study was to provide a framework for considering issues faced by parents of children with FASD. Four families took part in the study, which included one birth mother and three adoptive mothers. The birth mother experienced much guilt. Of the three adoptive mothers, only one mother was told prior to the adoption that the child had symptoms of FASD. The other two mothers noted difficulties in their children but had to fight for information and a diagnosis for the problems their children were experiencing. All parents expressed experiencing life as a constant battle full of emotional conflict, fear and anxiety. One parent compared her anxiety with Post Traumatic Stress Syndrome (Whitehurst, 2012, p. 191). Two adoptive parents struggled with whether they should tell people the child had FASD, fearing people would make assumptions about them as mothers and then the mothers would have to explain that the children were adopted. All parents stated they lacked knowledge and services, and that social services and mental health agencies argued over who would provide services for the family. Parents noted challenges in the children including areas of cognitive, social/emotional, and behavioral difficulties. Parents felt it was a struggle to have their children's educational needs met, as teachers often were not knowledgeable about FASD or which interventions might be effective. The two main problems the parents voiced were a lack of professional knowledge about FASD and a lack of support for the parents. When support was received, it was often fragmented and did not provide all the services the family needed. The study concluded that parents need to feel that their concerns are heard and that they and their children are supported by adequate services.

Toutain and Lejeune (2008) studied the effects of medical, social and judicial decisions in France on the families of children prenatally exposed to alcohol. Approximately 7,000 infants are born with FAS/FASD in France each year and the situation is recognized as a public health issue (Toutain & Lejeune, 2008, p. 426). Toutain and Lejeune followed 31 mothers who to drinking at least three glasses of alcohol per day during their pregnancies. Of the 31 mothers, 28 gave birth to babies who met the FAS/FASD criteria. They followed the 28 children for one to twelve years. Characteristics of the mothers included excessive alcohol consumption, smoking an average of 19 cigarettes per day, use of other drugs, and living in underprivileged socioeconomic conditions. Newborns had a mean duration of 26 days in the hospital, 71% had low birth weights, 48% were born before term, and 75% had full FAS. Other problems included respiratory distress, anemia, hyper-excitability, jaundice, thrombopenia, and cardiac disorders. Fifty-seven percent of the babies were temporarily or permanently moved from their biological families and placed into care. Seven of the other children were put in care at around the age of 12 years after initially living with their biological parents or extended family. The total is similar to the Streissguth et al. (2004) study in which 80% of the children were removed from their biological parents. Of the sixteen newborns that were released to their parents, two died of sudden infant death 24-34 days after discharge, slightly more than half still lived with one family member, and the remaining 40% lived in a variety of situations, either in care, with extended family, or with foster families. The study found that prolonged stays in state-run nurseries increased the risk of other disorders, and that foster families were often overwhelmed by their baby's behavior due to not understanding the implications of FAS/FASD. The study suggested that biological parents receive additional supports through a support team and more in-home supervision to avoid the trauma of out-of-home care.

These studies show that raising a child with FASD impacts quality of life for the family in several ways. Parents have increased stress as they attempt to meet the high needs of their child(ren). Parents are also frustrated as professionals do not understand the full impact of FASD. They often have to advocate for needed services and when they receive services, services are often inadequate or sporadic. The Toutain and Lejeune (2008) study also demonstrates the need for supports and supervision if children with FASD are going to be maintained within their biological families. The Olson et al. (2009) study and the Leenaars et al. (2012) study both suggest positive outcomes for family intervention programs that work within the home where parents are raising children with FASD.

Education

Children with FASD may have a normal IQ, appear to be of average size, and to function at their own age, yet have significant cognitive, behavioral, emotional, and/or social difficulties. These children may have an academic ability that is below their IQ level, may not fit the general theories of learning development, and may not make age-appropriate gains in intellectual function due to impaired learning, memory, attention, concentration, and executive functions (Blackburn, Carpenter, & Egerton, 2010). Even high functioning children with FASD may have difficulty with social and emotional development, hyperactivity and attention, comprehension of rules, understanding cause and effect, processing receptive and expressive language, the ability to generalize what they learn, and how to solve problems. Each individual with FASD has a unique set of learning difficulties that occur according to which area of the brain was damaged by prenatal alcohol exposure. Yet with all that we do know about FASD, it is not a formally recognized category under the individuals with Disabilities Education Act, and students with

FASD generally receive services under another category (Miller, 2006) if they receive services at all.

The state of Alaska, however, added fetal alcohol spectrum disorder (FASD) to its regulations governing the qualifications for receiving special education services (AK Stat. §§ 4 AAC 52.130 (k)) (2016). In October 2016, fetal alcohol spectrum disorder was added to the list of “other health impairments.” Before 2016, individuals with FASD did not qualify for special education services unless they fell under another category.

Numerous studies have been published on the needs of children with FASD within the classroom, the effectiveness of educational strategies for these individuals, and what strategies are most successful. A research project published in 2010 studied children in Great Britain with FASD, the training available for classroom teachers, and what classroom strategies seemed most effective. The project by Blackburn, Carpenter, and Egerton (2010), found that hyperactivity in children with FASD might improve with age, but inattention and impulsivity often did not. They discovered language delays often occur in children with full FAS. Children with FASD who seemed to have good language skills, often had difficulty with meaning and comprehension. They often had difficulty understanding oral instructions even when they were carefully listening.

The Blackburn et al. (2010) study found at that time there were few studies on effective educational strategies to work with children impacted by FASD, yet teachers were expected to know how to respond to individual learning needs and be well-informed, reflective, patient, creative, and empathic. The study showed the importance of building on the students’ positive strengths and talents and the need to individualize studies according to their abilities. Children with FASD often have strong visual memories and good verbal fluency. They tend to have high

energy levels and a fun-loving and caring nature. Many are skilled in visual arts, music, and have good athletic skills. Focusing on their strengths help them to be successful in the classroom, not only with educational pursuits, but also with the development of self-esteem and good social skills.

Carpenter (2011) found that teaching styles and structure in the classroom are often not effective in working with children with FASD. He worked with 20 teachers in primary, secondary, and special schools of the West Midland in Great Britain to explore existing practices of working with children with FASD. Carpenter found that even when expressive language and reading skills of children with FASD are good, social skills and emotional maturity may be at half their age. He also found that mathematics and numerical concepts were often challenging for these students.

Carpenter asked classroom teachers to identify the top challenges to the classroom environment for working with children with FASD. The top ten challenges reported included: hyperactivity; short attention span; erratic mood swings; poor memory; lack of social skills; deficiencies in auditory/vocal processing; difficulty with visual sequencing; sensory integration difficulties; poor retention of task instruction; and numeracy/mathematical difficulties. He used observations of children with FASD in the classroom, along with an extensive international literature survey, to identify ten primary teaching responses to the above classroom challenges. The responses were: a calm learning environment, free from clutter; specific tasks presented in small steps; personal space for the student with ongoing support and praise; visual structuring; use of role play; short, concise instructions; visual clarity and the use of simple graphics; frequent breaks using exercise; a breakdown of tasks using visual and tactile clues, specific times given for task completion; and use of multisensory learning techniques. Carpenter found that the

structure of the classroom was a key element in how well the child with FASD functioned. Teachers needed to carefully consider the seating of the child with FASD, keeping visual clutter to a minimum in order to create a distraction-free environment. He urged taking classroom lighting and sensitivity to colors into consideration. Children with FASD tended to be visually dominant learners and to excel in classrooms with high levels of engagement. Other techniques Carpenter found to be helpful were using activities that focused on the children themselves, providing a “safe area” (Carpenter, 2011, p. 41) in the classroom for when the child’s behavior is out of control, and using focused exercise to help with self-regulation.

Other researchers explored various teaching techniques as to their effectiveness in working with students with FASD. Green (2007) found the use of basic behavioral principals such as positive reinforcement and natural consequences were only effective when individuals’ executive functioning limitations had been assessed and taken into consideration. Effective teaching tools included the use of visual cues and schedules, teaching self-directed speech and problem-solving, role play, cognitive modeling and coaching. Difficulties with cause and effect could be addressed through concrete examples such as pictures and stories. The use of cognitive-behavioral strategies, social skills training, emotion identification, coping skills and anger management tools were also found to assist the student with maintaining good behavior within the classroom setting.

Miller (2006) found the following strategies used for students with emotion/behavioral disorders were also effective with students with FAS: social skills instruction; behavioral contracting, differential reinforcement; preferred activities; self-management; and self-monitoring. Other tools that Miller found to be helpful included visual aids, organizational tools, mnemonics, concept mapping and learning strategies. Researchers Green (2007) and Miller

(2006) both stressed individuals with FASD may need some level of ongoing support from parents, caregivers, teachers, and other significant adults throughout their lives, including during adulthood.

A study in the United States by Dybdahl and Ryan (2009) followed the experiences of regular education classroom teachers who worked with students who experienced FASD. Teachers expressed more concern over behavioral issues than academic problems. They perceived numerous problems among the students including wandering attention spans, being easily distracted, and avoiding assignments. Students experienced cognitive and content challenges such as difficulties with thinking skills, handwriting, and the writing process. Teachers in middle and high school noted manipulative behaviors, unpredictability, and volatile mood swings. All teachers mentioned that students were easily distracted with some individuals needing as many as ten prompts to refocus within a 90 minute class. Teachers saw several strengths in their students with FASD including good visualization, math and some physical education activities. Teachers felt it was important to keep a positive environment, and some teachers involved students in team-building activities or cooperative groupings to keep students involved. Teachers stressed the need for individualized attention and supplying additional explanations. They reported pressing students and/or becoming angry as ineffective in refocusing the student.

Interviews by Dybdahl and Ryan (2009) showed that teachers felt training on FASD was either non-existent or ineffective. All teachers were eager to learn better strategies and felt training should be extended to support staff. Recommendations included better in-service trainings and more research-based programs that focus on helping the classroom teachers.

Individuals with FASD often struggle with developing appropriate social skills. A study by Olswang, Svensson and Astley (2010) examined how social communication profiles during classroom activities differed between children with FASD and typically developing peers. Researchers observed how children spent their time interacting with other peers in the classroom. Children in the FASD group exhibited more adult-seeking, assertive, and hostile/coercive, behavior but the difference was not statistically significant. Both groups spent the majority of their time in prosocial/engaged behavior. However, children with FASD spent significantly less time in prosocial/engaged behavior and significantly more time in irrelevant or passive/disengaged behavior than the typically developing group. Overall, the children with FASD did not demonstrate the problems interacting with peers that has been seen in other studies. Researchers felt this was due to the structured classroom environment or that the children in this study were only mildly affected by FASD. As numerous studies describe the difficulty of individuals with FASD in developing appropriate social skills (Malbin, 2002; Rasmussen et al., 2010), I think this study shows the benefit of having a structured classroom.

The Streissguth et al. (1996) study found that 70% of adults with FASD had experienced some type of disrupted school experience including suspension, expulsion, or dropping out. Studies show that as individuals with FASD age, they frequently fall further behind in most areas of their life, including academics (Malbin, 2002; Rasmussen & Bisanz, 2009). Due to their inability to progress at the typical rate of their peers, many individuals with FASD will drop out of high school. Duquette, Stodel, Fullarton and Hagglund (2006) conducted a study examining persistence in high school of students with FASD from the student's perspective. The Duquette et al. (2006) study explored factors that motivate students to remain in school despite personal difficulties or obstacles. The research questions of the Duquette et al. (2006) study were: "What

are the school experiences of secondary school students with FASD, taking into consideration their background characteristics, academic integration, and social integration into the institution” and “Why do these adolescents persist in school?” (Duquette et al., 2006, p. 221). Data was collected from adolescents and parents through questionnaires and in-depth interviews. All parents reported that their children had problems with academic work, particularly math and reading; were easily frustrated with failure; and wanted to give up when they encountered a problem. Adolescents reported enjoying sports and three of the students reported enjoying art activities. The adolescents reported the aspect they liked best was being with their friends, and the least preferred was schoolwork. Most adolescents had started in a regular classroom and moved to more specialized placements when academic and behavioral problems started. None of the eight performed at grade level and all the students needed either academic or behavioral accommodations. From the adolescents’ perspectives, being successful meant passing their courses and earning a certificate or diploma. Although their academic requirements had been reduced to accommodate their disabilities, none of the students expressed concern that the courses were not the same for their non-disabled peers.

In the Duquette et al. (2006) study, of the eight students, five said they had a best friend, four said they had no trouble making friends, four stated they had trouble keeping friends but indicated they were comfortable with their peers at school. Yet, all of the parents reported that their children’s “friends” were actually only acquaintances (Duquette et al., 2006, p. 227). The data suggested that the youth were only aware of the conditions that were visible to them and were easily satisfied with their academic progress and their relationships with others. They felt academically and socially integrated into their schools.

The researchers concluded that the parent's support and advocacy, combined with their high expectations of the children, kept their children in school and helped the youth experience success both academically and socially. Important supportive factors of the youths' families included secure child-caregiver attachment, authoritative parenting style, and maintaining high expectations for their children. Those factors, along with the protective factor of parental advocacy produced a positive educational outcome. This study provides useful information on quality of life factors that my research will address.

Research shows that individuals with FASD struggle both academically and socially in the classroom. The studies also show affected individuals will have improved outcomes when using specific techniques and classroom strategies. Individuals experience more success at school when they are placed in a structured classroom with less visual stimulation. They also experience greater success when the teacher breaks down instructions, focuses on students' strengths, and finds ways to allow for frequent breaks. Classroom activities seen as helpful included team building exercises and cooperative classroom activities. Duquette et al. (2006) found that involved parents were key to the child's continuing educational success. These studies document that teachers and other educational staff need training on these key findings to ensure individuals with FASD be more successful at school.

Criminal Justice System

Numerous studies show that individuals with FASD represent a significant and disproportionate number in the Alaska and U.S. criminal justice system. For example, a report by the Alaska Behavioral Health and Research Services (State of Alaska DBR, 2006) states that corrections officers in Alaska estimate that 27% of the inmate population has FASD. Burd, Fast, Conry, and Williams (2010) researched fetal alcohol spectrum disorder as a marker for increased

risk of involvement within the U.S. corrections system. Using various studies of the overall prevalence of FAS and FASD within the United States, they estimated that up to 24% of the corrections population may have FAS or FASD. Streissguth, Barr, Kogan, and Bookstein (1996) had previously found that as individuals with FASD enter into adolescence, their risk of substance abuse and involvement with the correctional system increases significantly and may impact as much as 60% of this population.

Individuals with FASD are at risk of becoming involved with the youth or adult criminal justice system due to impulsivity, poor judgment, inability to foresee consequences and understand from their past mistakes, poor memory, deficient social skills and impaired abstract thinking. The trauma to multiple areas of the brain leads to difficulties in processing and integrating information, which may cause individuals with FASD to be easily led by others, have deficient risk perception, have poor attention spans, and miss the fine points or subtleties in communication. Their communication deficits may include being chatty and glib, and/or parroting information they have heard without understanding its meaning (Brown, Gudjonsson & Connor (2011, p. 47). Deficient executive functioning may cause individuals with FASD to hastily waive their rights, have difficulty understanding the legal implications of their legal circumstances and cause the individual to answer with whatever responses will satisfy the interrogator in order to end a stressful interview, and resulting in an unfair trial or a false conviction.

Brown et al. (2011) conducted a study to assess suggestibility as a vulnerability in individuals with FASD. They used the definition for interrogative suggestibility from a previous study by Gudjonsson and Clark (1986, p. 84): “the extent to which, within a closed social interaction, people come to accept messages communicated during formal questioning, as a

result of which their behavioral response is affected.” The researchers stated that suggestibility is relevant in understanding how individuals with FASD handle leading questions and the psychological pressure of police interrogation. Individuals with FASD showed significantly lower immediate recall for story elements when compared to general population norms. The total suggestibility for individuals in the forensic FASD sample was significantly higher than for the normative group. These findings cause concern about the accuracy of the individual’s statement in interrogations and the increased risk of false confessions (Brown et al., 2011, p. 61).

Burd et al. (2010) found that language and communication deficiencies in individuals with FASD may cause serious problems within the justice system and affect their right to fair treatment in all stages of the legal process. This would include initial interrogations, communicating with lawyers, participating in court, understanding the proceedings, ability to read social cues, and understanding the intentions of other people. Individuals with FASD may have impaired reasoning, which increases their chances of having difficulty in the legal system as well as being perceived as having a lack of remorse. A study by Burd, Cotsonas-Hassler, Martsof, and Kerbeshian (2003) found that 60-75% of individuals with FASD were impacted by attention deficit disorders, impulsivity, increased distractibility, and high activity level, further complicating their ability to manage their behaviors and comprehend the procedures within the court system.

Screening for FASD in individuals entering the corrections system in the U.S. seldom occurs. For example, although the prevalence of FASD in younger school children in the U.S. is estimated to be between 2-5% (May et al., 2009), a survey of the U. S. corrections systems by Burd, Selfridge, Klug, and Bakko (2004) showed that out of 3.08 million inmates, only one inmate was reported to have a diagnosis of FAS. With increased awareness of FASD in the

United States through the Center for Disease Control and Prevention (CDC), this survey needs to be updated.

Although there are no valid screening tools for FASD being currently used in the corrections system, Burd et al. (2010) recommends that all individuals who come into the correctional system should have their health records reviewed and be interviewed for mental health and substance use problems, along with undergoing a brief mental status exam. The Asante Centre for Fetal Alcohol Syndrome Probation Officer Screening & Referral Form has been developed for use with adolescents and is being used in Canada for children who are on probation. Other recommendations by the authors included: longer treatment or interventions; picture guides for teaching key concepts; maintaining a small group size for therapy or learning to allow the individuals with FASD to receive more attention; waiting to proceed with any new material until individuals with FASD have learned a concept; and staff training on impairments and appropriate accommodations.

Victimization

Victimization is a recurrent problem for individuals with FAS/FASD. The U.S. Department of Justice's 2007 National Crime Victimization Survey (NCVS) found that individuals age 12 and over who have a disability experienced approximately 716,000 nonfatal violent crimes including rape, sexual assault, robbery, aggravated and simple assault (Thiel et al., 2011, p. 122). A study by Baladerian (1999) suggests that crimes committed against individuals with FASD may be under-reported by 25-50%. Individuals with FASD are prone to social manipulation by others and may be hyper-suggestible. They are often eager to please others and may serve as the "fall guy" for real offenders who use them to commit a crime for the benefit of

the perpetrator (Brown et al., 2011). Yet most research on criminality related to individuals with FASD focuses on the individual as an offender rather than the victim.

For individuals with FASD, vulnerability and suggestibility may lead to numerous types of victimization. For example, Thiel et al. (2011) researched the vulnerability of individuals with FASD and how their victimization impacted families, various community services, and the judicial system. They explored how individuals with FASD are often victimized in ways that go unrecognized and unreported including children being labeled as having behavioral problems when the child has not been evaluated for FASD or individuals with FASD being used by others to commit a crime. They also explored the victimization of individuals with FASD when the system does not have adequate resources to assist them during law enforcement or judicial procedures when there are no accommodations to meet the special needs of these individuals. Thiel et al. (2011) discussed the three issues listed on the University of Washington's FASD Legal Issues Resource Center's Website that are likely to affect an individual with FASD in a judicial proceeding. First, individuals may not have a clear grasp of the distinction between reality and fiction which may impair their ability to assist their legal counsel. Second, difficulty with cause and effect processing, which may interfere with the ability to evaluate counsels' strategic advice. Third, individuals may be unable to follow the interchanges in a courtroom proceeding. These problems cause victimization when law enforcement and the judicial system do not factor in cognitive and other limitations associated with FASD when determining the appropriate legal procedures. Thiel et al. (2011) found that all areas of the justice system needs a better understanding of FASD and should develop appropriate interventions and accommodations. They recommend that communities need to work together to form interagency

task forces to address the problem of victimization among those with FASD and initiate public awareness (Thiel et al., 2011).

Incarcerating individuals with FASD in the criminal justice system is costly. Popova et al. (2015) conducted a study on the cost of individuals with FASD in the Canadian correctional system. The study estimated the number of youth and adults with FAS and FASD in the corrections system based on the overall estimated number of individuals with FAS and FASD in the general population, although data from Alaska and other studies would indicate that the numbers are much higher than in the general population (State of Alaska DBR, 2006; Burd et al., 2010). According to the Popova et al. (2015) study, the cost of corrections for youth and adults with FAS and FASD in 2011/2012 was estimated at \$373.7 million with \$330.7 million for males and \$43 million for females. The study estimated that the Canadian correctional system had over 4,000 offenders with FASD on any given day. The researchers argued that a portion of these costs could be avoided if standardized screening and diagnostic tools were standard practice. They also said that if the legal and correctional system understood FASD better, it would alter sentencing and help assist with probation plans. There are no similar studies in the U.S.

As these studies document, individuals with FASD are at risk of becoming involved with the criminal justice system due to their cognitive deficits. Research shows this population is easily victimized by social manipulation and suggestibility. Professionals within the criminal justice system need training on FASD to better understand the vulnerabilities of these individuals and how to best provide appropriate accommodations. The corrections system needs to screen for FASD so that individuals with FASD could receive appropriate interventions and make efficient use of limited resources.

Interventions

Several studies show progress in discovering effective interventions, or ways to improve quality of life, for individuals with FASD and their families. In 2001, the Center for Disease Control and Prevention (CDC) provided federal funding to help develop scientifically evaluated interventions appropriate for children with FASD and their families. Five grantees received federal funds to address the neurodevelopmental needs of children with FASD. All the interventions were designed to improve developmental outcomes by reducing secondary conditions and improving the lives of families (Bertrand, J. 2009).

Bertrand (2009) reviewed the outcomes of the five grant-funded innovative research projects. The first study was “project bruin buddies,” a social skills training program to improve friendships for children with FASD that researchers at the University of California at Los Angeles conducted (Bertrand, 2009, p. 989). The study examined the effects of parent-assisted children’s friendship training (CFT) on the social skills of children with FASD when compared with a control group (DTC) that later received the same treatment. Children were taught how to form a social network, interact with others during an activity, enter into a group of children already in play, social behavior needed for in-home play dates, and how to avoid conflict through negotiation. Parents taught the skills through simple rules of social behavior, modeling, rehearsal, and performance feedback during treatment sessions. Parents of both groups felt they learned more about FASD and had a high level of satisfaction with the intervention. Children in the CFT showed statistically significant improvement in their knowledge of appropriate social behavior, and results from a three-month follow-up showed that the children’s social skills knowledge, improvement in social skills, and decrease in problem behaviors were maintained over the three months.

Bertrand (2009) also evaluated the effect of a socio-cognitive habilitation program designed to improve the behavioral and mathematical functioning of children with FASD at the Marcus Institute in Georgia. This study used a psycho-educational program that provided learning strategies to compensate for core alcohol-related neurodevelopmental deficits. The program included intensive, short-term individual instruction along with training for the child's caregiver and teachers. The study aimed to provide a consistent method of instruction across all environments. Pre- and post-test scores showed significant gains in knowledge of FASD, advocacy topics and behavioral regulation. Of those children in the mathematics treatment group, 59% demonstrated a gain of over one standard deviation on any of the four mathematics outcome measures while only 23% of those in the psycho-educational group did so. There were no follow-up evaluations done to see if the improvement was long-term; however, the study shows that effective teaching methods can improve learning for children with FASD.

The third study evaluated by Bertrand (2009) was conducted by the Children's Research Triangle in Illinois, aimed to develop and evaluate a program of neurocognitive habilitation for children who had been in foster care or who had been adopted and who have FAS or ARND. The program provided education and support to enhance the families' ability to care for the children and focused on improving the children's executive functioning. Children who participated in the neurocognitive habilitation program demonstrated significant improvement in executive functioning skills compared with children in the control group. Children appeared to learn the regulatory strategies and techniques taught in group and parents saw improvements in the children's overall executive functioning skills. The study suggests that neurocognitive habilitation programs are a promising approach to help foster and adopted children with FASD improve their self-regulation and executive functioning skills.

Bertrand (2009) also evaluated a study conducted at the University of Oklahoma Health Sciences Center, which evaluated two group-based interventions for children with FASD that would reduce behavior problems and decrease parental stress. One treatment based on Parent-Child Interaction Therapy (PCIT) (Eyberg & Boggs, 1998), provided both parents and children with ongoing coaching of behavioral parenting skills. The other intervention was a parent-only Parenting Support and Management (PSM) program using components from other effective behavioral programs (Barkley, 1997; Webster-Stratton, 2001). Both groups showed improvement over time across outcome measures and intervention conditions, with no statistically significant differences found between the two interventions. Parental distress improved significantly over time, and child behavior problems also improved in both groups. The study shows promise for reduction in behavior problems through using a parent-only support and education intervention.

The fifth study evaluated an intervention called Families Moving Forward (FMF) conducted by researchers at the University of Washington. The FMF intervention was designed in 2002 to reduce child problem behaviors through helping to meet family needs, to develop caregiver self-efficacy, and to learn how to create “accommodations” in the physical and caregiving environment (Bertrand, 2009, p. 1000). The model was designed to modify parental attitudes and responses toward their children’s problem behaviors. Ninety-six percent completed the full nine to eleven month treatment. Results showed a significantly improved sense of self-efficacy following the intervention in addition to more self-care behaviors within the FMF group as compared with the control group. The FMF group showed a significantly improved sense of parenting self-efficacy and reported being involved in more self-care behaviors. Children in the FMF showed a significant decrease in the number of disruptive behaviors. There were no group differences regarding child-related parental stress.

The Bertrand (2009) study illustrates that parent education or training can improve the outcomes for children with FAS/FASD. The study also shows that children with FASD demonstrate the capacity to learn new skills through explicit instruction. Use of explicit instructions differs from observation or abstracting knowledge from ongoing situations, methods through which typical children often learn. Notably, this study used specific interventions for children with FASD, rather than using interventions developed for other populations with cognitive deficits (such as ADHD) and generalizing the interventions to individuals with FASD.

As an earlier intervention strategy, researchers are trying to identify the mechanisms that contribute to the alcohol's teratogenic effects and to block those mechanisms or identify protective factors that may control or improve outcomes. Indrus and Thomas (2011) conducted a review of experimental treatment and interventions being studied for individuals with FASD. Strategies considered included administering N-Methyl-D-Aspartate Receptor Antagonists during pregnant women's withdrawal periods to help reduce the alcohol effects, injecting Serotonin Agonists in vivo or in vitro to prevent alcohol-induced cell death, using pharmacological agents to reduce the severity of FASD, using various antioxidants such as resveratrol, curcumin, epigallocatechin-3-gallate from green tea, Vitamin E, C, and beta carotene to protect against alcohol-related growth retardation, and administering choline or other nutrition supplements to reduce the severity of alcohol effects.

Although most of these treatments/interventions are used during the pregnancy, Indrus and Thomas (2011) also researched treatments for individuals who are born with FASD. They found that choline may benefit children born with prenatal alcohol exposure. They also found that the ability of the brain to change (CNS plasticity) may be enhanced through the use of

pharmacological agents and through various environmental interventions, including social, motor and sensory stimulation.

Considering economic, family and societal implications, FASD represents a major public health issue. Yet little progress has been made in reducing these challenges. Researchers have made some progress in understanding the way alcohol damages the fetus and in the potential prevention of the damage incurred through pharmacotherapeutic interventions (Warren et al, 2011). Yet the only diagnoses of prenatal alcohol exposure currently accepted in the medical and psychiatric communities are Fetal Alcohol Syndrome (FAS), and now Neurobehavioral Disorder associated with Prenatal Alcohol Exposure (ND-PAE), which was added to the Diagnostic and Statistical Manual V in 2013 (Kable et al., 2016). Therefore, many FASD children never have access to services from which they could benefit. Studies on effective interventions for individuals with FAS/FASD continue at a slow pace with few clearly effective remedies. Some progress has been made in developing and testing interventions designed for children with FASD who struggle with primary and secondary behavioral characteristics. Yet we know that most of these studies have a limited sample size and do not include follow-up assessments. Most research-based interventions have focused on school-aged children and few studies address interventions for adolescents and/or adults. Although specialists know that early intervention is best, the Washington State FAS Diagnostic and Prevention Network showed that the average age of referral for diagnosis in its clinical sample was 9.5 years. A report by Paley and O'Connor (2011) show that more population-based studies are needed to identify alcohol-exposed individuals who exhibit significant impairments but do not have access to medical or mental health services. Many challenges lie ahead in developing appropriate interventions and effecting

collaboration of health services, education and community supports to assist families and individuals, as well as to decrease the societal burden of FASD.

FASD in Alaska

A 2015 Center for Disease Control and Prevention (CDC) report using 2011-2013 data from the Behavioral Risk Factor Surveillance System (BRFSS) showed that in Alaska, 53% of women who are of child-bearing age (between the ages of 18-44 years) report some use of alcohol and 21% report some binge drinking. The report showed that across the United States 10.2% of pregnant women report some alcohol use in the past 30 days and that 3.1% report binge drinking. According to the report, many women continue to drink through their first weeks of pregnancy before they know they are pregnant. Those first few weeks are a critical period for organ development. With Alaska having a high per capita alcohol consumption level (CDC, 2015), the percentages of pregnant women who drink alcohol may be much higher than the national average.

In 2002 the CDC published findings from the Fetal Alcohol Syndrome Surveillance Network (FASSNet), a standardized, multiple-source FAS surveillance system supported by CDC (2002), from four states: Arizona, Alaska, Colorado, and New York. Researchers reviewed records of children born between 1995 and 1997 to all mothers residing in the surveillance areas, to identify children with the diagnosis of FAS. Records for 1,489 children were reviewed. A total of 185 children met the definition of confirmed or probable FAS. The prevalence in Alaska was 1.5 per 1000 live births with the prevalence in the other three states ranging from 0.3 to 0.4 per 1000 live births. The higher prevalence in Alaska reflected the high rate within the American Indian and Alaska Native population. Substance abuse among First Nations people, particularly binge drinking, has been linked to historical trauma and loss of culture, resulting in lower health

status and health disparities (Myhra, 2011). Although rates of FASD are higher among these groups, FASD exists in all cultures that consume alcohol.

Khan et al. (2013) conducted a more recent study at Southcentral Foundation's Primary Care Center in Anchorage, Alaska. This center provides pre-paid primary care services to approximately 45,000 Alaska Native/American Indian (AN/AI) women from Anchorage and remote rural surrounding areas. In the study, 125 pregnant women in their third trimester completed a questionnaire on the amount and frequency of alcohol consumption the month before they conceived and during pregnancy. Of these, 56% reported no alcohol consumption in the first through the third trimester; 35% reported alcohol use only within the first trimester; and 20% reported binge drinking in the first and/or second trimester. Women who reported binge drinking the month before conception were significantly more likely to report binge drinking during the first and second semester. No participants reported binge drinking during the third trimester. This study shows that the alcohol use among pregnant AN/AI women continues to be higher than within the general population and continues the ongoing concern for AN/AI infants being disproportionately impacted by prenatal exposure to alcohol.

Although the rates of alcohol use among Alaska Native women are higher than the general population, it is important to note that FASD occurs among all peoples and cultures who drink alcohol. A report by the Fetal Alcohol Community Evaluation Services (FACES) Diagnostic Team in Fairbanks analyzed their completed diagnoses for 2010-2015. Of those diagnosed, 32.2% identified as White/Caucasian and 13.7% identified as Black/African American. The FACES report documents that FASD is a serious and prevalent problem within our state that affects all our communities.

The 2017 McDowell Report, prepared for the Alaska Mental Health Trust Authority on the economic costs of alcohol abuse in Alaska show the incidence of FASD in 2014 at 11.3 per 1000. This rate only includes infants who are diagnosed at birth. Infants with full FAS are easily diagnosed at birth but those within the FASD spectrum often go undiagnosed or are diagnosed later, such as when they have difficulties at school. The report states there were 129 individuals born in 2014 who were given a diagnosis within the FASD spectrum at birth. The report estimated the annual cost per person with FASD was \$23,115, with an estimated annual total FAS cost for these individuals at \$2,974,548. The report states there are no data available for children later diagnosed with FASD, so the annual costs are presumed to be underestimated for all individuals with FASD.

Johnson et al. (2010) conducted a study on the knowledge, attitudes and behaviors of various professionals in Alaska regarding FASD. Researchers mailed a survey to six groups of professionals: physicians, educators, correctional staff, social workers, public health nurses, and substance abuse counselors. Most of the participants had good basic knowledge of FAS and the risks involved with prenatal exposure to alcohol. The range for providing correct responses about FAS risk was 91.8% for substance abuse counselors to 64.5% for medical physicians. All professionals had good general knowledge of FAS with correctional staff scoring the lowest at 89.7%. Overall, all professionals reported becoming increasingly willing to confront a pregnant friend or relative about their drinking or recommend treatment as their consumption of alcohol became more frequent and severe. The most concerning finding in this study was that while physicians showed good understanding of the effects of FAS, scoring 95% general FAS knowledge, 17% of the physicians endorsed occasional alcoholic beverage consumption during pregnancy (Johnson et al., 2010, p. 633).

In 2010, Brems, Boschma-Wynn, Dewane, Edwards and Robinson assessed to what extent FASD education was being used in academic programs and included in curricula in Alaska. The on-line survey assessed FASD-educational needs and covered the healthcare fields of medicine, behavioral health and allied health programs. The 20-minute survey included questions regarding current FASD-related program activities, relevance of the CDC's FASD Core Competencies to their program, the perceptions of various FASD resources and whether FASD-related knowledge should be a requirement for maintaining a license or certificate.

The results showed that academic directors of medical and rurally-based healthcare training programs endorsed the idea of FASD education but showed little interest in adding FASD education to their curriculum or collaborating with FASD regional training centers (RTCs) to provide training. Approximately 13% of the programs in allied health offered courses that included education about FASD. In the behavioral health disciplines, 91% offered some FASD content. These educational deficits shed light on Alaska health care providers' difficulty in recognizing pregnant women at risk, and failure to make referrals for early intervention for children with FASD. Medical providers are often the first to interact with women of child-bearing age when they are seeking to become pregnant or when they first become pregnant, yet medical program directors ranked "screening and brief intervention" as their least relevant competency (Brems et al., 2010, p. 24).

In September 2012, Alaska became the first state in the United States to pass a statute that allows judges to reduce a felony sentence when there is clear and convincing evidence that the defendant committed the offense while suffering from fetal alcohol spectrum disorder (FASD) (AK Stat. §§ 12.55.155(d)(20)(A), 2012). An article by Tibbett and Jeffery (2016) reviewed the effects of this statute, along with progress made within the state of Alaska on

services or supports to individuals with FASD. In July 2014, twelve Alaska Superior Court judges in all four of the state's judicial districts were surveyed. None of the respondents reported having heard this statute or mitigating factor argued in court. Although the statute offers more humane treatment for those with FASD and the state would benefit from significant cost savings, if individuals with FASD spent less time in the correctional facilities, attorneys and judges do not use the statute likely because few adult individuals with FASD are diagnosed and the statute does not provide judges a means to secure a diagnosis. Other concerns expressed by judges and state personnel were the lack of general knowledge about FASD by both attorneys and judges, and the lack of services available to individuals with FASD as alternatives to incarceration.

In Alaska, where many professionals in the field believe Alaska to have the highest rate of FASD in the United States, there are few studies on FASD and how individuals, families, schools and communities are affected by this life-long disability. There is only one other study on FASD in Alaska, which is included under the next section on quality of life.

Quality of Life

Definition and History

Quality of Life (QOL), according to the Centers for Disease Control and Prevention, is “a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life” (CDC, 2011, p. 1). The concept includes health, housing, education, job opportunities, culture and other aspects of life, including values and spirituality. QOL is challenging to measure. Although the term “quality of life” has meaning to most people, specific meanings differ among individuals and across cultures.

Approaches to researching QOL fall into two broad categories: a health related approach that focuses on life quality as a result of a specific health problem; and a social approach that

considers the subjective experience of the individual. Before the mid-1900s, health professionals defined health in terms of morbidity or mortality (CDC, 2011). With better treatment and increased knowledge of nutrition, life expectancies increased and the focus of health broadened to include quality of life. The concept of health-related quality of life (HRQOL) came into being in the 1980s and includes overall QOL aspects that affect people's physical and mental health or well-being (CDC, 2011).

Improving HRQOL has become a national public health goal for the United States (CDC, 2011). Measuring HRQOL and QOL have become useful means for researchers, health practitioners, social service agencies, and policy makers to better evaluate service needs, service outcomes, and/or interventions. Both measures help assess the effects of disease, injuries and disabilities and monitor progress in achieving goals. All QOL data can help to identify unmet needs, develop future strategic plans and monitor the effectiveness of various community programs. The data from HRQOL and QOL studies are used to develop more effective health policies and other legislation (CDC, 2011).

An increased interest in QOL developed in the 1990s. The belief that scientific, medical and technological advances alone improved quality of life evolved to an understanding that personal, family, community, and societal well-being are also important (Verdugo, Schalock, Keith, & Stancliffe, 2005). Researchers shifted from only assessing community-based services to measuring outcomes associated with the individual's life in the community. Individuals' perceptions and values came to be recognized as key components in the concept of QOL. Consumer empowerment and the patients' rights movement helped place more emphasis on "person-centered planning, personal and valued outcomes and self-determination" (Verdugo et al., 2005, p. 708).

Measurement of QOL

Interest in measuring QOL rests on three premises (Verdugo et al., 2005). First, QOL is important to all people and should be considered in the same way for all people, regardless of their disabilities. Second, measuring quality of life is necessary to understand the degree to which individuals experience QOL and personal well-being. Third, QOL is a combination of factors commonly understood by individuals throughout the world, as well as aspects of life valued by individuals within their own environment; that is, factors that vary by region, culture, and individuals. QOL for individuals therefore seeks to discover their own perspectives and involves assessing the perceptions of their personal satisfaction or happiness.

Since the 1980s, researchers and institutions around the world, including the World Health Organization (WHO), have developed ways to measure quality of life. WHO's Constitution defines health as "a state of complete physical, mental, and social well-being not merely the absence of disease" (WHO, 1997, p. 1) At the Sydney Roundtable on QOL in October 2004, a focus group developed the following four principals to guide QOL measurement: QOL involves life experiences that individuals value; reflects domains that encourage a full and interconnected life; takes into account the physical, social and cultural areas that are important to people; and includes measured experiences that are not only common to all people but are also unique to individuals. The World Health Organization, with the assistance of 15 collaborating centers around the world, developed two instruments for measuring QOL: the WHOQOL-100 and the WHOQOL-BREF. The tools focus on the individuals' own views of their personal well-being. The six domains covered include physical health, psychological health, level of independence, social relationships, environment, and spirituality/religion/personal beliefs. Under each domain are facets or indicators of QOL. Both tools can be used in various

cultural settings and are designed to be used in medical practice, research, audit, and policy-making (WHO, 1997).

In the United States the primary focus of QOL has been on Health-related Quality of Life (HRQOL). The CDC defines HRQOL as “an individual’s or group’s perceived physical and mental health over time” (CDC, 2011, p. 1). The Office of Disease Prevention and Health Promotion established a Healthy People program to promote goals that increase QOL and years of healthy life, and that eliminate health disparities. The Division of Adult and Community Health (DACH), within the CDC’s National Center, established a set of measures that various states and communities can use to assess HRQOL. As a result, this standardized tool is now available for use in all states and communities and is used by the U.S. national health surveillance system. The Healthy Days Measure includes a combination of broad questions about perceived health status and activity limitation within the past 30 days. The measure assesses a peoples’ perceived sense of well-being concerning their health status and physical limitations (CDC, 2011).

The four core questions on the Healthy Days Measure are:

- 1) Would you say that in general your health is excellent, very good, good, fair, or poor?
- 2) Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?
- 3) Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?

- 4) During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

The first question measures overall self-rated health using a scale from poor to excellent. Questions two and three separate physical health from mental health, to link QOL to the appropriate medical, mental health, or behavioral medicine field. The combined total for questions two and three capture the overall number of unhealthy days. Research shows that the unhealthy days total provides a simple, yet valid, comprehensive measure for the individual's perceived physical and mental health over time. Estimating the gravity of disease or disability in days provides a concrete measure that can be understood by legislators and policy makers to assess cost-effectiveness of interventions (CDC, 2000). Question four is a global indicator of the individual's perceived disability, as well as an indicator for productivity and human capital. This core set of Healthy Days Measures has been used by all 50 states since 1993 when they became the first four questions of the Behavioral Risk Factor Surveillance System (BRFSS).

The BRFSS is an ongoing, state-based, random telephone survey of U.S. adults aged 18 and older and is the largest, ongoing telephone health survey in the world. The survey is a valuable source of systematic, comparable data on health in the U.S. The Healthy Days questions were also added to the National Health and Examination Survey (NHANES) in 2000, a program designed to assess the health and nutritional status of adults and children in the United States. It is unique as a standardized health measure in that it combines interview with physical examination data (CDC, 2011).

The four basic questions allow comparison of population subgroups to the general population, but the questions did not provide enough information to identify specific health issues or interventions. Therefore, in 1995, the CDC collaborated with several state and

community health agencies to develop the expanded HRQOL-14 questionnaire which allows states and communities to measure both short-term and persistent physical and mental health problems. The HRQOL-14 will allow disease-specific health planners and legislators to better allocate resources among health programs and guide health policy by tracking both short and long-term effects of various health programs. The CDC also sees the HRQOL-14 as a cost-effective means to assess population needs and susceptibility to the incidence of disease (CDC, 2011).

Since its inception, the HRQOL has revealed useful information that may shed light on the consequences of FASD in Alaska. The 1997 BRFSS report on selected sociodemographic groups shows that 15% of American Indians/Alaska Natives had 14 or more days of frequent mental distress in the last 30 days. This was the highest reported percentage among all groups, with the range for all groups being between 5.8% and 15%. Other studies have shown this is also the group with the highest percentage of individuals with FASD (Goldsmith et al., 2004). Also, a clear pattern emerged between healthy days and the four seasons. Unhealthy days were 10% higher in winter months. This may be significant to those who live in Alaska where winter months extend beyond the listed January, February and March.

Numerous other measures have been developed through the years to measure HRQOL, family QOL or individual QOL. Globally, and with some variation, most researchers today agree on eight major domains for assessment of individual QOL: interpersonal relations, social inclusion, personal development, physical well-being, self-determination, material well-being, human rights, and emotional well-being (Schalock, 2004). Schalock, Verdugo and Braddock (2002) stress that assessment of QOL domains and indicators needs to occur where the individual lives. They discuss three levels of systems that affect the individual's overall quality of life: the

microsystem is the immediate social setting that includes family, home, peer group and workplace; the mesosystem is the neighborhood, community, and service agencies or organizations; and the macrosystem is the culture, social-political trends, economic systems and society-related factors. Both objective and subjective QOL measures should be used to assess how all three systems affect quality outcomes for individuals.

Although quality of life has traditionally been evaluated by others, current research shows the value of involving the individual in the measurement process. Bertelli, Bianco, Rossi, Scuticchio, and Brown (2011) conducted research in Italy comparing quality of life for individuals with intellectual disabilities and the life quality of their families. Little relationship was found between the perceptions of the individuals with intellectual disabilities (ID) and other people, including family members. Other studies have also shown that individual self-reports and reports by caregivers, families and friends on QOL often differ (Schalock, Brown et al., 2002). The researchers advise that proxies (caregivers, families, or friends) should only be used to measure the individual's QOL when absolutely necessary, or as additional information to gain a broader perspective on the individual's QOL. Before using proxies alone, attempts should be made to simplify the wording of questions, provide pictorial response alternatives, or use interpreters. If individuals are unable to speak for themselves, direct observations should be made along with gathering information from families and friends (Schalock, Brown et al., 2002). This concept was important to my research as I chose to understand how FASD affected quality of life from the perspective of individuals.

Furthermore QOL measurements must take cultural differences into consideration (Verdugo et al., 2005). What is important in one culture may be completely insignificant in another. For example, views on material well-being vary greatly according to national and

regional norms (Verdugo et al. 2005, p. 712). Individualistic versus collectivistic cultures perceive self-esteem differently. Along with cultural considerations, it is also necessary to take the individual within the culture into account. Individuals, as well as cultures, may value and experience happiness, well-being, or life satisfaction differently. In Alaska, cultural differences vary according to personal beliefs, family values, traditions, and the level of assimilation by minority and indigenous groups and individuals into the dominant society. Individuals from rural areas may value the solitude and spirituality of the wilderness, whereas those from urban areas might be bored and lonely when surrounded by nature.

Quality of life is a relatively new concept that assesses health and other aspects of life which the individual values. Measuring quality of life has become an effective way for researchers, health practitioners, social service agencies and policy makers to evaluate service needs, service outcomes, interventions, and their cost effectiveness. My research gives individuals with FASD and their families the opportunity to share their perspectives on how FASD affects quality of life and what supports have been most helpful. This could provide valuable information on the effectiveness of current services and what supports and resources would be most helpful.

QOL for Individuals with FASD

All human beings have an interest in QOL, including people with intellectual disabilities. As has been demonstrated in this chapter, FASD is both a developmental and an intellectual disability. Individuals with FASD may have physical impairments, mental deficits, problems with behavior and learning, or any combination of these conditions. Assessing quality of life for individuals with FASD can shed light on the individual's disability, evaluate present interventions that are being used, and reveal how the disability affects life within the individual's

microsystem, mesosystem, and macrosystem. Individuals with FASD exhibit a broad continuum of strengths and deficits. It is important to measure both the individuals' needs and their own assessment of quality of life so that assumptions are not made based solely on their disabilities.

My review of the professional literature found only two QOL studies that focused specifically on individuals with FASD (Stade et al., 2006; Ryan & Ferguson, 2006) but extensive research has been conducted on how intellectual disabilities affect QOL. Verdugo, Navas, Gomez, and Schalock (2012) conducted research on how the concept of quality of life could enhance human rights for individuals with intellectual disabilities. They analyzed the relationship between the eight core QOL domains and the 34 Articles developed by the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to promote, protect, and ensure that individuals with disabilities can fully enjoy their human rights and receive full equality under the law. They noted that before the 2006 Convention, no international treaties or legally binding documents addressed the rights of individuals with disabilities. The United Nations General Assembly adopted the UNCRPD articles on December 13, 2006. The articles contain elements similar to the eight major life domains recognized by most researchers. This was a positive step towards ensuring that all individuals with disabilities, including those with FASD, have a better quality of life.

Verdugo et al. (2012) postulated that the adopted articles focused only on the political or macrosystem level. The researchers wanted to develop a cross-cultural QOL construct that focused on the personal life of the individual, and to operationalize and measure the rights endorsed in the articles. Table 1 illustrates the framework they developed to ensure that all people's rights are respected, and to assist policy makers, service providers, and other individuals

assess how human rights are reflected through improved human functioning and personal outcomes.

Morisse, Vandermaele, Claes, Claes, and Vandeveldel (2013) investigated whether the QOL paradigm domains are universal and can be used for individuals with intellectual (ID) and co-occurring mental health problems. This study is important for individuals with FASD because research shows these individuals often develop co-occurring mental health diagnoses (Streissguth et al., 1996; O’Connor, 2014). Although the QOL framework supports the right to

Table 1. Factors for Quality of Life

<i>Factor</i>	<i>Domain</i>	<i>Exemplary Indicators</i>
Independence	Personal development Self-determination	Activities of daily living Choices, decisions, personal goals
Social	Interpersonal relations Participation Rights	Social networks, friendships Social inclusion/Community Involvement Human and legal
Well-being	Emotional well-being Physical well-being Material well-being	Safety and security Health and nutrition status Financial status, employment

equality of all people, including those with intellectual abilities, the research aimed to assess the realities of daily practices, given the difficulties that individuals with co-occurring mental health problems experience. Morisse et al. (2013) established focus groups in the northern part of Belgium to address two questions: 1) “Are the QOL dimensions conceptualized in the model of Schalock (2004) applicable for persons with both ID and mental health problems?” and 2) “What are the indicators relating to the above-mentioned dimensions in relation to persons with ID and mental health problems?” (Morrisse et al., 2013, p. 1). In answering the first question, focus groups mentioned all eight QOL domains with emotional well-being, interpersonal relations,

self-determination, and social inclusion being mentioned the most often. The study confirmed the relevance of the eight-domain conceptual model for this population. Answers to the second question showed that indicators should be more specifically tailored to the individual needs of the person with ID. For example, the individual's desire for freedom often requires regulation, due to health and safety concerns. Although both family members and staff supported giving the individual choices, they felt, in most cases, that offering a limited number of choices was best. The study may be helpful in how to address individual needs for individuals with FASD.

Just two QOL studies on individuals with FASD have been published – one conducted in Canada and the other in Alaska, both in 2006. Stade, Stevens, Ungar, Beyene, and Koren (2006) conducted the Canadian study which measured health-related quality of life for individuals with FASD and the overall burden resulting from prenatal exposure to alcohol. In Canada, the estimated incidence of FASD is one in 100 live births, close to some estimates for Alaska. The researchers used the Health-Related Quality of Life (HRQOL) framework from Cadman's concept of HRQL (Cadman, 1986). Cadman focuses on how disease or illness impacts the functioning of an individual in everyday life and the individual's ability to have a useful and fulfilling life. The study sought to measure the impact of FASD on the HRQOL of children and youth ages eight to 21 years living in urban and rural communities in Canada. The study used the Health Utilities Index (HUI), previously used in Canada to examine the HRQOL in children and youth with and without other disabilities, so there was already a comparison group.

One hundred twenty-six children and their families participated in the study. The HUI measured eight health attributes: vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain. Results showed that the children with FASD had moderate to severe dysfunction on cognition and emotion, which negatively impacted their overall HRQOL scores.

The HRQOL of the children and youth in this study was significantly lower than that of the general Canadian population. When comparing children/youth with FASD to children with other disabilities or illnesses, the children/youth with FASD exhibited extremely low scores. The HRQL scores of children with Fetal Alcohol Effects (FAE) resembled those with FAS. The researchers surmised this might have owed to children with FAE being more assimilated into the general population, but unable to perform at the expected levels. Children and youth with FAS had more organ anomalies and lower cognitive functioning than others in the FASD spectrum. The mean HRQL scores of children/youth with FASD resembled most closely those of other cognitively impaired children and adults, as well as depressed adults. Children rated their HRQOL slightly higher than their parents did. All the children reported they had a close relationship with their parents, and some credited the support they received from their biological, adoptive or foster parents with their success in coping with FASD.

In the second such study, Ryan and Ferguson (2006) conducted a three-year examination of the lives and experiences of families and professionals who lived or worked with five Alaskan students with FAS or FASD. Parent navigators, who are parents whose role is to advocate and support a family through the diagnostic process, identified participants. Researchers interviewed 71 individuals including the five students; biological, adoptive, or foster parents; extended family members; parent navigators; diagnostic team members; and adults involved in their education system. Four of the five students, ranging in age from three to 21 years, lived in rural villages with populations from 554 to 7,900. Data included semi-structured interviews, classroom observations, meetings with families and professionals, and a review of documents such as

Individualized Educational Plans (IEPs)⁴ and school performance data. Observations included 400 hours in the students' schools, homes, and communities.

All five participants with FAS/FASD in the Ryan and Ferguson study (2006) experienced early trauma due to living with mothers who continued to heavily consume alcohol after birth, or being placed in homes where alcohol was a problem. Three of the five students had used alcohol and/or marijuana. Teachers and parents surmised that children with FASD were at increased risk of substance use due to their biological parents' history and due to their elevated vulnerability to peer pressure. All five students received special education services and two of the five children spent some of the time during the three year study in a residential treatment facility. Four of the five children interviewed were in the care of foster or adopted parents and most had lived in multiple foster placements or residential care facilities.

Findings from the Ryan and Ferguson study (2006) showed that experienced teachers were more able to adapt their instruction to the students' needs by using more repetition, consistency and practice. One teacher who had a background in Montessori philosophy used redirection and setting physical boundaries to better accommodate the needs of students with FAS/FASD. Inexperienced teachers struggled with using individualized instruction techniques and understanding how to address the wide range of educational needs within the classroom. Ryan and Ferguson (2006) identified an important component of individualizing services which was to focus on the strengths of the individual with FASD and reported that many of the students experienced good adaptive skills such as competence in the out-of-doors. All the teachers felt that the students with FASD would need lifelong supports within the community.

⁴ IEP: a document that is developed by a team of school personnel and parents to individualize services for a child who need special education.

Parents reported numerous challenging behaviors of their children, from simple annoyances such as inability to complete chores and lying, to serious misbehaviors such as stealing, setting fires, and using illegal drugs or alcohol. Most families were frustrated by the lack of supports and services available. Although all five students were assessed by FAS diagnostic clinics, receiving a diagnosis of FAS or FASD did not ensure that the students received additional services or increased supports. A few individuals received some respite care but services were often inconsistent. Caregivers reported they sometimes had to send their children to residential treatment facilities due to the serious nature of the children's behaviors. Ryan and Ferguson note that parents and caregivers were often overwhelmed with the challenging behaviors and expressed the need for additional services for students with FASD, as well as supports for family members.

Family QOL is becoming an area of interest as parents in studies on other disabilities express various concerns about how raising a child with a disability affects quality of life for themselves and other family members. Brown, MacAdam-Crisp, Wang and Iarocci (2006) conducted a study on family quality of life when raising a child with a developmental disability. The study compared QOL for families who had a child with Down syndrome, families with an autistic child, and families of similar household composition but without a child with a disability. Children with autism have several similar difficulties to children with FASD, such as acting out behaviors and lack of social skills.

Families without a disabled child showed statistically significant higher levels of satisfaction across all domains including health, financial well-being, support from other people, spiritual and cultural beliefs, careers and preparation for careers, leisure and enjoyment of life, and community and civic involvement. Families with a Down syndrome child had a higher level

of satisfaction than the families with an autistic child. Forty-one percent of the families with a child diagnosed with autism perceived they had little opportunity to engage in activities which would maintain or improve family health and 69% reported they had no time for leisure or education due to a lack of respite. These findings may resemble the experiences of families raising children with FASD.

Conclusion

The life-long effects of prenatal exposure to alcohol were first identified in the United States at the University of Washington in the early 1970s by Jones, Smith, Ulleland, and Streissguth (Warren & Hewitt, 2009). Since the identification of FAS, researchers now recognize a full spectrum of disorders based on the timing of the prenatal alcohol exposure, the amount of alcohol ingested, and other variables such as genetics, age of the mother, and nutrition. Individuals with FASD may experience physical abnormalities, central nervous system damage, and/or difficulties with executive brain functioning. Disabilities may include problems with speech and language, cognition and learning, or processing deficits. Current research shows that children with FASD perform lower in all three major life domains: communication, daily living skills and socialization (Ase et al., 2012). Due to these deficits, children and youth with FASD frequently struggle within their families, school and community settings, often needing more effective interventions (Dybdahl & Ryan, 2009; Ryan & Ferguson, 2006).

Individuals within the FASD spectrum may develop secondary disabilities that arise as they are unable to manage within their environment (Malbin, 2002). Secondary disabilities occur less often in individuals with FAS and more often in those with FASD and higher IQ's, likely because FASD oftentimes is undiagnosed, and the disabilities are less obvious and distinctive than for those with diagnosed FAS. These secondary disabilities include mental health problems,

disrupted school experiences, trouble with the law, confinement in an institution, inappropriate sexual behavior, or difficulties with substance abuse (Streissguth et al., 1996). All of these affect quality of life.

Individuals with FASD struggle within the educational system due to their significant cognitive, behavioral, emotional and/or social difficulties. Teaching styles are often not effective as individuals with FASD often struggle with hyperactivity, short attention spans, poor memory, auditory and vocal processing and poor social skills. Individuals within the FASD spectrum may not have a diagnosis, which causes them to be seen as behavior problems instead of having disabilities (Blackburn, Carpenter & Egerton, 2010; Carpenter, 2011).

Families raising a child with FASD experience many challenges. Biological parents may experience ongoing guilt and may continue to struggle with substance abuse or mental health issues, while trying to meet the needs of a difficult child. Adoptive and foster parents may not fully understand the effects of FASD and have difficulty understanding the challenging behaviors of the children while wondering why they are not responding to typical forms of instruction or discipline. Studies show that families of individuals with FASD often experience significant child-related stress, lack of supports, and the need for ongoing advocacy for their children within the professional community (Whitehurst, 2012; Olson et al., 2009).

Research shows that Alaska has a high incidence of alcohol use. The 2017 McDowell Report documents the prevalence FASD in Alaska of at least 11.3 per 1000 births. This rate reflects only babies diagnosed at birth and fails to include the many affected children, youth and adults who are undiagnosed or diagnosed later in childhood. The McDowell Report nevertheless shows that the costs to the state are high, with the lifetime expense of serving an individual with FAS estimated at \$2 million dollars or higher.

Research has established that living in a stable family environment with infrequent changes in the living environment is a protective factors for individuals with FASD (Streissguth et al., 2004). Yet many children and youth with FASD in Alaska experience multiple placements within the foster care system. In my research all of the individuals with FASD lived in adoptive homes or with foster families.

The high incidence of FASD, as well as the scarcity of services in Alaska has been well documented. Individuals with FASD significantly impact the child welfare system due to the serious effects of this life-long condition. Their disabilities and difficult behaviors also cause stress and frustration in the families who strive to raise them. Challenges surrounding individuals with FASD impact the Alaska educational system. Studies show that the Alaska criminal justice system is also affected with an estimated 27% of the inmates having FASD. The Burd, et al. (2010) study shows that as many as 60% of individuals with FASD are involved in the criminal justice system at one time or another.

There is little research on FASD in Alaska and even less research on how FASD affects quality of life for affected individuals and their families. Quality of life is significant to all people, but has different meanings depending on the individual's perspective, experiences, and culture. Previous research shows that to garner meaningful information on QOL, it is essential to ask the individuals impacted by their disability, as well as family members, about how a disability affects their quality of life (Bertelli et al., 2011; Schalock et al., 2002). Using qualitative interviewing, my study will help to fill the gap on understanding QOL for individuals with FASD and their families. This research will allow individuals and family members to share personal experiences about how FASD has impacted their lives, what supports have been helpful to them, and what supports are needed to assist them in obtaining a better quality of life.

Information from this research will provide better understanding of the challenges individuals with FASD and their families face, and provide valuable information to professionals and legislators on the supports and services needed for individuals with FASD and their families. Supports and services, based on the actual needs of individuals and families will increase independence and overall well-being for affected individuals, increasing the quality of life for both individuals with FASD and their families.

CHAPTER III: RESEARCH METHODS AND DESIGN

This study explores how Fetal Alcohol Spectrum Disorder (FASD) impacts quality of life for both individuals with FASD and their family members. The results of this study should help families, providers, and decision makers better comprehend the effects of FASD, not only on individuals and family members, but also within schools and communities, and can provide guidance on how to direct finite resources and services to the right people.

The study addresses four research questions: 1) How has FASD impacted quality of life for affected individuals? 2) How has raising individuals with FASD affected quality of life for the family? 3) What supports were most helpful to the affected individual or the family? and 4) What supports not currently provided would be helpful to individuals with FASD or families? This chapter describes the study's research methodology, including the research approach, sampling procedures, data collection process, data analysis tools, ethical considerations, issues of trustworthiness, and limitations of the study.

Rationale for Qualitative Research Design

For this research, I use a qualitative approach and descriptive statistics. Qualitative research promotes the knowledge of a social phenomenon from the understanding of the research participants. It allows for rich description and exploration (Bloomberg & Volpe, 2016). Fossey, Harvey, McDermott, and Davidson (2002) clarify that the researcher strives to illuminate the “subjective meanings, actions and social contexts” of the research participants. My interactions with the participants helped me gain a more holistic view into the phenomenon of living with FASD while using qualitative analysis assisted me to “authentically depict the voices of the participants” (Bloomberg & Volpe, 2016, p. 40).

This study is grounded in the constructivist framework, which strives to understand lived experiences from the point of view of the research participants (Schwandt, 1994). There are two approaches within the constructivist framework. The personal construct theory focuses on understanding life experiences from the individual's point of view. The individual's expectations, past experiences and culture all affect the meaning of any life occurrence. Social constructivism views reality as socially constructed, with people developing meanings based on their experiences together (Williamson, 2006). This research relies on both the personal and social constructs. As the researcher, I need to understand the realities from both the individual and family's perspective, while also maintaining awareness of world views or biases that may influence my interpretation of these constructs (Bloomberg & Volpe, 2016).

Qualitative research provides the best methodology for assessing how FASD affects quality of life for affected individuals and family members because the researcher gathers data directly from the participants, who give their personal perspectives. Quality of life involves life experiences that people value and individual perceptions of their position in life. To assess quality of life it is important to understand what the individual values, not just what is generally accepted throughout the world (Verdugo et al., 2005; Schalock et al., 2002). I sought affected individuals' views on their personal experiences within their families, schools, and communities. I also asked parents to share their life experiences within the family and their communities, and to give examples of how raising an individual with FASD affected their quality of life.

Methods of Data Collection and Analysis

Participant Recruitment

For this study, I used purposive and snowball sampling. Purposive sampling is a type of nonprobability sampling through which the researcher chooses interviewees based on having

characteristics of a selected population or having experienced phenomena relevant to the research (Beail & Williams, 2014). As my research is on individuals with FASD and their family members, I chose only interviewees that fit this criterion. Following my IRB protocol, all interviewees were eighteen years or older. I did not set any guidelines for gender, race or ethnicity.

Snowball sampling is another nonprobability method in which the researcher asks interviewees to suggest additional people for interviewing (Babbie, 2011). Although I used snowball sampling throughout my interviewing process, none of the suggested individuals were available for interviewing. All of my interviewees came from three different sources: professional recommendations from the University of Alaska, the Fairbanks Fetal Alcohol Community Evaluation Services (FACES) Diagnostic Clinic, and the Presbyterian Hospitality House (PHH), which provides services for individuals with FASD. Several professors on my committee have friends or acquaintances who have adopted children with FASD. After the professors contacted their friends or acquaintances to obtain permission, they gave me their phone numbers so I could contact them to set up interviews.

I contacted the Coordinator for the Fetal Alcohol Community Evaluation Services (FACES) Diagnostic Clinic in Fairbanks to identify potential interviewees. Going through the Coordinators was not only important to secure agency approval to do research, but it also helped build trust with the interviewees, as the coordinator vouched for my credibility (Rubin & Rubin, 2005). The FACES Team facilitates the referral, screening, assessment and diagnosis of children and teenagers who experience difficulties due to prenatal exposure to alcohol. I had worked with the Coordinator previously, through my job at PHH, and she had stated that she would assist me with my research. She sent out an e-mail message to all the families the diagnostic team

supports, asking for volunteers to take part in the study. The Coordinator sent the e-mail from her office to maintain the confidentiality of the families involved with her team, allowing families to decide whether they wanted to be a part of this study. The message gave my e-mail address and phone number, so I could be contacted directly. When the volunteers contacted me, we arranged a time and place to meet that was convenient for them and ensured confidentiality.

I also contacted the Coordinator of the PHH Therapeutic Foster Care Program to see whether long-term foster parents or individuals with FASD who were 18 years and over might interview with me. I worked at PHH for over eight years, learning of the struggles of individuals with FASD. At PHH I saw how FASD affected quality of life, particularly as youth transitioned into adulthood.

PHH is a residential treatment program for teenagers who are Severely Emotionally Disturbed (SED). PHH also has a therapeutic foster care program for children younger than twelve, teenagers who do not need residential treatment, and those who have graduated from the residential program but are unable to return home for various reasons. PHH also has an independent living program for individuals 18-23 years of age who need additional assistance before being on their own in the community. All children and young adults who are in PHH programs undergo a Behavioral Health Assessment, which ensured that I would interview only individuals with FASD.

Prior to my inquiry for help identifying possible interviewees, I received approval from the PHH Board of Directors to conduct research at PHH, following IRB guidelines. PHH gave me the names of foster parents and individuals with FASD that were at least 18 years of age. I contacted these individuals by e-mail to ask whether they would interview with me.

I conducted interviews with individuals with FASD, long-term foster parents, and adoptive parents of individuals with FASD who were willing to be interviewed. When possible, I interviewed both the individual with FASD and a family member. In one case I interviewed both adoptive parents but not the affected individual. In another case, the foster mother I interviewed had two young men in the home with FASD, and I interviewed both young men. In total, I conducted twenty-two interviews: eight with individuals with FASD, three with long-term foster parents, and 11 with adoptive parents. These interviews gave me data on 18 different cases or individuals with FASD (See Table 2).

Participants

I sought two categories of research participants: individuals with FASD or their family members. All interviewees were at least 18 years of age. Although I knew some of the interviewees from my work at Presbyterian Hospitality House as a Mental Health Clinician, none of the previous clients I interviewed were still receiving residential services.

Individuals with FASD ranged in age from six to 35 years. Of the four cases under 18 years of age, one was six years and the others were in their teens; I did not interview these minors. I interviewed eight adults with FASD who ranged in age from 18 to 30 years. Although I did not set any guidelines for balancing gender within my interview sample, I interviewed four men and four women.

Family members were either adoptive parents or long-term foster parents. No biological parents volunteered to be participants. All long-term foster parents had lived with the individual with FASD for at least four years, an adequate length of time to understand how FASD had affected the individuals' lives and the lives of family members. The foster parents had several years to view the challenges that the individual experienced in a variety of settings: at school,

within the family and community, and in some cases, with employment. All participants lived in interior Alaska except one family (who lived in a small town near Anchorage). Of the 14 parents I interviewed, one was a man and thirteen were women (See Table 1).

Of the 18 cases of individuals with FASD, thirteen (72%) were Alaska Native, three (17%) were White, one (5.5%) was African American, and one (5.5%) was Alaska Native/African American (See Figure 1). Although all 18 cases fall within the FASD spectrum, six individuals (33.5%) are diagnosed with FAS, one of whom was also diagnosed with schizophrenia. Two individuals (11%) are diagnosed with Neurodevelopmental Disorder-Alcohol Exposed; one individual (5.5%) is diagnosed with Static Encephalopathy-Alcohol Exposed and one individual (5.5%) experiences FAE, an older label which is no longer used. This term was applied to individuals who met some, but not all of the criteria for an FAS diagnosis. The other eight individuals (44.5%) have FASD, which is not currently a medical diagnosis. Specialists on FASD Diagnostic Teams, neuropsychologists and medical doctors apply the term fetal alcohol spectrum disorder (FASD) to individuals with disabilities related to confirmed prenatal alcohol exposure who do not meet the level of a more specific diagnosis within the FASD spectrum (See Table 2).

Table 2. Demographics for Research Participants

<i>Case Number</i>	<i>Gender</i>	<i>Age</i>	<i>Ethnicity</i>	<i>Interviewee</i>	<i>Diagnosis</i>
1	M	17	AN	AP	FAS
2	M	20	AN	I/FP	FAS
3	F	30	AN	I/FP	FAS
4	F	21	W	FP	FAS
5	M	35	AN	AP	FAS
6	M	26	AN/AA	I/AP	FAS/SCH
7	F	18	AN	I/AP	ND-AE
8	M	28	AN	AP	ND-AE
9	M	22	W	I	SE-AE
10	F	24	AN	AP	FAE
11	M	6	AN	AP	FASD
12	F	13	AN	AP	FASD
13	M	15	AN	AP	FASD
14	M	19	AN	I/FP	FASD
15	M	20	AN	AP	FASD
16	F	20	W	I/AP	FASD
17	F	22	AA	AP/AP	FASD
18	F	25	AN	I	FASD

Key:

Ethnicity: AN – Alaska Native; W – White; AA – African American

Interviewee: AP – Adoptive Parent; FP – Foster Parent; I – Individual with FASD

Diagnosis: ND-AE – Neurodevelopmental Disorder, Alcohol Exposed, SE-AE – Static Encephalopathy, Alcohol Exposed; SCH - Schizophrenia

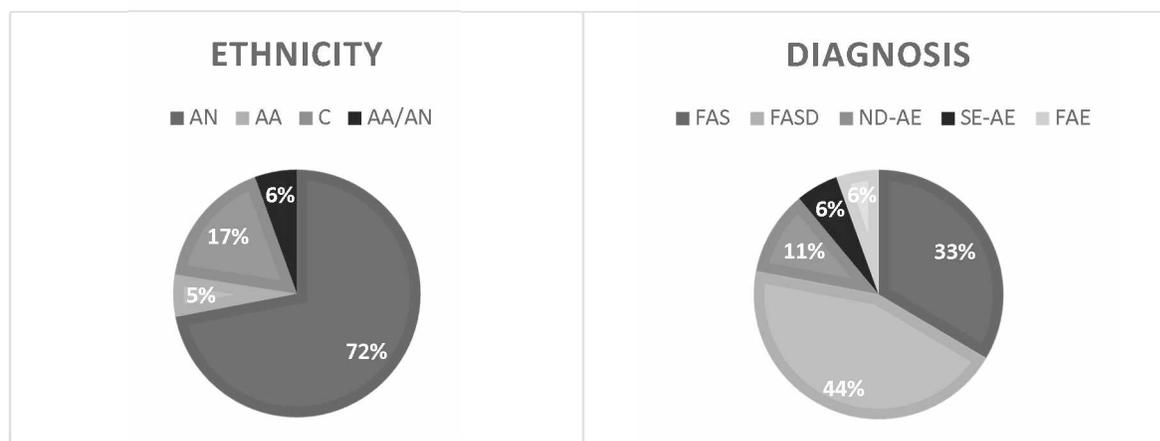


Figure 1. Ethnicity and Diagnoses of Research Cases

Key:

AN – Alaska Native; AA – African American, W – White; AA/AN – African American/Alaska Native

FAS – Fetal Alcohol Syndrome; FASD – Fetal Alcohol Spectrum Disorder; FAE – Fetal Alcohol Effects; ND-AE – Neurodevelopmental Disorder-Alcohol Exposed; SE-AE – Static Encephalopathy-Alcohol Exposed

Data Collection Instrument

My primary method of data collection is in-depth semi-structured interviewing, a well-established approach which I used to capture an individual or family member’s perspective on how FASD has affected his or her life and/or the life of family members. Qualitative interviewing allows for the in-depth discussion on a set of topics. The interview helps capture the rich description and in-depth understanding of their personal and collective perspectives (Bloomberg & Volpe, 2016). I developed a flexible interview in order to have an overall plan of inquiry, but allowed the interviewees to share their stories; I asked unanswered questions from my protocol towards the end of the interview. In most cases, individuals and family members brought up many of the topics on my guide on their own.

I developed an interview guide or set of general questions based on my research questions and related literature (Fossey et al., 2002). Although I wanted each interviewee to have

the freedom to tell his or her personal story, I needed to ensure that interviewees addressed my basic research questions. Verdugo et al. (2012) developed a cross-cultural QOL framework to assist service providers and policy makers in addressing the needs of individuals with intellectual disabilities. This framework is comprised of domains or factors that are accepted in the literature as covering the basic construct of QOL. Using the authors' basic guidelines of independence, social skills and well-being, I developed part of the interview guide to assist me in understanding what areas of the participants' lives are affected by FASD. For independence, I considered daily living activities such as cooking and laundry, graduation from high school, obtaining a driver's license and the ability to live on one's own. Under social, I listed questions about friendships and social inclusion. For well-being I addressed safety and security, health and nutrition, and employment. These activities have been included in the literature on quality of life for individuals with other developmental disabilities and are foundational in assessing quality of life.

I also used the work of Streissguth et al. (1996, 2004) to develop the guide. Streissguth has done extensive research on adverse life outcomes and secondary disabilities in individuals with FASD. Her work shows that individuals with FASD often have difficulty with adaptive behaviors, all of which affect quality of life. In the 2004 study, 80% of the patients were not raised by their biological mothers. Sixty-one percent of her sample had disrupted school experiences; 60% faced trouble with the law; 50% experienced confinement in either detention, jail, psychiatric or alcohol/drug inpatient setting; and 49% had exhibited inappropriate sexual behaviors. I added questions concerning these difficulties to my guide.

My research questions, the literature on quality of life domains by Verdugo et al. (2012) and the Streissguth work on secondary disabilities provided the overall basis for my interview questions. The previous work by Streissguth et al. (2004) showed that individuals with FASD

often have primary and secondary disabilities that would greatly affect quality of life. Using this loosely constructed guide would allow me to discover in my findings similarities and differences with published research.

I used the same general guide for both individuals with FASD and family members. I asked parents to start the interview by describing when the child first came into their lives (see Appendix A). I asked individuals with FASD to start with their first memories, which were often when they were still with their biological families (see Appendix B). One young lady chose to begin her interview with when she first met her adoptive mother because discussing life with her biological family was too painful. I interjected questions when the individual with FASD or parent did not discuss a certain question area while sharing his or her life story. I had to ask more questions of individuals with FASD. Parents usually addressed most of the following questions as they described life with the affected individuals.

Method

For my first interview, I piloted the interview protocol. I asked an individual with FASD with whom I had worked in the past if she would be my first interviewee and would provide a critique afterwards. This would include reading the transcript, providing me with feedback about the interview, and letting me know if I should ask any additional questions. She agreed to be my first interviewee and to give me feedback afterwards. We agreed that I would go to her apartment for the interview, where she made tea for us. Later I sent her the transcript by e-mail and she replied that it was correct. She felt the interview length and questions were good and did not offer suggestions or additional questions.

When interviewing individuals with FASD, I gave them the opportunity to share their life stories in their own words and discuss how they felt FASD had affected their lives. Seven of the

eight individuals with FASD were able to talk about how FASD affected their lives. One young man did not seem to understand the term FAS or FASD, even though I had explained to him the purpose of my research and he had agreed to participate, so we discussed his life in general and the struggles he had while in school and at work.

Interviews with individuals with FASD lasted between thirty minutes and one hour. Most of the interviewees had seen me in the past and knew that I had worked at PHH, so it was not difficult to establish rapport. I conducted interviews with individuals with FASD either in their homes or at the PHH office. Several of the individuals still received psychotherapy at the PHH office, so they felt comfortable there, and it also provided a private environment to ensure confidentiality.

All the individuals with FASD seemed happy to share their stories although half of them struggled with what to say at various points in their interviews. Open-ended questions were more difficult for that half, and I often had to be more specific with my questions. A study by Booth and Booth (1996) found that individuals with learning difficulties, which individuals with FASD frequently have, often experience trouble with open-ended questions and with generalizing from their own personal experiences. When I encountered this problem, simplifying questions or stating them in a different way seemed to be helpful. I used closed-ended questions towards the end of the interview concerning high school graduation, independent living skills, and employment, if the individuals had not discussed those quality of life elements previously.

While conducting interviews with family members, I encouraged them to share their life experiences while living with the affected individual and to explain how living with the individual impacted their own lives and the lives of other family members. I interspersed open-ended questions (Babbie, 2011) on quality of life when there were pauses in the interview or

towards the end, when I needed to make sure that we had covered the research questions. Interviews with family members lasted one to two and a half hours.

At the end of the interviews, I offered interviewees the opportunity to read their interviews once they were transcribed, to see if they wanted to add or change anything. This process is called member checking. Only one interviewee asked to have the transcript sent to her. She read the transcript but did not make any changes, saying it was accurate. I also asked interviewees if I could contact them if I had follow-up questions. After analyzing the data and discovering I needed additional information or clarification on some topics, I e-mailed several interviewees with follow-up questions. I incorporated interviewees' follow-up replies into the existing data.

I conducted all interviews in a mutually agreed upon setting. We met at their home or office, my home, the PHH office, or an agreed upon community setting. Family members often spoke at length, seldom needing prompts, as they seemed eager or almost compelled to share their experiences and ongoing frustrations. Through their stories, family members exemplified how all family member's lives had been affected in various ways. All interviewees had valuable knowledge to share about how FASD affects quality of life.

Data Analysis

In qualitative research using interviews, data analysis is the process of drawing meaning from the large amounts of data collected from raw interviews. The researcher organizes and transforms raw data into the "research findings" (Bloomberg & Volpe, 2016). This process includes data reduction, data reorganization and then a display of meaningful interpretation (Flick, 2014).

Some early analysis occurred throughout the interviewing process as I listened to the stories of the interviewees. I jotted down thoughts, impressions and observations at the end of the interviews for later consideration (Rubin & Rubin, 2005). When I transcribed the interviews, I added this information to the bottom of the transcripts. Memos or notes from the interviews assisted in beginning to identify emerging themes. (Rubin & Rubin, 2005). In addition to assigning identification codes to each transcript to maintain confidentiality, I also added some descriptive statistics including the age of the individual with FASD, the ethnicity, and the diagnosis.

After I completed the transcriptions, I divided them into two groups: one for individuals with FASD and one for family members. Family members included long-term foster parents and adoptive parents. I then immersed myself in the data, developing an overall perception of the content (Rubin & Rubin, 2005). I began reading through all the transcripts of individuals with FASD, highlighting areas or concepts that addressed my research questions and jotting down notes and thoughts. I then read through all the transcripts of family members, following the same guidelines. I read the transcripts again, highlighting topics or words that had been mentioned by several interviewees.

Working in a concept-driven way and using my interview questions as categories (Flick, 2014), I wrote down my four main research questions on separate sheets of paper, dividing the paper in two sections, one area for individuals with FASD and one for family members. I also listed the categories I had developed in my interview protocol on another paper: health, school, friendships, employment, housing, transportation, cooking, laundry, problems with the law, problems with substance use, in a relationship, and children. This was the beginning of an overall coding framework.

I kept the answers given by individuals with FASD separate from those given by parents for later comparability. I read back through each group of transcripts, jotting down concepts and themes that interviewees frequently mentioned. I charted the frequencies of the concepts and themes, looking for similar words that could be consolidated into subcategories. I also created categories and subcategories as I compared the interviews to prominent findings in the literature.

Throughout my ongoing analysis, I looked for participant quotations that would illustrate themes that individuals stressed as important. These I compiled into a separate list. Later I incorporated these quotations into my findings to assist me in better representing the interviewees' voices.

I compared and contrasted responses of interviewees within the same group, between the two groups, and between the cases where I had interviewed both an individual with FASD and a parent. Moving beyond concept driven coding and towards deeper analysis, I looked for themes that arose indirectly. These concepts and themes often came from the deep emotions interviewees revealed. Some themes not well documented in the published literature began to emerge from the interviews with the parents such as the difficulty in transitioning to adulthood by individuals with FASD and the stress of not knowing who will care for the adult child after parents have passed on. I then added these codes to my coding structure (Rubin & Rubin, 2005).

After coding the data, I consolidated codes into overall themes. As interviewees discussed the same topics and concerns, or as they covered areas brought up in the professional literature, themes emerged. I also combined certain codes or categories into themes that seemed to represent all of the individuals with FASD. I then ranked themes according to how often interviewees mentioned them. For example, the data showed that all 18 cases had experienced early childhood trauma and that all cases needed special services at school.

Based on my ongoing analysis and synthesis of the data, I identified important components of how FASD has affected quality of life for affected individuals and their families, and summarized prominent findings. I found comparing themes brought up in my research interviews with the Verdugo et al. (2012) cross-cultural QOL framework and the Streissguth et al. (1996; 2004) studies was particularly revealing. By making comparisons I recognized the broader implications of the data and how findings might be used to better support families and individuals with FASD.

Ethical Considerations

Human Subject Protection

As a social science researcher, I must follow ethical guidelines to protect my research participants. Research involving human subjects comes under the jurisdiction of the Institutional Review Board (IRB) or governing board of institutional research under which a researcher works (Bloomberg & Volpe, 2016). The IRB follows the federal mandate on research to ensure that risks to human participants are minimal and that the subjects' rights are protected.

Prior to starting my research, I completed the Collaborative Institutional Training Initiative (CITI) web-based training program on the protection of human research subjects through the University of Alaska Fairbanks (UAF) IRB. I then followed UAF's IRB protocol to ensure that the recruitment process, consent process, data collection and storage were conducted in an ethical and confidential manner.

The IRB requires that researchers use an informed consent form that relates to participants the purpose of the research and any risks involved. Individual participants must read and sign the consent form before they participate in the research study (Babbie, 2011). For my

study, I developed two separate informed consent forms: one for the individuals with FASD (See Appendix A) and one for the family members (See Appendix B).

After approval of the forms, I practiced IRB protocols. I informed all participants about the aims of the study and took active steps to protect them from harmful consequences (Babbie, 2011). I obtained an informed consent from each person interviewed. I gave each individual time to read the form and ask any questions before signing. I also asked if I could tape-record the interview, explaining that a recording would assist me to remember their stories and perspectives. All individuals agreed to be recorded.

Given that individuals with FASD are a vulnerable population, I spent additional time verbally explaining the purpose of the interview and that the interview was voluntary. I also explained that they could choose not to answer any question or stop the interview at any time. Informing the interviewees of these rights minimized the likelihood of emotional or psychological risk. In two cases, we agreed the parent would remain in the room with the individual during the interview, to ensure that the adult child understood the consent and to ease any discomfort. At the end of the interviews with individuals with FASD, I offered either a \$15 iTunes or a Starbucks gift card.

The IRB also requested that I establish a protocol for telephone interviewing. However, I never used this protocol, finding ways to meet with all of my interviewees in-person. In two cases, I drove to areas outside of Fairbanks to conduct interviews. My past work experience has shown me it is easier to establish rapport with eye contact (Babbie, 2011).

All interviewees agreed to participate. A few times individuals with FASD were hesitant to answer a question, and so I asked them if they wanted to skip the question. Several individuals chose that option when I offered it. In one case, the question was about legal charges the young

man had incurred when he was younger, and in another case, a young woman chose not to discuss a previous marriage that involved domestic violence. Parents were more open about difficult circumstances and did not exercise their option to refrain from discussing certain topics.

To ensure the confidentiality of data, I followed the guidelines approved by the IRB. I assigned a number to all individuals whom I interviewed before I transcribed their interviews. After I transcribed the interviews, I deleted the recordings. All quotes used in my dissertation are de-identified, replacing real names with pseudonyms. Any use of PHH records used to validate diagnostic information was approved by the PHH Board of Directors. All participants from PHH had previously read and signed the Resident Handbook, which explains the guidelines for approved research, states that all personal information will be kept confidential, and informs residents they have the right to refuse if they do not want to participate. All participants agreed to be part of the study. All consent forms, research-related records and data were safely locked away so that no one other than the researcher and committee members have access to the material. At the end of the project the data will be stored, maintained, and secured in the Arctic and Northern Studies office on the sixth floor Gruening Building.

Issues of Trustworthiness

Credibility

Credibility in qualitative research resembles validity in quantitative analysis. The concept refers to whether the findings accurately represent the interviewees' perspectives (Bloomberg & Volpe, 2016). The researcher must ensure the study examines or measures the identified topic(s) (Shenton, 2004). This can be done through several ways.

One method to ensure credibility is to use research methods that are well established in qualitative investigation (Shenton, 2004). In-depth interviewing is a well-accepted technique

used in qualitative analysis as it allows the researcher to gather data directly from the interviewees. Interviewing both adults with FASD and parents helps to ensure that we get a more complete view of life with FASD.

Interviewing individuals with FASD is particularly important to ensure credibility as my research sought to understand their experiences. Disability researchers used the slogan, “Nothing about us without us” in reaction to research that did not include the individuals with disabilities who were being researched (Charlton, 2000). The constructivist paradigm also relies on information collected directly from the individuals at the center of the study.

To achieve credibility, the interviewer must build rapport with interviewees, who must feel that their information is important and valued (Marshall & Rossman, 1989). All my interviews took place face-to-face to help establish rapport. I used a few moments before starting the interview to thank interviewees for coming and to let them know I thought their story was important, encouraging the interviewee and building trust. Throughout the interview I used active listening skills, allowing individuals to talk for lengthy periods of time. I used verbal and non-verbal cues to encourage interviewees to continue speaking and to show my interest. I chose not to take notes during the interviews, to foster a more conversational atmosphere and put the interviewees at ease, but I jotted down a few impressions afterwards. In my IRB protocol I had made allowances for conducting interviews by phone, but I conducted all of my interviews face-to-face, in one case driving 320 miles for the interview.

Data triangulation is another method that ensures credibility (Shenton, 2004). Instead of recruiting my interviewees from one source, I had three different sources for volunteers. Using different sources helped to assess whether individuals with FASD and their families shared many experiences; that is, whether they faced similar challenges. I had access to some records to

confirm diagnostic information given by interviewees. Also when available, I interviewed both the individual with FASD and a family member or in one case, two family members. By interviewing family members, especially more than one family member, I was able to confirm information and broaden my understanding of how FASD affected the individual and family members.

Researchers also must take measures to ensure forthrightness (Shenton, 2004). All the interviewees were volunteers; I gave them the opportunity to refuse to participate, helping to ensure that those who did participate wanted to take part and were comfortable with sharing openly about their lives. All the interviewees completed the interview although several of the individuals with FASD stated they did not want to answer at least one specific question.

Shenton (2004) suggests that another way to enhance credibility is for researchers to examine previous research findings to determine the degree to which their research findings correlate with those of past research. This was a major component of my analysis. Throughout the research and analysis of the data, I continually examined past research findings through my literature review, comparing and contrasting the findings to my own research. I will integrate these comparisons throughout the discussion in the findings section.

Dependability

Dependability refers to whether the findings are consistent with the data and whether a systematic process has been followed (Babbie, 2011). Some qualitative researchers refer to this as trustworthiness. Shenton (2004, p. 71) states that to address dependability “the processes within the study should be reported in detail, thereby enabling a future researcher to repeat the work, if not necessarily to gain the same result.” I address dependability by reporting the

research design and implementation in detail, followed by the conclusions and limitations of the study.

Confirmability

Confirmability refers to whether the findings reflect the accurate interpretation of the research data, rather than the biases of the researcher; confirmability is comparable to objectivity in quantitative research. The concept also acknowledges that “research is never objective” but the findings, discussion and conclusions should represent the situation being researched rather than the biases of the researcher (Morrow, 2005). To help confirm the findings in this study, I have created an “audit trail,” providing a detailed methodological record to help appraise the validity of this study. It is important to note once again that in qualitative research the researcher is the primary instrument for data collection and data analysis (Bloomberg & Volpe, 2016). My experiences of working with individuals with FASD for over 20 years provided me with knowledge of how FASD has affected quality of life for the individuals with whom I worked. My thorough review of the literature, along with my experience and interactions with individuals with FASD, helped to broaden my perspective when completing the data analysis. I note that my work experience provides valuable information about quality of life for individuals with FASD but may also create researcher bias. To address subjectivity and strengthen credibility I created an audit trail, used triangulation of data sources when possible, and involved participants in member checking.

I also used participant or member checking for confirmability (Bloomberg & Volpe, 2016). I recruited two of my research interviewees to read my findings chapter and provide me with feedback. This technique helps to confirm the accuracy of my interpretation and that I am representing the voices of the involved participants (Flick, 2014). Both interviewees confirmed

my findings. One stated the findings were very informational and liked that I had substantiated my findings with other research. She wished that this information could be shared with those who work with children with FASD “because they just don’t know.” The other individual responded positively to my findings and thought the data spoke to the need for a central agency or organization where families could obtain assistance with needed services.

Transferability

Transferability refers to the way a reader determines if and to what extent a particular phenomenon in a particular context can transfer to another similar context or situation. This is sometimes called generalizability, although in qualitative research transferability is a more accepted term (Lincoln & Guba, 2000). Many qualitative researchers emphasize the use of “thick description,” a term developed by Clifford Geertz, a cultural anthropologist, to assist the reader in developing a thorough understanding of the context (Geertz, 1973, p. 9). Although the sample size in this research was small, I have provided thick description of the phenomena to assist readers in determining whether my findings would apply to other contexts (Shenton, 2004). I also maintained a detailed audit trail of my methodological decision making, data collection procedures and data analysis to assist in determining the “fittingness” of any transferability (Leavy, 2011).

Comparing the findings to the literature, looking at the “thick description,” within the interviews and comparing the interviews to each other, I found that individuals with FASD spoke of similar problems, while parents as a group tended to speak of other problems. The published literature also identifies several of these challenges. I therefore believe the findings are significant and transferable to other young people living with FASD.

Limitations

This study exhibits several limitations, some due to the ongoing critiques of qualitative research methodology and some due to the limitations of this study. One limitation is that analysis of the interviews involved my thought processes and choices, therefore involving some subjectivity and the possibility of personal bias. This may also be considered a strength, given that I bring over 20 years' experience working with individuals with FASD to this research which gives me valuable knowledge and insight into how FASD affects quality of life. Understanding that my experiences could also bias my judgment, I used member checking, sending my findings to two research participants, before proceeding with completing my analysis. I also triangulated data sources when available and my committee chair reviewed the transcripts to provide oversight and accountability of coding schemes and findings.

A second limitation was my sample being limited geographically. The FACES Diagnostic Clinic in Fairbanks processes referrals made from the interior and northern regions of Alaska. Most children and young adults who are referred to Presbyterian Hospitality House (PHH) come from either interior or northern regions, although some are from the southcentral region. Thus my findings may not hold across Alaska. Some areas of Alaska may have more or fewer services available to individuals with FASD and their families, which could cause differences in how FASD affects quality of life.

Although interviews were also limited to the interior region of Alaska, several of the individuals with FASD came from other parts of Alaska and two individuals were born outside of Alaska. Nevertheless, Fairbanks and the surrounding area would be considered a small urban setting. Individuals with FASD within a village or small rural areas may have different perspectives as people may be more accepting of individual differences or disabilities.

Individuals with FASD within larger urban settings may also have different perspectives and experiences due to the availability of additional services.

My main focus was on quality of life for teens or young adults, so that I would be able to interview parents, in addition to individuals with FASD. None of my eighteen cases were over the age of thirty-five years. My findings may not entirely apply to middle-aged or older adults with FASD. The research on middle-aged or older adults with FASD is very limited. Many of these individuals are undiagnosed due to the relatively recent recognition of FASD and because diagnostic clinics across Alaska focus on children. Middle-aged and older adults with FASD may have a different perspective than those in my research sample on how FASD affects quality of life. Also, since only one of my cases was elementary school age, findings may not apply to individuals with FASD under the age of twelve or thirteen. From my literature review I discovered that individuals with FASD develop more difficulties in the various areas of their lives as they become older (Malbin, 2002, Pei et al., 2011). This would affect their perspective on quality of life.

All the parents involved in this research were adoptive parents or long-term foster parents. I interviewed no biological parents. In the Streissguth et al. (2004) study 80 percent of the individuals with FASD were not raised by the biological mothers. In this research, 100 percent of the cases were not raised by their biological parents. This study depicts perspectives of adoptive children and parents, and those involved in long-term foster care. The perspectives of biological parents may not be represented in the data: they may have different experiences.

Conclusion

This chapter provides a detailed description of the methodology used for this research. I employ qualitative research methodology to develop an understanding of individual and family

perspectives of how FASD affects quality of life. Using purposive sampling, I recruited twenty-two research participants from three different sources. I use semi-structured, in-depth interviewing as my primary data collection method. I conducted the research over a four month period. I analyzed the data from the interviews, seeking emergent themes, while comparing findings to the existing literature. Although this research has some limitations, I believe that my findings and recommendations will help family members, service providers and legislators develop a better understanding of how FASD affects quality of life and that the research will lead to improved quality of life for these individuals and their families through public education and through expanded and enhanced services.

CHAPTER IV:

FINDINGS: HOW FASD AFFECTS QUALITY OF LIFE

This research explores how FASD impacts quality of life for individuals with FASD and their family members. This chapter presents the key findings from the twenty-two in-depth interviews I conducted with individuals with FASD and their parents. I interviewed eight adults with FASD and 14 parents. When possible, I interviewed both an adult with FASD and one of the parents. In one case I interviewed both the mother and the father, but was unable to interview the affected individual. This resulted in eighteen cases.

Following the guidelines provided by the University of Alaska Fairbanks' Institutional Review Board, I interviewed only individuals over the age of 18. In four cases, adoptive parents of underage individuals with FASD volunteered to be interviewed. One was the adoptive mother of a six-year-old and the other three cases involved teenagers (see Table 2 for additional information on cases). Those interviews provided insight into quality of life issues during the early years of the child.

The four main research questions were: 1) How has FASD impacted quality of life for affected individuals? 2) How has raising individuals with FASD affected quality of life for families? 3) What supports or services were most helpful to the affected individual or the family? and 4) What supports or services not currently provided would be helpful to individuals with FASD and families? Throughout the findings presented here, I have used illustrative quotations to represent the views of the participants. As affected individuals and their parents shared their experiences of living with FASD, shared meanings emerged that could be used to improve services. I have also interwoven findings from the published literature for comparison.

Impact of FASD on Quality of Life for Affected Individuals

Interviewees named and discussed numerous ways that FASD had negatively impacted quality of life for the affected individual. Some of these corresponded with findings in the published literature on FASD. Other effects cited have little or no coverage in the literature, demonstrating the importance of the present study in adding to the literature on FASD.

Adverse Childhood Experiences (ACEs)

The most prominent finding in my research was that all 18 individuals with FASD (100%) experienced serious adverse childhood experiences (ACEs), in addition to being prenatally exposed to alcohol. ACEs are traumatic events, to include abuse and neglect, which occur in the early years of a child. In my research all 18 individuals with FASD were raised or were being raised by someone other than their biological mothers. All 18 children were removed from their biological mothers due to abuse and/or neglect and taken into state or tribal custody. In at least two cases, adoptive or foster parents identified sexual abuse by a father or male partner as a reason for removal from the biological mother. Although no individual with FASD spoke about their sexual abuse, one old female discussed her physical abuse: “My parents were alcoholics and they would... my mom would abuse us. We would have to go to school the next day with bruises and my hair was falling out. It was really rough, just terrible.” Other individuals with FASD made references to abuse and/or neglect, indicating their early childhoods had been difficult.

Individuals with FASD spoke of their loss of early childhood innocence when they spent their first few years with their biological mothers. One young adult with FASD stated: “I didn’t really have a childhood... my mom was drinking a lot.” Another young man with FASD stated: “Well, mom and dad were into drugs and obviously heavy into alcohol... and trouble as we

know. They were not the greatest parents, definitely a lot of abandonment and that sort of thing when drugs took over.” In three cases, the individuals experienced early maternal death, with one individual with FASD sharing that she discovered her deceased mother’s body.

When taken into custody, children are seldom placed with their siblings, which created additional trauma. One young man with FASD explained the problem:

There was me and my younger brother and sister. It was one of those things where one foster kid isn’t bad but when you have three young ones it makes it a little bit harder, especially with higher needs like we had... behavior issues or stuff like that. It took a toll on many different foster families. It was one of those things where they didn’t want to split us up, but they couldn’t care for us as a group. We went through a large number, at least seven different foster homes before we were adopted.

This young man has struggled to maintain contact with his siblings through the years but he recently visited them. Losing one’s family is a significant trauma with life-long implications.

In addition to multiple foster placements, eleven of the 14 individuals with FASD over the age of 18 were placed in residential treatment centers outside of their foster or adoptive homes, creating additional trauma. Of those 14, six (43%) were hospitalized for severe acting out behaviors, including suicidal ideation or suicidal attempts, causing the determination that they were no longer safe in their home. Three of the 14 (21%) also experienced out-of-state placements.

Several individuals with FASD discussed the long-lasting effects of their ACEs, or early trauma, in their interviews. One young woman said she thought her early trauma led to her ongoing depression. Another interviewee discussed her inability to talk about life before she was adopted due to all the trauma, and her need to use a weighted blanket when she becomes

overwhelmed. A 22-year-old individual with FASD, who is independent in most areas of his life, stated he now has a service dog “to help me with night terrors, PTSD, anxiety, stuff like that.” It was evident from the interviews that adverse childhood experiences had seriously impacted their lives as adults.

These illustrations of adverse childhood experiences are troublesome as research shows early trauma has lifelong implications, to include increased mental illness, disease, and early death. The groundbreaking ACE Study (Felitti et al., 1998) examined the long-term impact of abuse and household dysfunction during childhood on quality of life in adulthood, including risk factors for disease, use of health care, and mortality. The study found a strong relationship between the number of adverse childhood experiences and adult health risks and/or diseases. Persons who experienced four or more categories of ACEs had increased health risks for alcoholism, drug abuse, suicide attempts, and depression. Those with higher numbers of ACEs also experienced increased risk for adult diseases including ischemic heart disease, cancer, and liver disease. All these health risks and diseases affect quality of life. Since the groundbreaking research by Felitti et al.(1998), many other studies have produced similar results.

Streissguth et al. (2004) conducted a study on the risk factors for adverse life outcomes for individuals with FASD. The study showed that environmental conditions frequently found in connection with prenatal alcohol exposure include early maternal death, living with an alcoholic parent, child abuse and neglect, removal of the child from the home by authorities, experiencing ongoing periods of foster care or other placements, and being raised in a foster or adoptive home. My findings corresponded with these, with all children being removed from their biological home by authorities, experiencing multiple foster homes, and three experiencing early death of their biological mothers.

Streissguth et al. (1996) confirmed that experiencing a stable home environment provides a protective factor for children as they mature, especially those on the FASD spectrum. Yet all 18 children (100% of my cases) experienced multiple home placements owing to their high level of needs and/or acting out behaviors. In only one case was the individual with FASD raised by family members, who were an aunt and uncle. In sixteen of the other seventeen cases, the Office of Children's Services or tribal councils placed children with multiple unknown families, multiple times, with twelve of the seventeen children (71%) living with families outside of their culture. One individual experienced multiple placements, partly to reunify with the mother, which caused additional trauma when the mother left a residential substance abuse program and abandoned her child. Given the prevalence of ACEs among my cases and the extensive literature on the lifelong detrimental effects of such experiences, the Discussion chapter of this dissertation will analyze the implications of ACEs on individuals, families, communities and the state.

Health Problems

Six of the 18 individuals (33%) experienced significant health problems at birth. Two of the individuals were diagnosed with Failure to Thrive. One individual was born with a cleft lip and a cleft palate, and hearing problems that she continues to have as an adult. One individual's adoptive parents, who were not in attendance at birth, reported that the individual was born with a very low AGPAR⁵ score, although they do not have the details. Another male was born with a herniated diaphragm; his stomach had moved into the heart and lungs cavity, which required surgery. Another young man was born with a bilateral brain bleed, a collapsed lung, a heart rate of 40 and an AGPAR of 2. He remained in the hospital for 12 days after birth. All these serious

⁵ AGPAR: a score to summarize the physical health of newborn children against infant mortality

health conditions would cause significant trauma in the life of a young child and could lead to attachment difficulties.

Difficulties in School

A third finding under this category is that all eighteen children experienced difficulties in school and needed additional educational services. Seventeen of the 18 individuals with FASD (94%) received Special Education Services. Additional services included the use of teacher aids or special pull-out classrooms where they received assistance in specific subjects. One individual needed remedial help only with reading. Notably, except for the one case, all the other students needed Special Education whether they had a diagnosis of FAS or were somewhere else on the FASD spectrum. This finding supports the study by Streissguth et al. (2004) that showed that individuals who experienced Fetal Alcohol Effects (all those on the spectrum that do not have full FAS) exhibit intellectual, academic, and adaptive behavior deficits. In fact, other studies (Malbin, 2002; Stade et al., 2006) found that individuals on the FASD spectrum without full FAS often display significant problems in multiple settings, perhaps owing to the absence of facial characteristics of FAS, which leaves others unaware of the disability. As one parent related: “I mean these kids look normal, present as normal; you just have to sit and talk to them for 20 or 30 minutes and then you go... whoa, this doesn’t make sense.”

Difficulties in school included struggles with academics, friendships, and appropriate social skills. Interviews with individuals with FASD revealed their perceptions of how FASD affected their school experiences. One young woman described how FASD affected her academically:

I slowly catch on to learning things that other students can easily grasp. Math is my biggest weakness in school. I always had one of the teacher’s aides from the Life Skills

class follow me to that class. It was always very difficult for me... It takes me a while to retain information and to utilize it the best that I can.

Struggles in school started early on and increased as students entered high school. One mother described her daughter's struggle with adapting to kindergarten.

[She] had a really hard time in school... in kindergarten she would sit underneath the desk in her kindergarten room for long periods of time and would not come out. They couldn't coax her to participate. As she got older she would have temper tantrums; something wouldn't go her way or she wouldn't understand something and you could hear her through the whole school wailing... It wasn't like high pitched crying, it wasn't moaning, it was just wailing.

High school was especially difficult, as the needs of adolescents with FASD differ substantially from those of typically developing youth. One adoptive mother explained the conundrum:

The schools struggle because they're looking at everything through the high school developmental lens, while the parents, if they get it, are looking at a high schooler who is not a high schooler. But they have to function safely in high school and the brain isn't developed enough to do that. So how do we keep that kid safe and still let the other kids thrive and do what they developmentally need to do?

All 18 individuals had trouble with comprehension and memory, a finding consistent with other studies presented in the literature review, as individuals with FASD have cognitive and executive functioning deficits (Green et al., 2009; Pei et al., 2011). Malbin (2002) states that individuals with FASD often have difficulty making connections or generalizing information. Seventeen (94%) of the individuals in my study struggled with cause and effect or the ability to

“connect the dots.” The adoptive mother of a now thirty-five-year-old male with FAS shared a story about when he was younger:

Here’s a perfect illustration of an FAS thought process... he went to let’s say Penney’s and he stole something; so his dad took him back in there and talked to the manager.

They made the restitution and George (pseudonym) got the message you don’t steal. A week later he goes into Market Basket and he steals something else. A week later it might be over at Safeway. And every time we take him back, we talk to the manager and George did not understand why we were so upset about this. He said, ‘I didn’t steal at Penney’s.’ It was so contextual. There was no translation of that concept from don’t steal here. ‘I don’t steal here anymore.’ But over here maybe they’re OK because I haven’t stolen from them yet.

This anecdote addresses another common problem individuals with FASD experience – stealing and lying – discussed below.

Interviews with parents and individuals with FASD showed that all 18 individuals needed a highly structured classroom environment and a fixed routine to function and learn best. Six of the interviewees described difficulties with transitions, which is supported by other research. For example, as one adoptive mother explained:

...he was in sixth grade and that was an absolute disaster at school. It was exactly the wrong kind of learning environment for a kid with FAS. It was you go to this teacher for reading, this teacher for math and this teacher for whatever.

This finding of a need for structure and fixed routine again concurs with other research.

Individuals with FASD are often easily distracted and impulsive, have memory problems, and have difficulty generalizing (Malbin, 2002). Dybdahl and Ryan (2009) discusses the need for a

structured environment with a predictable schedule, reduction in physical stimuli, use of explicit and direct language, and providing praise and gentle reminders to stay on task. Yet few teachers organize their classrooms in this way, and less structure and more transitions occur as students grow older.

Two parents described end-of-school-year activities that were designed to be special events for students but lacked the structure needed for individuals with FASD. One adoptive mother recalled:

They have field day and they have all that so called “fun stuff?” that wasn’t fun for him which you see a lot in autism too. As long as everything is going the same way... but transitioning... oh that was terrible. One time they were doing all this fun stuff and everyone was trying to get their ice cream. There was chaos all around him and he was just sitting there. He was so overwhelmed and no one even noticed, of course. He didn’t even know to go up and get his ice cream!

This incident illustrates the need for structure and consistency. Many children with FASD are not able to adapt to changes in the schedule without some intervention or special accommodation.

Of 17 individuals with FASD (I excluded the interview with the mother of a six-year-old as he does not have homework), 15 individuals (88%) had serious difficulty with their homework. Challenges described in the interviews included not completing the homework and difficulty with organizational skills: for instance the child would complete the homework but fail to submit it. Some parents reported that exhaustion following long school days with overstimulation would hinder children from completing homework. One foster parent explained:

Teachers have the tendency to make these kids, after they sit in school for hours, to come home and do their homework. They expect these kids to remember to turn it in. It takes

routine, prompts, reminders, putting it in a special place and they still may not do it. They still may not turn it in and as an average person you would think that's on purpose. But it really isn't. They completely forget.

Fourteen (78%) of the 18 individuals struggled with social skills, which affected their ability to maintain friendships at school. One individual with FASD, when asked about friendships during high school said:

I was very much a loner and didn't hang out with people during that time because people didn't understand me... which I was pretty fine with and then I met a girl... and she pretty much tore through my life like a tornado by the time our friendship ended and looking back I'm like "why did I become friends with her? Well I can tell you, I know for a fact that some of the things that happened while I was friends with her were because of suggestions from her.

Later in the interview she added: "Yes, so I was pretty much a loner... and a weirdo."

This finding correlates with the work of Rasmussen et al. (2010), who conducted a study on the social skills of children with and without prenatal alcohol exposure (PAE). In this study the term PAE was used to describe children who did not have a formal diagnosis of FASD but had confirmed prenatal exposure to alcohol. Sixty percent of the PAE children had a diagnosis. The other PAE children had suspected effects but the level or pattern of drinking in the biological mother could not be confirmed due to the child being in a foster or adoptive home, or the child's not having received a multidisciplinary assessment. The study found that alcohol-exposed children scored significantly worse on responsibility, hyperactivity, internalizing problems, and on overall social skills. A study by Ase et al. (2012) found individuals with FASD fall further behind on their social skills as they age. This corresponds with my own findings that

students encountered increasing difficulties as they progressed through school. In my findings, children with FASD were often able to maintain in the classroom during the early years of elementary school. However, parents described increased difficulty with social skills and friendships as their children reached middle and high school.

The child's inability to pick up social cues often causes isolation and/or victimization at school. When asked how FASD has affected her life, one young woman with FASD explained:

It's made it so I have problems catching social cues and made high school really hard because I could never catch the social cues and I was always offending someone. And no one really wanted to hang out with me. That's why I spent time at the library every lunch break. But I have learned how to cope with that and I've been able to catch it most of the time.

This young woman has the ability to look back at high school and understand her difficulties with social skills. Many individuals with FASD are unable to make this connection. Individuals with FASD often attract the wrong friends, or friends that will get them into trouble, due to their lack of social skills and poor judgment. One adoptive parent explained:

You want them to have friends so they can learn how to be socially appropriate, yet nobody else wants their kids to be around them, so they don't get that interaction. That pushes them toward kids that do accept them, who are usually also kids with issues and maybe parents that don't pay attention. And then there you go; you're on the rollercoaster!

This lack of social skills, along with impulsivity and poor judgment, often leads to interaction with the criminal justice system, both as the offender and as a victim (Thiel et al., 2011; Baladerian, 1999). The individual's vulnerability due to a lack of social skills coupled with a need for friendship may lead to other problems. An adoptive mother of a fifteen-year-old chose

to pull her son out of public school and homeschool him owing to social vulnerability. She told me:

He isn't doing well socially. He cannot go to public school. They taught him all kinds of nonsense on the computers... all sorts of adult nonsense and he's a follower. He got in a bunch of trouble at school getting on inappropriate sites... So instead of learning he was getting into a bunch of garbage.

This finding of difficulty with judgment and good social skills corresponds with the Streissguth et al.'s (2004) findings that 49% of the individuals with FASD studied had inappropriate sexual behaviors on repeated occasions.

Behavioral problems at school due to immaturity and the inability to regulate emotions impacted the overall school experience for 16 of my 18 cases (89%). Again, this corresponds with published research. Dybdahl and Ryan (2009) examined how teachers work with students with FASD in the classroom. The study reports that overall teachers recounted more difficulty with behavioral problems than academic issues. In my research, 13 (72%) of the 18 individuals experienced hyperactivity and/or impulsivity, which hampered their staying in their seats and on task. Twelve (67%) of the 18 individuals experienced extreme anger, often exhibiting destructive behavior. Seventeen of the 18 individuals needed an Individualized Educational Plan (IEP). The adoptive mother of a six-year-old reported:

In his first IEP they were basically stating he was escalating six times within the four hours he was at school... He would be escalating his body, he would throw things, he would turn tables over, he would toss a chair, he would throw stuff at people, he would hit, scratch, kick, punch, bite.

Later when I asked this mother what she meant by "escalating his body" she replied:

When I use the word escalate, it seemed like a light switch would turn on and he used his body as his emotional outlet, as though he was completely full inside and needed a release...He also was not ever able to hear our words while he was in a physical melt down. During the entire escalation his body was ridged...Once this episode would run its course, a light switch would flip back on and his body became calm again...That's when I was able to comfort him and then he would apologize for his behavior.

Eleven (61%) of the 18 individuals suffered bullying and victimization, often at school. Six of the eight individuals with FASD whom I interviewed mentioned being taken advantage of or being bullied. One nineteen-year-old male said: "It was pretty hard. I got bullied a lot most of the time. And after the years I got used to it, but it is still stressful."

The findings show that FASD seriously affects quality of life for affected individuals within the school setting. Individuals were not only affected academically, but had difficulty picking up social cues, which resulted in social isolation, vulnerability, and oftentimes victimization. Although all 18 individuals had various difficulties within the educational system, eleven of the 14 who are over 18 years of age (79%) graduated high school or completed a GED. Seven of the individuals (50%) graduated from regular high schools using special accommodations. Three of the individuals graduated from an alternative high schools (21%), and one (7%) completed a GED.

Difficulties in the Home

In a fourth finding under this question, 17 of the 18 cases (94%) experienced ongoing difficulties in the home. Only one of the individuals with FASD discussed behavioral problems in the home but all the parents spoke extensively about such difficulties. This finding of difficulties in the home concurs with the literature (Whitehurst, 2012; Olson et al., 2009).

Thirteen of the 18 cases (72%) exhibited anger and destructive behavior in the home. O'Connor (2014) stated in her study that one of the most common findings in children with prenatal alcohol exposure is the prevalence of externalizing and disruptive behaviors such as physical aggression, disobeying rules or destruction of property. The adoptive mother of a thirteen-year-old stated that when her daughter first came to her house at nine years, she had difficulty adjusting to her new home:

We just had this complete blow out, we had all these behaviors that were extreme and very hostile, very physical, very angry... throwing things and destroying things and property, hurting herself... we had to deal with all that before we could even begin the learning process.

Another mother told me: "He started exhibiting anger issues between the ages of two and three. He tried to light a chair on fire, did a lot of hitting and throwing, kicking and just acting out behaviors." These perspectives shed some light on the challenges of parenting children with FASD.

Interviews in eleven of the 18 cases revealed various difficulties with attachment, including Reactive Attachment Disorder, a mental health diagnosis of a child who either persistently fails to respond to social interactions in appropriate ways or is "excessively inhibited, hypervigilant, or highly ambivalent with responses to attachment figures" (American Psychiatric Association, 2000, p. 128). One mother who adopted three boys with FASD, shared this story about her middle son, who is not one of my 18 cases, but nevertheless, a helpful example:

He has never called me 'mom.' He has never said he loved me. But what he would do when a caseworker would come to the house, he would take my leg and squeeze and

squeeze and never let go of my leg until they left. So I knew that he loved me and I knew that he was scared they were going to take him away.

Another mother shared a different expression of the inability to form loving bonds with others:

Even during the adoption process here's what I found with her. Here's her response to the whole adoption thing. You'd ask her: "Do you like living with Ms. Annie?" "Yes." "Do you love Ms. Annie?" "Yes." Does she make you feel like family?" "Yes."... But "do you want Ms. Annie to adopt you?" "No, I don't want to live with her anymore. I've lived with her long enough. I'm ready to move on."

Although this child was content in her adoptive home, she had not made a permanent attachment with her adoptive mother at that time. Often, it is unclear whether the problem with attachment is a result of the prenatal exposure to alcohol or early trauma or both, but attachment problems in these children should be recognized and addressed. Problems with attachment will cause difficulty in future relationships with friends, partners and children. This condition, which is not well addressed in the literature on FASD, affects well-being and quality of life into adulthood, and therefore merits further study.

Ten of the 18 cases (56%) exhibited lying or stealing behaviors. One mother of a twenty-year-old with FASD stated: "She is a pathological liar. She will not tell you the truth to save her life. Often I think she just doesn't know it. She's just making things up to fill in the blanks." The adoptive mother of a six-year-old told me:

He really does have a hard time... lying, stealing... because he saw something on the table he'd say, "Oh, I like that. It's mine now." He doesn't understand ownership unless it's being taken away from him... We have to literally pat him down before we leave a store.

The anecdote cited earlier, about George's difficulties in making connections, sheds light on how individuals with FASD frequently have difficulty generalizing information and rules of behavior, including norms related to lying and stealing. Structure, routine, and repetition may help George and others with FASD begin to make these important connections.

Various sleep problems arose in eight of the 18 cases (44%). Ipsiroglu, McKellin, Carey, and Loock (2013) found that children and adolescents with FASD are at high-risk for developing sleep problems, which contribute to other problems such as inattention, hyperactivity, and cognitive impairments. The study estimates that children with neurodevelopmental disorders or disabilities have a 75 to 80% prevalence rate for sleep problems, in contrast to a 30 to 35% prevalence rate in other children. The mother of a 26-year-old I interviewed reported:

So sleeping has always been a problem and is still a problem. He is still on medication that is supposed to help him sleep. I used to try everything... I tried melatonin... so going to sleep has always been a problem. He would get up in the middle of the night and walk around so therefore I didn't get much sleep either.

Another mother of a 15-year-old related: "He's in bed at 8:30. He has to sleep 10-12 hours a night. If he doesn't get his sleep, he is a mess. It's food and his sleep. You can even see it on him physically." In another case, a 22-year-old with FASD discussed his sleep problems, attributing the difficulties to early childhood trauma, resulting in ongoing night terrors. He talked about his use of a service dog to help him with his night terrors.

It's been a huge help, especially at night with my night terrors... at times she'll bark to wake me up, she'll pounce on me and stuff like that... she helps me wake up from my night terrors a lot faster and just having something, not necessarily someone, but

something awake for me to pet and calm down has really helped me with my anxiety and night terrors.

These findings exhibit how FASD impacts quality of life for the affected individual and for all family members. The children exhibit serious behavioral challenges, difficulty with attachment and difficulties with sleep. Additional findings on difficulties at home appear under the second question on how raising individuals with FASD affects quality of life for the family.

Mental Health Problems Requiring Treatment

Of the 14 cases in my study with individuals with FASD over the age of 18, 13 (94%) met criteria for a mental health diagnosis under the Diagnostic and Statistical Manual (DSM) which would qualify them for residential or outpatient services. Eleven of the 14 individuals (79%) spent time in residential treatment centers for mental health problems and six individuals (43%) had serious enough mental health problems to be hospitalized in a psychiatric facility. This finding again concurs with the literature. According to O'Connor (2014), the prevalence of mental health problems in adolescents and young adults with prenatal alcohol exposure is reported to be higher than 90%, with the most individuals falling in externalizing and disruptive behavior diagnoses.

A study by Streissguth et al. (2004) on individuals with FASD found that 50% of the individuals they interviewed experienced confinement in detention, jail, prison, psychiatric, or an alcohol/inpatient setting. In my findings, 12 of the 14 individuals over the age of 18 (86%) had been confined in one of the above categories. The Streissguth study found that 60% had experienced trouble with the law; in my study seven of the 14 individuals (50%) had trouble with the law due to fighting, minor consuming, drug use, or sexually inappropriate behaviors.

The Streissguth et al. study (2004) also found that 49% of the individuals interviewed had exhibited inappropriate sexual behaviors on repeated occasions. In assessing the 14 adult cases in my study, parents or records revealed that five individuals (36%) fell into this category.

Inappropriate sexual behaviors included sexual exploitation of younger children or siblings, promiscuous sexual behavior, exposing behavior, sexting, and accessing sexually explicit websites at school. Two individuals were charged with a sexual offense by law enforcement.

Difficulties Transitioning to Adulthood

Although five of the adult individuals with FASD in my study are only in the 18 to 20-year age range, the overwhelming majority of individuals with FASD and their caregivers expressed serious difficulties in their transition to adulthood. The literature on FASD does not extensively address problems with transition to adulthood. However, 13 of my 14 cases (93%) met with significant challenges in moving into adulthood. The one without difficulties had just graduated from high school and was still living at home.

I first examined the ability to live independently. Of the 14 cases, eight individuals (57%) live independently. Of those eight individuals, two live in low income housing and one individual lives in his own residence on his parent's property and the parents subsidize his rent. Of the other six individuals, one lives in an assisted living facility where caregivers help him with daily living activities and transportation. One young man works in the oil industry on Alaska's North Slope, so he has housing through his work, and he lives with family when he is on leave in town. Three individuals continue to live in their parents' homes or foster homes. One of the individuals who is still in his foster home is moving into an assisted living facility soon. One individual is homeless and living on the streets.

Although eight individuals live somewhat independently, most continue to need assistance with money management, struggle to find affordable housing, or need ongoing assistance with other needs. One former foster parent of a 30-year-old female with FASD reported: “So she lives in ‘dive’ places or she was living in places that were not good. Her son got MRSA in July 2016 which was a result of the apartment... just really horrid conditions.” The consequences of MRSA, which is an antibiotic-resistant staph infection has lifelong consequences for her son. In another case, the adoptive mother of a 21-year-old female who lives on her own, remains the daughter’s guardian. She related:

I go there every Friday. I only let her have seven days of meds at a time. I go there every Friday to make sure her house is clean, refill her meds, take her shopping and also just make my presence there.

Other parents assist their adult children with tasks such as filling out paperwork, taxes, or making appointments. As one adoptive father of a twenty-two-year-old stated: “She still to this day calls up and says, ‘what’s my Social Security number?’” Further findings regarding parents’ concerns about their children transitioning to adulthood appear in the section on how raising individuals with FASD has affected quality of life for the family.

Of the 14 adult cases, five individuals (36%) work full-time and six (43%) work part-time. Four of the individuals receive special accommodations at work. One individual is not working because she recently had a baby, but she worked in the past. The individual who is homeless does not work. Another does woodcutting on occasion. Individuals with FASD who live independently often have difficulty finding employment that pays enough to cover their basic living expenses or they struggle with other difficulties such as unreliable transportation.

One twenty-five-year-old reported:

The only time I worked was a couple years ago and that was at Dustbusters. I didn't have my own transportation. They let me go because of no transportation... I was going to work late because the only transportation that I had would come to my house 10 minutes before we were supposed to work.

The workplace accommodations vary for the four individuals who have them. One individual has "cards for him to remember to mop, empty the trash, clean off the tables." Another person has a job coach who stays with him throughout his time at work to guide him and help him stay on task. Two other individuals have supervisors who are aware of the disability and make accommodations as necessary. One individual with FASD shared with me:

Luckily my boss is aware of my needs and she usually, like this week she is on vacation, but she'll call and check in and make sure I didn't need anything, um and she actually notices when I get frustrated and she'll be "Okay, take a deep breath, it's not the end of the world."

Nine of the 14 adult individuals (64%) have driver's licenses. Three of the nine have struggled with driving for various reasons. One of the individuals who has a license is not currently driving due to having multiple accidents. Her previous foster mother told me about her first accident:

She passed her driving test. In the meantime, she had been saving her money from her working and she ended up buying a little car and getting herself to work. Then she wrecked it within a month... she just drove off the road. Again, it's that multitasking.

Another individual has been involved in four or five accidents and one individual has two DUI convictions. The other six are doing well with driving.

Of the 14 adult cases, six (43%) receive assistance in managing their money. One individual has a legal guardian, who helps manage her life decisions including medical, housing, and finances. Two individuals have conservators, who manage only their money but no other life decisions. One individual has a representative payee who generally manages only Social Security or SSI for the individual. In Alaska, representative payees may also be responsible for Permanent Fund Dividends (PFD's) or Alaska Native Corporation dividends. The Alaska Permanent Fund is a constitutionally protected fund established in 1976 to hold a percentage of the state's oil revenues for the benefit of current and future residents of Alaska. The fund pays yearly dividends to Alaska residents. Two individuals remain in foster care so they receive assistance from their foster parents in managing their money and filing for their dividends. Guardianship paperwork has been filed for one of the individuals in foster care as he prepares to move into assisted living.

Both adoptive and foster parents expressed concerns about individuals with FASD being considered "adults" at the age of 18 when they are not ready for adult responsibilities. One adoptive mother related to me:

She turned 18 before graduation and we just hung on for dear life because in society these kids are told all along that when you turn eighteen you're an adult and can make your own decisions. But they're not ready at 18.

In Alaska this problem takes on added significance when individuals with FASD have been in State custody and receive their Alaska Permanent Fund Dividends (PFD's) or Alaska Native Corporation dividends at 18 years. The state holds in trust the dividends of children in state custody, releasing it to the individuals on their eighteenth birthdays. Families shared stories about how individuals spent this money immediately upon receiving it, how they were

victimized by friends, or how extended family members suddenly came into their lives to exploit them. An adoptive mother related:

He had just gotten his Native money [his Native corporation dividend] and unbeknownst to us he had taken it all out of the bank, \$5000, and he had it in his apartment... He showed her [a friend], "look what I have." He was so proud of himself. Well, about six hours later it was gone.

This victimization of individuals with FASD due to their cognitive deficits resembles findings in published literature (Thiel et al., 2011).

Another adoptive mother of three brothers with FASD shared a story about the oldest son, who is not one of my eighteen cases but whose story is nevertheless relevant:

So like all the boys are Arctic Slope Borough [they are shareholders in the Arctic North Slope Borough regional corporation and therefore receive sizeable dividends each year], so they've been getting their money. At eighteen they gave my oldest kid \$28,000. And I couldn't touch it because I didn't know how to maneuver the system and get him what he needed... to get the help he needed. To get someone to supervise him... And he drank; he gave it away... he bought a truck and he didn't have a license... he was scammed.

This adoptive mother learned from her eldest son's experience, and later accessed services to protect the assets of the two younger sons. Many adoptive and foster parents shared similar stories, highlighting the need for protection of the assets of individuals with FASD.

Another set of challenges for individuals with FASD as they transition into adulthood relates to accessing SSI disability, low income housing, and other social services. As the previous story illustrates, sometimes foster or adoptive parents learn to access services for their children before they become adults. For most adults with FASD and their parents, accessing

services presents a substantial obstacle. An adoptive mother of an adult child with FASD who works with other families who are raising individuals with FASD told me:

She's on SSI, on disability, which I got on the first try and other families have not; families where the children have harsher diagnoses. I have families on my caseloads that have full FAS diagnoses and they couldn't get on SSI.

Another adoptive mother shared her thoughts on obtaining services:

Once they turn 18 it's a big fight... And who with a disability has the ability to sit there and fill out all that darn paperwork? And now it's not paperwork anymore, it's on-line. If you don't have access to computers or it frustrates you, it's hard! And then you need an advocate because you're going to get denied the first time.

Individuals with FASD, who cannot obtain needed services, often become homeless, struggle with mental health or substance abuse problems, and have increased involvement with the correctional system. Parents experience the ongoing stress of not being able to assist their children, especially if they have limited resources.

My interviews also revealed that individuals with FASD continue to struggle with having healthy relationships as adults. Even as adults, they continue to misinterpret social cues or attract people who are abusive or have mental health problems. One difficulty described in the literature is that the maturity level of individuals with FASD often does not reflect their chronological age (Malbin, 2002). One adoptive mother's experience demonstrated this:

She did say that all of her boyfriends have been younger than her. She said, "If this one doesn't work out, I'm going to get an old man." I told her, "Well there is something to be said about maturity." Not that they have to be old, but these men are very immature. The significant others that she has been involved in have been two or three years younger than

her. And you know if you're 20 and you're dating someone two years younger than you they're just 18.

Another former foster parent of a 30-year-old recounted how her daughter was involved in multiple abusive relationships:

It's funny because the people that she's attracted to are the people who have issues like her or similar with a lot of abuse and that type of thing. So she did get into that relationship. She ended up getting married again and this guy was just as abusive to her.

I found almost no published literature on how FASD affects the individual's transition to adulthood yet this issue is significant to quality of life for both the affected individual and for the parents who continue to assist them well into adulthood.

Although the number of parents with FASD among my cases is small, findings from my interviews indicate that individuals with FASD tend to struggle as parents. Four of the 14 adult cases have children, with two of the four (50%) currently raising children in their homes. One new mother recently had a baby and seems to be managing the baby's care, calling on her adoptive mother frequently for advice. The other young mother who is raising children, had her first child removed by the State of Alaska and he is currently in an open adoption. She is now raising her second and third children, having been pregnant with her third child at the time of the interview. She struggles with ongoing depression and expresses being overwhelmed at times. She stated in the interview: "I never knew parenting would be so hard."

In the other two cases, one child is being raised by the adoptive grandparents after the State of Alaska took custody of her, and one child is currently in foster care with his mother's previous foster parents. The foster father shared his thoughts about her difficulties with parenting:

She struggles with the social pieces... the relationship pieces. She lacks parenting skills... And she had the relationship stuff she was trying to learn on how to be a parent. But because of her social deficits, she doesn't have the friends that she needs to have as an adult, so she puts that on her son... [he] was the person she confided in, talked to... it didn't matter the age. And so that's too much for him to handle.

My findings thus show that FASD impacts almost every aspect of individuals' daily life. Most of the respondents continually need some assistance and struggle with maintaining housing, employment, and/or relationships. As one adoptive parent told me:

George (pseudonym) did tell me once, and this is probably the saddest thing I've heard – I was in the emergency room with him. I can't remember what he had done. Oh, I know what he did. He was mad again and he put his foot through a glass window and he had a big laceration. So we were waiting there and he just started crying and he said, "If I hadn't been born this way I could be so smart."

How Raising Individuals with FASD affects Quality of Life for the Family

All 14 adoptive or foster parents related how raising individual(s) with FASD has affected their family lives. The eight individuals with FASD all described their adoptive or foster parents as very supportive, but only one acknowledged her own impact on the family. She related a story about how disruptively she behaved when she first came to live with her adoptive mother when she was six years old:

Yeah, a six-year-old who refused to go on walks? My mom had to buy a special stroller so when I threw a tantrum on the sidewalk she could put me in a stroller because I weighed too much to carry all the way home... She took care of me even though I was probably a pain in the butt for her, but she was there and took care of me and took me in.

I found relatively little research on how raising a child with FASD impacts the family, although a few studies have been published in the last few years. A study by Leenaars, Denys, Henneveld, and Rasmussen (2012) evaluated a family intervention program and observed impacts of FASD on families. They found that 92% of the primary caregivers reported clinically significant child-related stress on a scale called the Parenting Stress Index. Olson et al. (2009) found that behavioral challenges play a more significant role in parental stress than developmental disabilities. Olson et al. (2009) also note that due to lack of professional knowledge about FASD, parents often must actively advocate for additional services. I had similar findings.

Need for Structure and Routine

All 14 (100%) of the adoptive or foster families described the need for more structure, routine, and consistency than they thought other families generally require. Deviating from the established routine could cause severe upsets. One adoptive mother explained:

We have to have more structure. I mean literally we have structure. We wake up at the same time every morning. Even down to cereal, “this is our weekday cereal and this is our Saturday cereal.” And he knows that the Fruity Pebbles are the special Saturday cereal. And all the other cereals are Monday through Friday cereal. That’s a huge thing in our house is knowing about food and structure.

Another adoptive mother discussed the use of charts and repetition to establish familiar routines:

We had a lot of little charts... the one I remember vividly had a lot of little doors. So after you brushed your teeth you closed a door and after you got dressed you closed a door... it was a whole list of morning schedules and routines, but the same routine every day. I used to say it’s so boring here. We did the same thing over and over and over again.

These anecdotes emphasize the memory problems and difficulty in generalizing information individuals with FASD often exhibit. An established routine with repetitive behavior helps to reinforce learning and stabilize behavior.

Continual Stress, Vigilance, and Uncertainty about the Future

Eleven of the 14 parents (79%) described ongoing household and personal stress due to their children's chaotic behaviors and worry about the future. Morrissette (2001) found similar results when he interviewed foster and adoptive parents of children diagnosed with FAS. He described their effort to ensure the children's well-being as "constant vigil" or "hypervigilance" (Morrissette, 2001, p. 8). One mother who adopted multiple children with FASD told me "it's a struggle because it always seems that someone is having a crisis... we're always in a crisis." Another adoptive mother shared her chronic stress; never knowing when a tantrum was going to occur. She explained that she had to be "super aware of his environment and [be] aware of his emotions because I have to be in tune with him." An adoptive mother whose adult daughter now lives in her own apartment related that when she lived at home: "We were exhausted. It was so much work and it was so tense all the time at our house because you never knew; you never knew what was going to happen. So you walked in feeling paranoid."

Nine of the fourteen parents (64%) discussed the stress they endured as they realized their children might never become totally independent. As noted earlier, six of the fourteen adult cases (43%) needed help managing their finances, with most of the adults with FASD needing assistance with some aspects of their lives. One adoptive mother, who provides housing on the family's property for her son, shared her concerns about George (pseudonym) after she is gone:

It's a nice two-bedroom place for George to live. And we established a trust so that when we're gone, there will be protected living for him, at least if he chooses it. I don't know if he will or not.

She remains fearful that he will not make safe choices after she and her husband have passed away, even though they have made provisions for him. Another adoptive mother, who has guardianship over her twenty-one-year-old daughter, expressed concern about someday needing to turn the guardianship over to the State of Alaska. She said she had spoken with her daughter about this eventuality:

Yes, I'm still caring for her. I will be for quite some time. If I turn her over to the state, and she and I talk about that... they're not open on holidays. And they're not going to give you another \$50 because you gained 50 pounds and can't get into your swimsuit that you need for going to the lake tomorrow.

One adoptive mother expressed her fear of not being able to secure guardianship of her fifteen-year-old son after his eighteenth birthday:

It's great until they're eighteen, nineteen, or twenty and then they're so called legally adults, you know, in the United States. Well they are not adults really, you know, so that's when it's really a showdown. We are never really going to be able to get guardianship of him because he's functional. So he knows... I said, "We have three more years to work with you so you can function in society."

Other parents discussed stress due to lack of sleep and having no time for self-care or going out with friends. As one mother told me: "And she wouldn't sleep. We would be up until 3 a.m. most nights." Ipsiroglu, McKellin, Carey and Loock (2013) found that children and adolescents with FASD are at high risk for developing sleep problems, causing additional stress

on families. Due to the child's sleeplessness, parents are overtired. Children with sleep problems tend to have more daytime behavioral problems such as inattention, hyperactivity and emotional impairments, which causes additional stress on parents.

Parents found the stress of maintaining a safe, stable environment for their children a primary concern. They discussed the additional vigilance necessary to ensure their children's safety at home and school. They also conveyed the ongoing stress of uncertainty about their children's future. These concerns suggest improved services may help enhance the quality of life for both individuals with FASD and family members.

Effects on Siblings

Seven (50%) of the parents discussed how having a child with FASD impacted the siblings. Five of the families included siblings with FASD. Parents described both negative and positive effects on siblings. The parent of the 35-year old man shared some of the negative effects on the younger sibling due to his brother's requiring so much attention:

He [sibling] did not make it unscathed. I think we need to have paid more attention than we did. All our family energy went to dealing with George (pseudonym). And at the time I did notice that Jim (pseudonym) was quiet and had issues. He didn't have very many friends. Well, first of all, nobody would let their kids come to our house. So there were no friends. Not only for George but for Jim. He is now thirty-one years old. He just can't abide by his brother. He will not deal with him at all.

Some parents discussed positive effects on the family. The mother of a twenty-year-old shared how her biological son, who was near in age, became the adopted son's mentor: "I made sure Russ (pseudonym) was always in his class and we had a diagnosis, so Russ would give him verbal prompts. So how we got him to learn things...it took Russ, bless Russ!" As adults, these

two brothers have continued to have a close relationship. Their mother stated: “They like to go to the movies. They play basketball. Their new thing is to go out to eat.”

The mother of several adopted children with FASD, in addition to her biological children, shared her thoughts on the benefits of having a large family:

Yes, well we had a large family and you’re pretty much accepted. There’s issues and arguments and fights, but there was pretty much always someone you could go to for talking or hanging out. I did have one who I’m not sure had anybody but it didn’t give you that feeling of being alone or being excluded or being different or shunned.

Parents thus related showed both positive and negative effects on siblings. Raising children with FASD can cause additional stress within the family due to their high level of needs. Parents emphasized the importance of making an effort to meet the needs of all children within the family and identify ways for siblings to support each other.

Impacts on Parents’ Relationships and Employment

Seven of the fourteen foster or adoptive parents (50%) spoke of their loneliness and isolation stemming from others not understanding their situation, or other parents not wanting their children to be around the children with FASD. A single adoptive mother explained:

I don’t have anybody. I don’t know anybody who is doing and dealing with what I’m dealing with on a day to day basis... it’s a struggle. I met a couple people... who are dealing with autism, or similarities and it’s like, oh dear, you know what I’m talking about... But that’s two minutes of a day. I just don’t have anybody... and my frustration level is really high.

Another mother, whose daughter had been sexually abused as a very young child, shared her loneliness. She spoke of one especially sad event:

I lost friends. She [adopted daughter with FASD] molested one of my best friend's kids and I never spoke to her again. Even though I had told her a million times, "Do not let her be unattended," and this is what she would do. But she didn't believe me and said she would be OK, that she was adorable.

Bobbitt et al. (2016) had similar findings on loneliness. In their study, 125 caregivers of individuals with FASD completed a survey that contained a Perceived Stress Scale. Fifty-nine percent responded with either "quite a bit" or "a lot" to a question about feeling isolated and lonely, owing to their responsibility for an individual with FASD.

Seven of the fourteen adoptive or foster parents (50%) I interviewed discussed how raising a child with FASD had caused strained family relationships. This is a phenomenon seldom addressed in the literature. Morrissette (2001) described some of the stress and strain on the marital relationship, including the likelihood of dissolution. In my study, several parents related that their spouses had difficulty understanding the impact of FASD on the child(ren). Others said that they did not have the time to work on their marriage relationships due to the high demands of the child(ren) with FASD. One parent explained how her husband had trouble grasping and remembering that their son needed a regular routine, and that they could not make spontaneous plans, for instance:

You're going along on this track and for his dad to say, "Hey let's go to the cabin."

Whoa, he has to shift... it's very hard on them. What happens is my husband forgets how hard it is on him. He has expectations and then he starts being hard on him and then I have marital problems.

When asked how FASD has affected her family, one mother of three boys with FASD said that her marriage fell apart, owing to the stress of parenting three needy children:

Well I started out with a husband... I had to make my choice--my husband or my boys. We were going to try and work it together and when I got back here it just didn't pan out. So I actually adopted the boys as a single parent. So I started off married and was divorced by the time... yeah. That was tough, having to do that.

The parent of the six-year-old shared the importance of always presenting a united front on decisions regarding the children. She explained that she and her husband were a good team but expressed her frustration about trying to find time to work on their relationship. She explained the difficulties and costs surrounding a simple "date night" with her husband:

We went on a date Saturday, my husband and I. We went to a movie. We had to pay two babysitters, two babysitters \$30 each so that is \$60. That's just for my husband and I to go to a movie. Then we got text messages all night, "he escalated" and "how do I help him with escalation?" It's really hard to be able to find respite care, even for something as simple as going on a date.

Five of the 14 parents (36%) described their frustration with teachers and other people not understanding why they needed to provide ongoing structure for the child. One mother described her frustration:

So we had to continually supervise her. We fought a lot with the school. She had figured out how to hold it together at school and the school thought we were a little crazy [for insisting that she needed continual supervision]. They thought we were overprotective of her.

Another parent shared similar thoughts about people not understanding the need for structure and supervision:

If I've left him I always come back to more problems because nobody understands him. I mean if you aren't dealing with people who understand, you get tired and worn out from explaining why you are keeping them in such a structured environment. They think you are a parental Nazi.

Three parents (21%) discussed their employment difficulties while raising a child with FASD. One reported that she quit her job to stay home with her adopted sibling group of three, all with FASD. She could not manage employment while meeting the needs of her children. Furthermore most of her paycheck was going to childcare costs. Another parent shared her difficulty in balancing her work schedule with the needs of her daughter when the child first came to her home as a foster child:

We would be up until 3 a.m. most nights. Eventually they [the state of Alaska] actually sent someone in because I called and said, "I can't go to work anymore because she wouldn't go to school... They got a grant or something to help me, so they sent someone in to help her get ready in the morning and then someone in the afternoon because I couldn't work. I just said, "I can't do this anymore. I can't afford not to work."

This was a foster child who was particularly difficult to place due to being sexually abused as a young child in her biological family. Due to her abuse, she reacted sexually to all male father figures. The state provided the extra support, in this case, to help ensure the placement would be successful.

Although all interviewed parents recognized and understood the struggles of their children with FASD, and were supportive of them, three parents (21%) discussed their inner conflicted feelings. One mother told me:

So, I sometimes feel that we all got cheated or robbed or something. Sometimes there's a twinge of jealousy of parents that have kids who are excelling in something... anything... do well at school... have good friends... have good relationships.

Yet overall, parents exhibited pride and enthusiasm when they shared their children's success stories. Even when the road to adulthood had been extremely bumpy, most parents related happy memories. The mother of a seventeen-year-old explained: "[he] has improved my life significantly just by being who he is. Even as a baby I felt that [he] is paying his way just by the way he makes me laugh... [he] has brought a lot of joy to me."

Most Helpful Services for the Affected Individual or the Family

My two final research questions seek my respondent's views on what support have been most helpful and what needs remain unmet. These questions have received less attention in the literature, and thus the present study makes a significant contribution to research on QOL for people affected by FASD. Researchers in the field of FASD have conducted program evaluations on a specific program or conducted some comparison evaluations between programs (Bertrand, 2009; Paley & O'Connor, 2011). Yet individuals with FASD and their families have rarely, if ever, been asked what services and supports have been most beneficial to them. I found no literature asking adult individuals with FASD what has been helpful to them and what supports they need. Asking individuals with FASD and family members about helpful supports can inform policy in a variety of fields. As Verdugo et al. (2005) note, in order to assess quality of life, one must consider the individual's perspective to discover what is meaningful to them.

Although the interviews with the eight individuals with FASD were shorter in duration than those with family members, all eight identified at least one support that had been helpful to them. Two of the eight adamantly put "Mom" at the top of the list, while all eight (100%) young

adults said that their adoptive or foster parents had been good supports. This correlates with Streissguth et al.'s (2004) study that identified living in a warm and stable family environment as a protective factor for individuals with FASD. Two young adults stated that connecting or reconnecting with their biological parents has been helpful, and three individuals mentioned siblings or cousins being supportive. Two individuals said their friends offered them support.

Seven of the eight young adults (88 %) interviewed identified various state and/or community services as helpful. These services included residential treatment programs, mental health clinicians, and transitional funding after high school through both the Office of Children's Services (OCS) and Fairbanks Youth Facility (FYF). Six of the eight young adults had been in State of Alaska custody through OCS, which gave them access to transitional funding when they became adults. One young man was incarcerated through part of his high school years and he had access to FYF correctional transitional funding upon his release. Five of the young adults mentioned teaching parents, who are the house parents in residential group homes, or other staff within residential treatment programs as beneficial supports.

Four individuals (50%) said individuals and programs at school were helpful. Supportive persons listed included teachers, life skill aides, a school liaison placed in the school by a residential treatment program, and other school staff in general. One individual mentioned sports as being a good support because they provided an incentive for him stay in school and helped build self-confidence. Importantly, all eight interviewed individuals listed parents as their main support system. The Duquette et al. (2006) study found that a high level of support and advocacy by parents helped to ensure that their children with FASD graduated high school. Seven of the eight individuals in this study graduated high school.

Individuals with FASD mentioned a few other forms of support they found helpful. Two young adults mentioned the benefits of having a supportive work environment, where their supervisor understood their disability. One young woman stated that her weighted blanket had been helpful in relieving her anxiety. A young man who needed to be constantly moving said that skateboarding had been helpful to him. Another young man stated that learning to ride the bus had been helpful to him in fostering independence, while another individual shared that having a service dog had helped him with trauma/night terrors. These observations are especially noteworthy in their simplicity and low cost. This documentation of the perceived value of these solutions, interventions, and services could help others with FASD enjoy a higher quality of life.

Parents were much more verbose in identifying helpful forms of support and other services. All parents (100%) mentioned the benefits of supports at school, although some thought that enhanced services were needed. Parents stated that classrooms where their children received additional help or could take tests, and classroom aides, were especially helpful in assisting their children to complete assignments and pass classes. All parents (100%) discussed the need for positive structure, routine, a calm environment, and explicit instructions within the classroom. This again corresponds with the literature regarding education for individuals with FASD (Miller, 2006; Carpenter, 2011). Six parents (43%) noted the importance of parents working closely with teachers. One mother explained how critical parent-school collaboration was to her child's well-being and development:

My son is at school for most of the day. So if I'm not working with the teachers and the principal and the behavioral aides there, then we're not unified and he's not going to thrive. And my thought is if we can get him the help he needs now and help him learn to self-regulate now, then it's only going to get better in the future.

In addition to working closely with the teachers and staff, parents discussed various special accommodations that had helped their children to be more successful. One explained:

He goes to school and he doesn't go straight to the classroom because it is too loud and there's too much going on so he goes straight to the resource room. They have him doing physical therapy so he throws balls into a hoop, weighted balls. He would go into this weighted roller thing and put a puzzle together and then [they would] put him in a swing and turn the lights down. He'd only be there for fifteen minutes or so. And by the time he went to the classroom, it was calm.

Parents mentioned another accommodation, sometimes called a "hot pass," whereby individuals who are escalating in the classroom have standing permission to leave the room as needed. They usually sit outside in the hallway or go to the counselor's office to calm down or self-regulate.

Four parents (29%) discussed how alternative schools or programs were helpful to their children. One mother said: "[The alternative school] was wonderful because [he] needs time outside being active." This charter school emphasizes spending time out of doors and learning through hands-on activities. Another mother shared her son's transition back into the school district after he had gone to a treatment program outside of Alaska. He was placed in an alternative program in the school district building with one teacher and just five children in the class:

She just adapted everything for him. She would give him a text book here and then at the other end of the long cubby or desk was his worksheet. And she put him on a rolling stool and he would roll back and forth, back and forth. He would roll to the book and then back

down to the worksheet. And do you know that in less than a month and a half he completed a whole quarter!

Ironically, when the student made progress, the school district personnel sent him back to the regular classroom with pull-outs for special education. He failed, and never completed high school.

Parents appreciated several other school supports. Two parents discussed having a peer mentor within the classroom, an interesting cost-free concept. One mother explained:

In first grade he was paired up with a Chinese boy who didn't speak much English. The Chinese boy would ask [him] the word for something and [he] could help him and then [he] could ask him for help with math.

Parents identified other supportive measures, including a preschool language program, school liaisons, or aides, and school sports.

Eleven of the 14 parents interviewed (79%) noted that various residential and community programs had been beneficial for their children and for themselves. As noted above, eleven of the 14 individuals over 18 years of age had been to residential treatment. Overall, parents valued residential treatment programs to be helpful. Community programs that parents found to be helpful included transitional services, mentors or youth counselors, psychiatrists, and other mental health professionals.

Parents praised other forms of support for the home or family. Six parents (43%) spoke positively of support groups, with five of the individuals referring specifically to an FASD support group. Three parents expressed appreciation for funding previously provided for child care during the support group meeting, noting it was seldom available now. Having to care for

their children during more recent support group meetings diminished parents' ability to relax and share their feeling with others, they reported.

Four parents (29%) identified respite care as being helpful. One parent had a share-care arrangement that allowed her son to stay with another person at times. This gave her time to focus on other family members and her relationship with her husband, while having some time for herself. Others spoke of having mentors who took their children into the community for activities, giving them a chance to catch up on chores or enjoy some personal respite.

Parents mentioned various other supports in their interviews. Three parents brought up the FACES Diagnostic Clinic as beneficial. The Clinic not only facilitates the referral, screening, assessment and diagnosis of children and teenagers with prenatal alcohol exposure, but it also provides ongoing training and supports. Three parents stated Adult Protective Services was helpful in navigating the Guardianship or Conservator process. This process is necessary for adult individuals who need assistance in managing their own affairs. The court may appoint a legal guardian for individuals who need multiple forms of assistance with daily tasks. If an individual only needs help in managing their finances, a conservator is appointed. One parent thought Job Corps, a program administered by the U. S. Department of Labor that offers free education and vocational training to young men and women ages 16-24 years, was helpful in providing training for their daughter and in assisting her to find employment afterwards.

One parent cited support received from a Family Advocate. A Family Advocate assists the parents in obtaining the correct services for their child and usually attends school IEP meetings. Another parent said she had learned how to work with her infant son through Project Teach. Project Teach, an education program for pregnant or new mothers of infants 6 weeks to 2 ½ years, advise new mothers in parenting skills. Other supports within the classroom, home or

workplace included index cards, charts, pictures, and demonstrations to clarify and remind individuals of tasks and obligations. Five parents mentioned medication as helpful to their children and two parents discussed their children learning to play musical instruments as an enjoyable hands-on activity that also stimulates brain development.

Overall, my interviews with both individuals with FASD and their parents left no doubt that parents are the most devoted and effective support systems and advocates for their children. Their interventions and advocacy helped ensure that their children received assistance at school, in the workforce, and from adult services when needed. Given that foster and adoptive parents provide the most effective and enduring support for these individuals, it seems prudent to provide them with the services they need, so they can offer the best quality of life possible for their children and help their children to transition to adulthood as smoothly as possible.

Forms of Support that would be Helpful

The eight individuals with FASD interviewed struggled to identify forms of support that might have helped them or their families. Four of the individuals (50%) did not express a need for any additional support. Four identified a need for more supported employment opportunities. Two of those individuals discussed the need for additional types of support in the workplace and two individuals spoke of needing help in finding or maintaining employment. Two individuals mentioned the need for additional forms of support at school and one conveyed his wish for more assistance while transitioning to adulthood.

Parents were much more eager to offer their perceptions on needed supports or services. Their suggestions fell into forms of support in three broad categories: schools, home and families, and adult services. Their suggestions resembled the types of supports they had

identified as helpful, but they often thought the level of support should be increased; they also noted the need for additional forms of services.

Ten of the 14 parents (71%) identified a need for better understanding of FASD in the school districts, and resources and accommodations to better fit individual needs. The State of Alaska requires FASD training for school personnel, but as one mother explained, the mode of delivery does not allow personnel to grasp the complexities of the condition or the special need of the children:

You have to take FASD training every two or three years. And you have to do it on-line, which means you can click and click through... you really can. You don't have to really learn and you don't have the experiences.

This parent went on to describe a training she considered more effective. First, a video about FASD was shown. Then a panel of parents, all of whom had children with FASD, shared their struggles and successes in raising their children. The format gave the audience a chance to ask questions and better understand some of the many challenges.

Parents spoke of the need for better, more person-specific Individual Educational Plans (IEP), along with better testing for individual needs. One parent described her frustration during an IEP meeting when IEP members allowed her daughter to set unrealistic expectations for career goals after graduation:

They were doing her IEP and during her senior year they're supposed to be transitioning into the work force... And in it they were repeating things [she] was saying but [she] was saying, "That sounds like a good thing to do." In there [she said she] was going to be a veterinarian. So we talked with someone that we know that has worked with kids on

IEP's, and he read the IEP, and he said, "That needs to be torn up and you need to start it all over again."

In this case, the parents called another IEP meeting, during which they set realistic goals. After high school the young woman went to Job Corps and she is currently working full time.

Another mother shared her disappointment with the school district's lack of understanding about individual needs, including their testing conditions:

He could be put in an IR [Intensive Resource] room with some access to regular ed but you can't convince the school district of that... Whenever you take a kid into a room and you have one on one and you test, he looked good. If you put him back in the room with twenty some kids, he just couldn't do it... And that's how we do it. We don't test them out in the open with twenty-some kids... but when he tests in a quiet room, he could do it.

Parents also brought up the need for after-school programs, not only to provide help with tutoring and completing homework, but to offer a safe space and oversight, while parents are at work. Oftentimes, adolescents who have aged out of daycare programs continue to need adult supervision, owing to their emotional or behavioral needs, yet the youths are too old for daycare. Other helpful forms of support parents mentioned included better assistance in tracking homework, and more overall support in high school, including one-on-one assistance at times.

When discussing other types of home and family supports or services they would find useful, eight out of the fourteen parents in my study (57%) spoke of the need for respite. The literature addresses this prevalent need for families caring for children with FASD (Bobbitt et al., 2016; Olson et al., 2009), with 90% of the parents surveyed in the Bobbitt et al. study wanting respite services. Parents discussed the need for respite due to their children exhibiting many

challenging behaviors and consuming much of the parent's time. Their responses illustrated the need for respite to allow time to focus on siblings and marital relationships, and to have personal time for self-care.

Parents identified several other forms of support that would ease the strain of raising children and young adults with FASD. Three parents expressed a desire for mental health clinicians better trained to work with individuals with FASD, who could interact with the parents as well to provide more coordinated, consistent, effective care. Two parents noted that early diagnosis would have been helpful to their families. Two parents discussed the need for summer programs or "jobs" for young teens who are too young for paid employment but too old for daycare. Another two parents noted the need for better training for daycare workers or babysitters equipped to work with children with special needs. One parent expressed interest in a support group that meets in person, rather than on-line. Another parent discussed the need for expanded Medicaid coverage to support visits by both parents and siblings when children with FASD are living in residential care or are hospitalized. Currently, Medicaid pays for only one parent to visit quarterly. This is particularly difficult on families when children are placed out of state.

Ten out of the 14 parents (71%) identified the need for greater support as the individual transitions into adulthood. Because the chronological ages of most individuals with FASD differ from their developmental ages (Malbin, 2002), these young adults are rarely prepared to live independently at the age of 18 to 20 years, and sometimes older. Not only does their immaturity cause parents anxiety and create stress between parents and adult children, but their vulnerability often leads to their victimization. Eight of the 14 parents (57%) specifically addressed the need for better management and safeguards of Permanent Fund Dividends (PFD's) and Native

Corporation dividends so that the asset is protected when the child turns 18 years. Three parents discussed the ongoing need for medication management for adult children, particularly as parents become older. Two parents identified the need for more effective interventions for physical health, as their adult children may not understand the long-term implications of their decisions. The parent's numerous suggestions for additional forms of support illustrate the scope and weight of the challenges they face while caring for their children with FASD.

Conclusion

My research has identified myriad ways in which FASD negatively affects quality of life for affected individuals and family members. My respondents – individuals who have lived this experience – bear credible witness to the struggles these individuals and families face. The constructivist framework I adopted illustrates the importance of understanding a social phenomenon from the point of view of those who live it (Schwandt, 1994).

My interviews indicated that all 18 individuals with FASD had suffered significant Adverse Childhood Experiences (ACEs). All faced difficulties at school, with 17 of the 18 cases had ongoing difficulties in the home including destructive behaviors, lying and/or stealing. Thirteen of the 14 cases who were over the age of 18 years had serious ongoing mental health problems, meeting criteria for a mental health diagnosis. Thirteen of the 14 adult cases had trouble transitioning into adulthood, with the one exception still living at home.

All parents described the need for structure, routine, and consistency within the home with many giving examples of how any deviation from the established routine would cause severe upsets. Eleven of the 14 parents described continual stress within the home, either due to the need for constant vigilance when children were younger, or the uncertainty about the child's ability to be independent as the child became older. Findings also included the serious impact of

raising a child with FASD on personal relationships with 50% of the parents experiencing strained family relationships and 50% of the parents discussing isolation and loss of friends.

All individuals with FASD who were interviewed identified their parents as their best supports. Individuals spoke highly of services they presently received with four individuals identifying the need for more support with employment or in the workplace. All parents expressed appreciation for the forms of support they or their children currently received but said additional services were needed at school, within the home and family, and as their children transitioned into adulthood.

Both individuals with FASD and parents provided valuable insight into how FASD has affected their lives, describing what forms of support have been helpful, and additional supports that would improve their quality of life. This knowledge can contribute to expansions and improvements of support services that may not only assist individuals and families directly affected by FASD, but also their schools and communities.

CHAPTER V: DISCUSSION OF FINDINGS

This study explores four research questions regarding how Fetal Alcohol Spectrum Disorder (FASD) affects quality of life for affected individuals and their families. The 22 in-depth interviews I conducted with individuals with FASD and family members elicited rich descriptions of their lives. As such, the interviews contribute to my research goal of developing an understanding, *based on their own experiences*, of how FASD affects quality of life of affected individuals and their families to educate others on the lifelong struggles of these individuals face, the tremendous commitment required on the part of their families, and the unmet needs of both. My research, combined with findings from published literature, offers guidance on specific policy changes that could improve these people's quality of life.

Individuals with FASD and their families undergo myriad challenges throughout life. While prenatal exposure to alcohol can cause multiple significant physical and neurological defects, diagnosis eludes many of those affected because no biomarkers or identifiable substance(s) in the body signify FASD. Many individuals with full FAS or partial FAS receive a diagnosis at birth but others within the FASD spectrum go unrecognized (Coles, 2011; Malbin, 2002). Even when distinct physical feature of FAS are present, diagnosis requires confirmation of prenatal exposure to alcohol. Without a diagnosis, many services remain inaccessible and opportunities for beneficial early interventions are lost. Individuals may go for years or even through life without anyone recognizing the root cause of their difficulties. One adoptive mother's story illustrates this conundrum:

Her biological mom would not admit to drinking alcohol. She said it was probably because her biological father had given her alcohol in her bottle to keep her quiet when

she was a baby. But [she] has all the facial features so we were able to go to the [diagnostic] team [and receive services] but that's why she isn't given the full FAS diagnosis.

Without maternal acknowledgement or documentation in the medical records, the foster and/or adoptive parents may be unaware of maternal drinking during pregnancy.

Thus, for myriad reasons, children and adults within the FASD spectrum often go undiagnosed (Malbin, 2002). Chasnoff, Wells, and King (2015), conducted a study in which 547 children underwent a comprehensive multidisciplinary assessment following referral to a mental health clinic primarily for behavioral problems. The clinic in Illinois specializes in assessing and treating high-risk children and adolescents, and it receives referrals primarily through the child welfare system. At referral, 36 children had a diagnosis of fetal alcohol syndrome (FAS) and 15 children had a diagnosis of Alcohol-Related Neurodevelopmental Disorder (ARND). The comprehensive assessment found that 156 children met the criteria for a diagnosis within FASD: 93 with FAS, 1 with partial FAS (pFAS), 61 with ARND, and 1 with alcohol related birth defects (ARBD). Thirty percent of the children receiving assessments had a diagnosis within the FASD spectrum. Prior to the assessment, the children had a broad range of mental health diagnoses, the most common diagnosis being attention deficit hyperactivity disorder (ADHD).

This study highlights another difficulty in identifying FASD – differentiating the effects of prenatal alcohol exposure from other conditions. Research and my own experience as a mental health clinician find that individuals with FASD frequently receive a diagnosis of ADHD due to similarities in behavior difficulties (Coles, 2011, Malbin, 2002). Many individuals within the FASD spectrum have struggle with attention and self-regulation, as do those with ADHD. Individuals with FASD who receive an incorrect diagnosis may receive unnecessary and

ineffective medications. These individuals also fail to receive the early intervention and treatment options that will be most effective for their disability. In the 2015 Chasnoff, Wells and King study, changes in diagnosis led to adjustments in medication as well as significant modifications in recommended therapeutic approaches.

Other factors contributing to problem behaviors complicate the diagnosis of FASD, as well, including early negative environments and adverse childhood experiences (ACEs). Loss of parents, institutionalization, abuse and neglect, and frequent changes in foster placements all may lead to cognitive deficiencies, along with behavioral and emotional problems. In extreme cases, these may affect physical growth (Coles, 2011). With children prenatally exposed to alcohol often experiencing numerous other environmental difficulties, it is hard to identify the source of the problem.

Finally, unless individuals meet criteria for full FAS or pFAS, receiving a diagnosis is challenging. Some indicators are relatively subtle and require a full assessment by an FAS diagnostic team or a neuropsychological evaluation. Neither of these are easily accessible. Diagnostic teams can evaluate a limited number of individuals per year, and few individuals are referred for neuropsychological evaluations without a significant event such as admission to a psychiatric hospital or severe behavioral incident. Although Alaska has several FASD diagnostic clinics, the FAS Diagnostic and Prevention Network website lists diagnostic clinics in only fourteen states.

These complexities surrounding recognition of symptoms and obtaining a diagnosis illustrate some of the many challenges individuals with FASD and their families face as they navigate through life burdened by deficits that hinder reasoning and communication, lead to impulsivity and distractibility, render simple tasks more complicated, and ultimately make living

independently as an adult unlikely. The following discussion analyzes my findings from the interviews I conducted, integrating them with the literature and considering the implications for individuals, families and communities. As the discussion illustrates, early diagnosis and intervention can be critical to mitigating some of the most debilitating effects of FASD. Without such early diagnosis and intervention, the difficulties these individuals face oftentimes compound, leading to serious psychological, social, and legal consequences.

How FASD Affects Quality of Life for Affected Individuals

The findings from published research and this study clearly demonstrate that FASD impacts almost every aspect of the daily lives of affected individuals. Although experiences vary and some of the themes cross-over, six key findings dominate.

First, individuals with FASD often endure other Adverse Childhood Experiences (ACEs) in addition to their prenatal exposure to alcohol, and such incidents and conditions create additional life stressors. In my study all 18 cases had numerous ACEs in addition to FASD, which correlates with existing research on FASD, such as the work by Streissguth et al. (1996) and Olson et al. (2009). All these adverse childhood experiences create additional trauma and/or stress for a child, with life-long implications.

ACEs have been shown to greatly affect quality of life. The Felitti et al. (1998) study shows a direct correlation between ACEs and health risk behaviors and disease in adulthood. Along with an increased risk of adult diseases, this influential study showed that individuals who sustain four or more ACEs have an increased risk for alcoholism, drug abuse, smoking cigarettes, a high number of sexual partners, severe obesity, depression, and suicide attempts. A strong relationship exists between the number of ACEs and the risk factors for the main causes of death in adults, suggesting that the impacts are powerful and cumulative.

My interviews with parents correspond with published studies that show the importance of quality caregiving and a stable, structured environment for individuals with FASD (Streissguth et al., 2004; Olson et al., 2009). Studies show that children who suffer trauma, along with FASD, have more difficulty in school with attention, memory and language. They also exhibit more oppositional behavior and social problems, all of which affect quality of life. This finding confirms the need for early diagnosis and the use of effective interventions for individuals with FASD. Professionals need more comprehensive training to increase awareness of the effects of FASD and give them the tools they need to work with individuals with FASD and family members. Moreover, quality caregiving requires that caregivers receive the supports and services needed to provide a stable home. This will enhance quality of life for the individuals and their families, while lessening secondary behavioral characteristics, to include mental health and substance abuse problems, which research shows develop as individuals with FASD are unable to cope with their environment (Streissguth et al., 2004, Malbin, 2002).

Secondly, many of my cases suffered from significant health problems at birth, which aligns with the findings in the literature. Health problems among my cases included failure to thrive, a cleft palate, a herniated diaphragm, and a bilateral brain bleed. Such health problems compound the alcohol-induced deficits of these children and adults.

Adverse childhood experiences and significant health problems at birth may lead to attachment disorders which can develop when children receive inadequate social and emotional caregiving. Such attachment problems often extend into adulthood (Thomson & Jaque, 2017). According to the DSM-V (American Psychiatric Association, 2013) there are two types of attachment disorders in children: reactive attachment disorder (RAD) and disinhibited social engagement disorder (DSED). A child with RAD exhibits a pattern of emotionally withdrawn

behavior toward adult caregivers, shows minimal social and emotional responsiveness towards others, has limited positive affect and has periods of unexplained irritability, sadness, or fearfulness that occur even in nonthreatening interactions with adult caregivers. In contrast, children with DSED will, for instance, actively approach and interact with unknown adults and willingly follow unfamiliar adults with little or no hesitation. Both RAD and DSED can result from not having basic emotional needs met as an infant or from repeated changes of primary caregivers.

Several parents mentioned problems with attachment among their children. As noted in chapter four, one mother stated that her son had never said he loved her or called her mom. Another mother talked about her daughter saying she loved her, but never being able to say she wanted to live with her. Another parent related the following:

So we took him home with us and right away I noticed there was probably some bonding and attachment issues because he never cried and he just waved bye-bye to her [his former caregiver]. I thought hmmm and I'm a total stranger. That kind of concerned me but of course it makes it easier to care for him that he didn't fuss.

Other parents only mentioned briefly the possibility of attachment issues saying, for instance, a five months old infant with “no eye contact and no smiling” or a child who “didn't hug back.” Attachment difficulties greatly affect quality of life, as they inhibit the ability to bond and have meaningful relationships throughout adulthood, which contributes significantly to satisfaction and happiness. Attachment difficulties, along with early life trauma, may result in poor mental health including depression, anxiety, eating and personality disorders, and suicidality (Corcoran & McNulty, 2018; Thomson & Jaque, 2017). Serious attachment problems can also lead to psychiatric problems, including narcissistic and borderline personality disorders.

Again, early identification and intervention are necessary to address attachment disorders, as they are difficult to overcome and have lifelong consequences to the individual and to those around them.

Third, all eighteen individuals experienced ongoing difficulties at school relating to behavior, academics, friendship, and appropriate social skills. Problems increased in high school, a time when socializing and friendships become a priority for many adolescents and greatly impact quality of life. Interviews with both individuals with FASD and parents revealed that individuals struggled constantly with friendships, often experiencing bullying or victimization. A young woman made this statement about other students at school: “They were the ones to spread rumors and it got me in a depressed stage for a while. I think that’s when my depression started.” I asked a young man who was discussing school if he struggled with friendships. He replied, “Basically yeah, since I got bullied.”

As I listened to young adults with FASD and their parents discuss school challenges, I became more aware of the ongoing struggle for positive self-esteem. I found this especially true in high school, when the focus in life changes from family to friends. No individuals with FASD mentioned self-esteem. However, they voiced resignation as they discussed their difficulties with relationships at school – recognition that other students shunned, mocked, or took advantage of them, that such difficulties were likely inevitable, and that it was they who were somehow at fault. One mother explained, “As she got older, she would realize more that she was excluded at school from a lot of group friends and things.”

Individuals with FASD shared many challenges related to cognitive deficits, including struggling with focus, memory, emotional self-regulation, and the inability to pick up social cues. They acknowledged their need for special education services due to their academic

weaknesses or behavior problems. Often feeling ostracized, victimized, and left out of activities due to a lack of understanding about their disability on the part of schoolmates, their schoolmates' parents, and teachers, these students' self-esteem suffered further. Not only did they struggle to make close friends, they felt others viewed them as peculiar. In high school, especially when young people feel so keenly the desire to fit in, to be accepted and liked by others, these individuals recognized well that they did not fit in. They knew they were different and that others did not accept them.

Although individuals with FASD and parents identified good supports at school, they also identified the need for better and additional services. Parents stressed the importance of additional training within the school systems, with training on FASD emphasizing the importance of focusing on individual needs. Prenatal exposure to alcohol affects individuals differently according to many factors, including amount of alcohol ingested and the timing of use (Malbin, 2002). Parents emphasized that teachers and parents must work closely together to develop a learning plan that focuses on the needs and the strengths of affected individuals. Research has identified that individuals with FASD require structure and consistency within the classroom, yet benefit from high levels of engagement (Blackburn et al., 2010; Carpenter, 2011). Several of my parent-respondents identified alternative schools as beneficial. Schools and parents must collaborate to identify the best school and classroom fit for the child. Finally, my research detected low or no-cost solutions within the classroom or school. Two parents gave positive examples of peer mentors. This could be a positive solution for not only for individuals with FASD, but also for school children with other challenges.

Fourth, seventeen out of the eighteen individuals with FASD experienced serious difficulties in the home resembling those identified in the literature (O'Connor, 2014; Olson et

al., 2009), including physical aggression, property destruction, disobeying rules, attachment problems, and sleep difficulties. Providing that structure creates less stress within family relationships, as discussed below. Moreover, structure mitigates disruptive behaviors but does not eliminate them. Despite these parents' evident devotion to their children and extensive efforts to provide the healthy and supportive environment, seven of the children went to residential treatment, foster care, were hospitalized in a psychiatric hospital, or were incarcerated after they were in their adoptive home. These institutionalizations illustrate the seriousness and the persistence of the psychological and social problems individuals with FASD experience and the toll the disability takes on the individuals and their families. These are adoptive parents who made a conscious decision to provide a home for children with life-long disabilities. The public, professionals who interact with individuals with FASD, and policymakers must understand the challenges these children bring to the family system so that appropriate and helpful supports and services can be provided for them. This discussion will continue under the second research question.

Fifth, thirteen of the fourteen individuals with FASD over the age of 18 met criteria for a mental health diagnosis, qualifying them for residential or outpatient services. Six of the individuals exhibited behaviors serious enough for them to be hospitalized in a psychiatric facility. This again concurs with the literature showing that individuals with prenatal alcohol exposure are vulnerable to mental health problems that continue throughout their lifespan. Living with mental illness greatly affects quality of life for affected individuals and their family members. Individuals with FASD are over-represented and under-recognized in clinical settings, the child welfare system, and detention and correctional facilities (O'Connor, 2014; Streissguth et al., 1996). One young woman with FASD I interviewed, who is now the mother of three

children, struggles with depression and substance abuse. A young man with FASD, whose mother I interviewed, is homeless and frequently incarcerated due to mental health problems and substance abuse. These findings support the need for increased professional awareness and training, along with early diagnosis. Such early diagnosis and intervention could assist people with FASD in avoiding or reducing mental illness symptoms and in developing skills to mitigate behaviors that contribute to incarceration and other difficulties. Early diagnosis would also help individuals access appropriate help when and if they encounter trouble with authorities.

The sixth key finding was that individuals with FASD have serious difficulties in their transition to adulthood. The literature scarcely addresses this issue, but the few published articles that identify the problem show similar findings. Malbin (2002) refers to these difficulties when addressing chronological age versus developmental ability. In the United States individuals at 18 years are expected to be on the verge of independence. They typically graduate from high school, drive, have an idea of what they want to do after school, engage in romantic relationships, and understand the concept of “safe sex.” Yet Malbin explains that many 18-year-old individuals with FAS/FASD are as young as 10 years developmentally. They continue to need structure and guidance, often remaining dependent; lack the skills necessary to plan ahead; and are often immature, inappropriately curious, and impulsive (Malbin, 2002).

Verdugo et al.’s (2012) framework for measuring quality of life includes three key factors: independence, social relations, and well-being. My research showed that only 8 of the 14 cases of individuals with FASD over 18 lived independently, with all but one of those continuing to receive help from parents or community agencies. Adult children continued to need assistance with various daily tasks, including money management, medication management, employment, maintaining appointments, and completing paperwork. These findings illustrate the enduring

nature of the difficulties that individuals with FASD face and the continuing toll these needs take on individuals, families, and communities. Identifying methods and securing the means to help these young adults become more independent would improve both individuals' and their families' quality of life and mitigate the burdens on others as parents become aged or and/or can no longer assist them.

Research shows us that individuals with FASD mature more slowly than the average person, yet social services do not acknowledge or make provisions for the extra support needed as they transition to adulthood unless they have a low IQ. This serious gap in social services demands further research, understanding, and action to protect this vulnerable population. Because they are developmentally younger than their typically developing age cohort, individuals with FASD may make poor decisions that will affect the rest of their lives. Parents shared stories of how their adult children were victimized by “friends” or extended family members. In Alaska, where young adults receive Permanent Fund Dividends (PFDs) or Alaska Native dividends when they become 18 years of age, this is particularly troublesome. Parents found that unless they applied for and were granted guardianship or conservatorship for their child(ren), they are unable to protect them and their financial assets after they became 18 years of age. Many individuals with FASD have difficulty in maintaining employment or only work at entry level jobs. It is important that any dividends or other funds they receive be protected.

Another concern for adult individuals with FASD that arose in my interviews was their lack of access to Supplemental Security Income (SSI). For some the inability to navigate the difficult application process kept them from receiving these funds for which they should qualify. Others' IQ is too high to qualify, even though they did not have the ability to secure a good job or maintain employment. Ongoing research recognizes that functional ability is not solely a

function of IQ level, but also of adaptive skills, which are the practical, everyday assets needed to independently take care of oneself and interact with others. Ase et al. (2012) compared children with FASD, children with similar IQ's to those with FASD but with a specific learning disorder (SLD), and children in a typically developing control group (CON). They discovered that the FASD group consistently performed less well on adaptive skills than the other two groups, even if IQ's were similar. They also found that the social skills of the children in the SLD group improved with age, whereas in the FASD group, the older children's socialization skills were worse. Yet SSI qualifications do not reflect these research findings, nor do qualifications for other services available to individuals with disabilities. Individuals with FASD need such services to maintain as much independence as possible and attain a better quality of life.

Finally, although my sample size was small and this finding fell under transition to adulthood, the challenges of parenting for adult individuals with FASD warrant discussion. Few articles in the published literature address this topic specifically, but it is increasingly becoming a topic of interest as individuals diagnosed with FASD have children of their own, and parenting generates an array of challenges to the individual with FASD and the children. Four of my adult cases have children, with two raising their children in the home. This 50% rate of child removal resembles the percentage reported in published literature on maintaining children in the home for individuals with intellectual disabilities (Llewellyn, McConnell, Honey, Mayes, & Russo, 2003).

In April 2018, I attended and presented my research at the 8th International Research Conference on Adolescents and Adults with FASD in Vancouver, British Columbia. After the closing plenary, entitled: "Parents with FASD: Challenging the Stereotypes," another plenary panel entitled, "We Are Parents: What It Looks Like" followed. The panel consisted of

individuals with FASD with children. One young man shared a particularly impactful story about becoming a father. He reported attending all the doctor appointments with his pregnant wife. At one point during the pregnancy, the doctor inquired about family history and whether there were any problems or medical complications in the family of which he should be aware. The young man said no, but after his wife prompted him to talk about having FASD, he explained his condition to the physician. The doctor looked at him and stated he would document in the medical chart that although he had FASD, he was not violent. The physician wanted to ensure that another doctor would not fear having him in the room. This story illustrates the misperceptions surrounding FASD within the public, even in the medical and other professional communities, concerning FASD.

Denys, Rasmussen, and Henneveld (2011) conducted a study in Canada evaluating the effectiveness of Step by Step, a Catholic Social Services program in which mentors worked one-on-one with parents affected by FASD for up to three years. The study showed the program reduced secondary disabilities, such as anxiety, depression, or low self-esteem among parents with FASD and improved outcomes for both the parents and their children. In a similar study by Grant et al. (2004), the Parent-Child Assistance Program (PCAP) was modified for women with FASD who were parenting. Outcomes for this 3-year home visitation program showed improved connections with medical and mental health services, increased use of contraception, a reduction in alcohol and drug use, and improvement in obtaining stable housing. Both programs found the need to help individuals meet their basic needs while also assisting them in understanding child development and in developing better parenting skills. These studies, which encompassed a three year period, demonstrate the effectiveness of mentoring programs and that with supportive services, some parents with FASD can raise their own children. Adults with FASD who are

parenting their own children is a new area of research that needs additional study. Keeping biological families intact through supports and services, can result in less trauma for both the mother and child, if the parents can maintain a loving and stable home.

How Raising Individuals with FASD Affects Quality of Life for the Family

Little research has focused on the question of how FASD impacts quality of life for the family raising a child or children with FASD until recently, as professionals have become more aware of the effects of prenatal exposure to alcohol on individuals. Findings from recent research and this study confirm that raising children with FASD greatly impacts families' quality of life. Notably, in my research, only one individual with FASD made statements regarding her impact on the family. This may be due to those individuals' inability to generalize or see how their behavior affects the family. It is possible that as they age and mature they will have more to say on this question. Parental responses generated four key findings regarding this question – issues that overlap and interrelate with one another.

Foster and adoptive parents spoke extensively on how raising children with FASD affected their families both positively and negatively. All but four parents of the eleven adoptees knew their children were prenatally exposed to alcohol before adopting them. Two of the four adoptive parents who did not know about the exposure learned soon after the child came into the home. One mother said she immediately recognized signs, so she had him evaluated by the FASD diagnostic team. The other child arrived in the adoptive home before diagnostic teams existed. That mother stated she became aware of his prenatal alcohol exposure when she took him to see his pediatrician and the doctor concluded the exam with the comment, "Maybe his mom had one martini too many." The other two families did not know their children were alcohol-affected for several years. Both families stated that early diagnosis would have been

helpful and may have alleviated some of the serious problems they experienced, or at least might have enlightened them on the underlying causes of their children's behaviors.

After learning of the many challenges parents experienced with these children, I find it remarkable that six of the parents I interviewed adopted additional children with FASD, with four of the families adopting the siblings of the cases in my study. This illustrates the extraordinary level of commitment of these adoptive parents towards children with special needs. These are parents who selflessly devote themselves to raising children in need, sometimes to the detriment of social activities, friendships, and even their marriages. Providing families the supportive services needed to maintain healthy and nurturing home environments seems a wise public investment, especially when the lack of services could result in children undergoing the additional trauma of a failed placement, being returned to the foster care system, and increased risk for mental health problems, substance abuse, or incarceration as adults.

In my first key finding, parents expressed most frequently the need for a high level of structure and routine in the home. Parents related the serious negative consequences to be expected with any variation from the schedule. Even during vacations, parents often kept regular bedtimes and maintained strict routines. Although all parents discussed the need for structure, they also talked about the stress this created within the household by the need for such structure. Spontaneity was out of the question, which sometimes led to resentment by other family members. Parents expressed the importance of both parents being on the same team, and how marital discord resulted when one parent had less understanding of the effects of FASD and how removing structure could cause disruptive behaviors.

Siblings were also affected, as attendance at birthday parties, school activities, and other special events might depend on how the sibling with FASD was managing that day. One mother,

who adopted three brothers with FASD, discussed how “transitions were really hard for all three of the boys.” She took the younger boys to school activities of her older biological children, but said, “I always had to be prepared for the meltdowns.” Such incidents could result in embarrassing moments for the older siblings. Another mother related that her older son later told her that his younger sister with FASD had often embarrassed him as they were growing up. He said he had hated to go anywhere with her because her behavior was so humiliating. These anecdotes illustrate the ongoing stress within the family and the need for support.

Second, concerns about the children’s and other’s immediate safety, as well as uncertainty about the child’s future, caused high levels of stress within families. Parents discussed the need for hypervigilance due to safety issues, poor impulse control, and never knowing when their child would have a “meltdown.” They described their exhaustion resulting from the children’s abnormal sleep patterns and lack of emotional control, for instance the “two hour raging tantrum” after being told, “just brush your teeth and go to bed.”

Parents discussed the stress and worry they experienced when they realized their adolescent children might never become fully independent, and as they discovered the limited services available to maintain them in the community. They shared their stories of adult children being victimized. One mother related how her son became homeless when his assisted living home closed. This adult son with FASD, who was not receiving any services, eventually died of a drug overdose.

Chamberlain, Reid, Warner, Shelton and Dawe (2017) conducted a study in Australia that evaluated caregivers’ experiences following their children’s assessment by the FASD diagnostic team. Caregivers were either foster parents, adoptive parents, or legal guardians. The first theme that emerged from the study was the caregivers’ concern for their children’s future. Caregivers

wanted their children to become happy and contributing members of society and to have friends, families and services that would support them into the future. Parents in my study expressed similar concerns, often wondering who would take care of their children when they became elderly or passed on. The state of Alaska provides no services for adult individuals with FASD unless they have sufficiently low IQs. Yet, parents understand, and research indicates, that their children will not be able to maintain a good quality of life on their own. Services for individuals with FASD are necessary, especially through the transition into adulthood. For some, the services must continue indefinitely.

Professionals' lack of understanding about the many ways prenatal exposure to alcohol may affect individuals also causes parents anxiety. The Chamberlain et al. (2017) study found that most caregivers had prior knowledge of FASD and understood that their children's difficulties flowed from the condition. Yet caregivers felt that others, including health and education professionals, and society at large, often judged their parenting styles as inadequate or overzealous due to a lack of knowledge about FASD. Parents in my study made similar comments, indicating that such misunderstandings and the need for ongoing advocacy caused them additional stress. For instance one parent said school authorities that the parents were irrationally protective, and that the child needed less supervision than the parents recommended. Another parent told of being disbelieved because her son "looks so normal." The teacher denied the parent's request for a "cubical" on his desk to help him concentrate. Having their own parenting skills and instincts challenged by others creates stress within the family, along with increased feelings of isolation. Increased public awareness of the effects of FASD and more training for professionals, along with ongoing support for family members, possibly in the format of support groups, could alleviate this stress.

Third, my interviews with parents revealed quality of life impacts on the siblings of children with FASD – both positive and negative ways. Virtually no research has been done on the impacts of FASD on siblings. In my study, five of the families had other siblings with FASD.

The parents expressed most concern regarding the child with FASD needing so much focused attention that they struggled to meet the needs of other siblings. Parents discussed siblings feeling unsafe and afraid when a brother or sister was violent or destructive. They also told of other parents keeping their children from visiting the home, owing to the erratic behavior of the child with FASD. Such concerns deprived siblings of contact with friends and left them feeling isolated, especially when they were younger. One parent shared how their younger son, who does not have FASD, “can’t abide his brother.” She expressed that the younger son struggled with his transition to adulthood due to inadequate attention from his parents, their energies having been so focused on the older brother with FASD. Enhanced respite care services could mitigate this problem and help ensure that all members of the household have their needs met.

Parents also discussed positive effects on siblings, for instance a brother mentoring his adopted brother through school and maintaining a close, affectionate relationships into adulthood. Parents raising siblings with FASD stated that siblings generally felt accepted by one another, which was helpful when they struggled or felt left out at school. In my study, however, as individuals with FASD moved into adulthood, most did not maintain close contact with their siblings, other than through their parents. This may result from relationship and attachment problems of individuals with FASD, which greatly affect their quality of life as they leave their families and move into adulthood, unable to form healthy attachments.

Fourth, raising a child with FASD affected relationships with others, including spouses and employment, sometimes seriously affecting quality of life. Parents discussed feeling isolated and lonely due to the difficulty in making and maintaining friendships. They felt judged by others, in particular having their parenting skills perceived negatively and knowing that others avoided their children with FASD, owing to difficult behaviors. These findings resembled those of Bobbitt et al. (2016).

Parents also spoke of how raising a child with FASD affected their marriages. They expressed difficulty in setting aside quality time to spend with their spouses, often struggling to find babysitters who understood and could manage their children's behaviors. As noted above, marital tensions arise when one parent fails to grasp the need for structure and routine for the child. One mother related that her marriage failed, primarily because of the demands of raising multiple children with FASD. A struggling or failing marriage creates a tremendous amount of stress in the household, greatly impacting quality of life for all. Parents who are fostering or raising adoptive children with FASD need respite and other support services to reduce stress within the home that negatively impacts all family members and minimize the risk of a failed placement, which would cause further harm to the child.

A few parents, especially single parents who adopted children with FASD, discussed their struggles with maintaining their employment, owing to the high costs of child care and difficulties in leaving the house on time in the morning with a child with FASD. Although all families experience these challenges, children with FASD make balancing work and home obligations especially difficult.

The various impacts of raising a child with FASD on relationships and employment exemplified by these parents' accounts illustrate the need for better overall awareness of the

impacts of FASD and programs or other forms of support for affected families. My research aligns with studies by Ryan and Ferguson (2006) and Streissguth et al. (2004) in documenting the necessity of having supportive parents and a stable home environment to achieve the best outcomes possible for these individuals. Moreover, it is essential that these parents, who have chosen to raise individuals with a lifelong disability, receive the services they need. Societal investment in such forms of support would not only improve quality of life for families of individuals with FASD, but could avert costly negative consequences of neglecting these needs.

Helpful Forms of Support

Individuals and families using various supports and services provided valuable insights into the forms of support they have found helpful and how to best use limited resources. All respondents with FASD who were interviewed, along with parents, identified helpful supports within the family, school, community, and at their place of employment.

All of the interviewees with FASD identified their adoptive or foster parents as their best support system. They expressed appreciation for the various treatment programs they attended and the individuals who worked in the programs, including teaching parents, mental health clinicians, and mentors. Individuals acknowledged supportive persons at school, including teachers, life skill aides, a school liaison, and other school staff. They appreciated working with school or employment staff who understood their disabilities. Individuals noted simple, low cost forms of support, outlets, and achievements including a weighted blanket, skateboarding or sports, and learning to ride the bus, all accessed through the helpful support of others at school.

Listening to these young adults with FASD, I was struck by their appreciation of their parents' support in guiding them and providing a stable home environment. They may not recognize the tremendous amount of effort needed throughout the years to meet their needs, but

they acknowledged the love and guidance their parents had provided. Although most mentioned FASD-related difficulties, implicitly acknowledging the ongoing assistance they needed, they also expressed the desire to be as independent as possible. Individuals also spoke of acquiring skills that helped them transition to adulthood such as learning to ride the bus and having supportive supervisors at work. Such comments demonstrate the progress toward independence that individuals with FASD can make with the understanding, patience, and guidance of others.

Parents reported numerous forms of support that helped both their children with FASD and themselves. All parents interviewed mentioned supportive individuals and practices at their children's school. They appreciated teachers working with them closely, as well as having special accommodations to meet their child's needs. Parents often reported having to advocate for their children to ensure accommodation of their individual needs within the school and community. Parents noted the importance of structure, routine, a calm environment, and instructions being broken down explicitly in the classroom, as well as at home. Many of these accommodations and supports do not require significant additional funding. They require that the teacher and school be trained to better understand how FASD affects the brain and how best to meet the individual's needs.

Parents discussed the value of outlets and options within the school district, such as a resource room or alternative schools, in meeting the special needs of their children. From research we know that individuals with FASD often do better in a structured environment but they also need to move around and do better with hands-on than passive-learning activities (Ryan & Ferguson, 2006; Carpenter, 2011). Some parents thought that alternative or charter schools provided a more effective learning environment for a child with FASD due to emphasizing more hands-on or outdoor activities.

Parents also acknowledged the value of residential and community programs. Many of the individuals with FASD required hospitalization in a psychiatric facility or residential treatment, even after placement with their adoptive or foster parents. Forms of community support that parents identified as useful included transitional services, mentors or youth counselors, psychiatrists, and other mental health professionals. The variety of helpful services and professionals that parents identified speaks to these children's extensive needs, as well as the continuing support that families require to cope with the children's disabilities.

Parents noted the usefulness of additional forms of support as their children began to transition into adulthood. These included Adult Protective Services, which helps navigate the Guardianship or Conservatorship process; Project Search, a training program in the local school district giving children an extra year of schooling; and Job Corps. The mention of these programs highlights the frequently overlooked needs of young adults with FASD. Individuals with FASD tend to need support well beyond their eighteenth birthday, the age of majority in America, with some individuals needing lifelong assistance. Not only individuals and families facing the challenges of FASD, but whole communities in Alaska and elsewhere, would benefit from greater recognition of these transitional needs and from providing services that would ease transition to adulthood and reduce the risks of harm to these individuals or others.

Transition to adulthood is a crucial time period that sets the stage for the rest of one's life. Typically, eighteen-year-olds are expected to perform as adults and be prepared to make their own decisions. However, research shows that individuals with FASD may have much younger developmental ages, even as young as half their chronological ages (Malbin, 2002). Parents and other adults may have unrealistic expectations of these individuals which causes stress for parents, exasperation on the part of community members who do not understand, and extreme

frustration for the affected individuals. Due to increased freedom and lack of maturity, individuals with FASD may exhibit acting out behaviors that lead to interaction with law enforcement, and/or they may abuse drugs and alcohol. These behaviors may also result in victimization or homelessness. For individuals with FASD and their families, additional supports and services could assist with transitional needs and alleviate many future problems.

Parents reported several helpful groups and services, including support groups, respite, and ongoing training about FASD. Parents found it beneficial to share parenting techniques that were or were not working within their home, and to hear how other parents of children with FASD were parenting. They expressed feeling isolated from other families with more typically developing children and the need to share their stories and ideas with parents who would understand. Although parents voiced the importance and helpfulness of these services, they also noted difficulty in finding time for these interactions due to the extensive needs of their children.

Parents who had received respite care reported it was very helpful. The break from child responsibilities allowed them to work on other relationships within the family or to have personal time to relax and recharge so they would be more effective in attending to their children's needs. Parents also recognized the FACES Diagnostic Clinic, not only for facilitating their child's diagnosis, but also as a place that offers support and training.

Significantly, all parents in this study chose to parent children outside of their biological families, many of them knowing that the children had experienced early trauma and would face additional challenges. Most knew that their children had been prenatally exposed to alcohol. Caring for such challenging children requires extraordinary compassion, patience, persistence, and self-sacrifice. These parents clearly have enhanced quality of life of their children with FASD. All of the young adults with FASD said these parents were their very best support

system. Considering the many challenges that both individuals with FASD and their families experience, and the costs to society of failing to meet their needs, it behooves policy makers, service providers, and school systems to identify and adopt policies and practices that reduce burdens on these individuals and families and help improve their quality of life.

Needed Forms of Support

Overall, individuals with FASD expressed contentment with the forms of support they currently enjoy, saying that their parents or caregivers assisted them with their various needs. Individuals mentioned the desire for more assistance with employment, which would allow greater independence and increased quality of life. Individuals said they needed help both with finding and maintaining employment. Some noted additional forms of support at their places of employment that would be helpful, while others discussed their difficulties in finding a job that paid an adequate wage to maintain themselves or their households. All of the individuals with FASD expressed their desire to be as independent as possible. Identifying and adopting appropriate interventions to ensure safety, while fostering independence, would be beneficial and increase quality of life.

Parents expressed the need for additional forms of support within the home, at school, and in transitioning to adulthood. Although they found existing services helpful, parents stressed the need for additional support, suggesting existing services should be expanded or improved. Given parents' intimate knowledge of their children's needs, these recommendations should be seriously considered. Medicaid and other government programs do not cover many in-home services and training programs, even those that program evaluations show to be effective. Parents often cannot afford these services themselves. Also, in-home services are not funded for foster homes, even though such support in the foster home could save a difficult placement.

Most parents said that while schools provide multiple forms of support, many school personnel fail to understand sufficiently how FASD affects individuals, and schools lack the resources to accommodate individual needs. Current research shows how individuals with FASD learn best. School districts in Alaska, where the incidence of FASD is quite high, should use in-service days to train teachers and other school professionals in how to best meet the needs of individuals with FASD. Schools could also work with parents to select optimal classroom settings for their children.

Parents also mentioned the need for after school programs to assist their children assistance with schoolwork and to provide them with a safe place to stay while parents work. Research shows that chronological ages of individuals with FASD do not align with their developmental ages (Malbin, 2002). As adolescents, they are often experience victimization and peers frequently lead them into making poor choices. After school programs could provide a safe and healthy environment while providing them with needed enrichment activities.

Parents also discussed the need for increased respite care. Research on individuals with FASD and their families documents the high level of stress within the home due to their behaviors and to the constant monitoring they require (Olson et al., 2009; Whitehurst, 2012). Given the tremendous care these parents *voluntarily* provide for these children with special needs, society should provide the assistance necessary to maintain their health, as well as the health and stability of their families.

Most parents identified the need for greater assistance as individuals with FASD transition to adulthood. As a vulnerable population, individuals with FASD clearly need ongoing assistance to meet their needs and protect them from victimization. Early diagnosis of individuals

with FASD and better recognition of FASD as a disability would do much to protect this vulnerable group and help them receive helpful services that will improve their quality of life.

Other needed assistance parents identified included medication management for adult children, help with securing SSI, and better understanding among mental health and other professionals of the special needs of individuals with FASD. Enhanced training and awareness could help alleviate these concerns. Knowledge of current research on FASD could assist professionals and legislators in providing more helpful services for this vulnerable population.

Conclusion

This research demonstrates that FASD greatly affects quality of life, not only for the affected individual but also for the family. While individuals and parents I interviewed expressed appreciation for a variety of forms of assistance helpful, they also identified the need for additional services that would ease the many challenges they face and thereby improve quality of life. Asking individuals with FASD and their families how FASD has impacted their lives, what services and assistance are helpful, and what additional support would foster greater independence and help relieve the burdens on families has provided much insight that, *if translated into revised practices and reformed policies,* can improve quality of life for these individuals and families.

My research, as well as the published research of others, shows that individuals with FASD often face significant challenges in early life, in addition to their prenatal exposure to alcohol (Streissguth et al., 2004). These children may receive a broad range of mental health diagnoses without identifying of the root cause of their problems (Chasnoff et al., 2015). They may struggle throughout life with mental health problems, substance abuse, repeated encounters with the law, and homelessness without understanding why they have such difficulties. As

individuals with FASD enter the school system they encounter an array challenges due to attention and learning difficulties, lack of emotional self-regulation, and their ongoing struggles with socialization. Self-esteem tends to suffer, owing to lack of acceptance by peers, and poor self-worth often leads individuals with FASD to become people pleasers, which in turn can result in unhealthy relationships or becoming victimized.

Many individuals with FASD struggle as they transition to adulthood owing to their developmental age being younger than their chronological age. They continue to need assistance with life skills including securing housing, managing medications, completing paperwork, making and keeping appointments, and finding and maintaining employment. In Alaska, Permanent Fund Dividends (PFD) and Alaska Native dividends exacerbate money management challenges for many and heighten the risk of victimization.

The exceptional needs of individuals with FASD, many of them lifelong, place tremendous stress on their families, many of whom have chosen to open their homes to these children in need. Parents become exhausted and overwhelmed due to sleep deprivation, the difficult behaviors their children exhibit, and the constant vigilance required to ensure their safety and that of others. As the children approach adulthood, they continue to need a high level of support. With recognition of the unlikelihood of their adult children becoming fully independent, their anxiety increases. The weight of this stress can undermine relationships with friends and even spouses, leaving parents feeling alone and isolated.

My respondents' stories speak of many trials they face. My research supports published studies that identify effective ways to address many of these challenges. Early diagnosis and various interventions can improve quality of life for individuals with FASD and families. Public and professional research-based education, along with expanded and more effective services, can

ease their burden, promote independence, and improve quality of life for both individuals and families. Such proactive investment will benefit not only this population, but society at large. Assisting these individuals to reach their potential will foster independence, help them parent their own children more effectively, and result in fewer legal system interventions.

CHAPTER VI:

CONCLUSION AND RECOMMENDATIONS

Fetal Alcohol Spectrum Disorder seriously compromises the quality of life of affected individuals and family members. The impacts are often multi-faceted and far-reaching, with consequences spilling over into our schools and communities. Although Alaska is one of the few states that addresses some aspects of FASD, the general public and policymakers lack awareness of the incidence of FASD, the scope of the challenges affected individuals face, the myriad impacts on families, and the need for additional supports for both individuals and families.

FASD is complex and often difficult to diagnose, for three primary reasons. First, the condition is seldom recognized at birth in the absence of the physical characteristics that signify full Fetal Alcohol Syndrome (FAS). Researchers in the field believe that the number of individuals with FASD is five to ten times greater than those with full FAS (Malbin, 2002). Thus perhaps ten to twenty percent of those born with FASD are diagnosed at birth. Second, recognition of FASD is complicated by the prevalence of other Adverse Childhood Experiences (ACEs) among children with FASD (Streissguth et al., 2004). Individuals with multiple ACEs may have similar symptoms or characteristics to those with FASD. Without identifiable biomarkers for FASD, and unless prenatal exposure to alcohol is confirmed, it is difficult to know whether the individual's difficulties stem from prenatal exposure to alcohol without a full evaluation. Third, FASD symptoms often resemble those associated with other conditions. Affected children often receive multiple incorrect diagnoses by medical professionals who do not suspect prenatal exposure to alcohol (Chasnoff, Wells, & King, 2015), including Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder, Conduct Disorder, or Reactive Attachment Disorder.

Published research shows early diagnosis and intervention can help children overcome the deficits they incur with prenatal alcohol exposure. Early intervention also mitigates secondary behavioral characteristics such as anxiety, depression, and aggression (Streissguth et al., 2004; Malbin, 2002). Early diagnosis requires better screening, beginning with the initial prenatal visit to a medical facility. After considering the perspectives of individuals with FASD and their parents on how FASD affects quality of life, I offer the following recommendations to increase the likelihood of early diagnosis and improve interventions.

1) Improvement of Early Diagnosis

First, early diagnosis requires effective screening, beginning with the initial visit of the mother to a medical facility. Currently, medical personnel in some facilities use an assessment tool to screen for alcohol use and other risk factors at the first prenatal visit. This assessment tool needs to be part of the protocol in all clinics and hospitals to identify cases in need of intervention. Medical personnel need training in using the tool, best practices for addressing alcohol use, knowledge about available services, and proper documentation so the information follows the pregnancy. This information could assist with identifying future concerns about the infant and result in early diagnosis and intervention.

Second, better communication is needed between state children's services and medical personnel. State law requires that children taken into state custody be medically screened within 24 to 72 hours. If the child is removed from the biological family due to substance abuse in the home or if drinking by the biological mother during pregnancy is confirmed, it is important that the information be shared with health care practitioners. The information will help to differentiate between the effects of early trauma or prenatal exposure to alcohol and increase the likelihood of early diagnosis and intervention.

2) Improved Services for Adult Individuals with FASD

One significant finding in my research is the serious difficulty individuals with FASD have in transitioning into adulthood. Although there are limited published studies on adults with FASD, research has demonstrated that the developmental age of individuals with FASD is typically much younger than their chronological age (Malbin, 2002). Parents of adult children in my study described their vulnerability and victimization and their lack of readiness for adulthood. It is important that transitional services are put into place to protect these individuals.

Individuals with FASD often have difficulty qualifying for adult services due to the qualifications being based on IQ levels rather than adaptive functioning. Adaptive functioning focuses on the ability of the individual to handle everyday life skills such as money management, making appointments, or personal care. Due to permanent cognitive disabilities, individuals with FASD frequently struggle in these areas. Many individuals with FASD have an IQ above 70, which is the standard cut-off for adult services, yet are unable to manage day-to-day activities. Researchers and those who work in the disability field recognize the problem but the qualification guidelines have not changed. To ensure individuals with FASD receive the services they need, these guidelines need to be updated.

3) Expanded FASD Training.

My research, along with other published research show that most individuals with FASD experience out-of-home placements (Streissguth et al, 2004; Leenaars et al., 2012). Social workers, educational professionals, and foster and adoptive parents need training on the multiple ways FASD can affect their children's lives. Alaska offers training on FASD, but some of the foster parents and adoptive parents I interviewed did not understand the complexities of FASD

and its effects on children. Some recognized the symptoms of FASD right away, while others did not understand why their children acted out. They thought early diagnosis would have been helpful. Professionals and foster parents need more extensive training on FASD, to give foster parents the needed tools to work with challenging behaviors. Training and support would also help reduce the number of failed and multiple foster placements, which create additional trauma for the children. More effective training could also assist professionals and foster parents in identifying children and adolescents who need additional services to alleviate future psychological and behavioral difficulties. Educators and other professionals must understand that FASD affects individuals variously. By understanding individual differences, interventions can be tailored to fit each person's needs. Counselors developing Individualized Educational Plans, for instance, must comprehend FASD's effects on children, to ensure appropriate classroom accommodations, as well as planning for the future. Finally, educational professional training on FASD should be regularly updated to ensure awareness of current best practices.

4) More effective collaboration between parents and educational professionals

Individuals with FASD struggle in the school setting with both academics and socialization (Miller, 2006; Dybdahl & Ryan, 2009). Parents are a valuable resource and are often the best advocates for their children (Ryan & Ferguson, 2006; Duquette et al., 2006). Listening to parents can provide valuable information on their child's individual needs. Parents in my study had many suggestions on how the education system could adjust to be more beneficial to their children. Parents expressed the need for teachers and schools to work closely with them, listening to suggestions as they know their children's needs so well. Several discussed the need for structure and hands-on activities. Numerous studies have shown what type of teacher and classroom are the most effective for students with FASD. Research shows

individuals with FASD do best in a calm learning environment, free of clutter and distractions, yet providing high levels of engagement (Blackburn et al., 2010; Carpenter, 2011). Parents and schools need to work together to find the most effective classroom environment for their child. In addition, training on FASD needs to address the multiple ways FASD can impact the students and be regularly updated to assist educators in having the latest knowledge on FASD.

5) Revisions to school policies

Parents provided insight on other ways the school district could be more effective, including testing for special services. Currently, children are tested one-on-one in a quiet space to determine the need for additional services. Some quiet settings and one-on-one testing do not replicate classroom settings and therefore cannot assess the student's abilities within the classroom. Students should be evaluated in environments that replicate the classroom as closely as possible to identify individual students' needs and appropriate accommodations.

6) Revisions to the criminal justice system

My research findings provided little insight into individuals with FASD within the criminal justice system in Alaska, although 50% of my cases had encountered trouble with the law, including those under 18 years of age. Other research estimates individuals with FASD represent 27% of the criminal justice system in Alaska (State of Alaska DBR, 2006) and 24% in the United States (Burd, Fast, Conry & Williams, 2010). Both figures are multiple times the estimated rate of FASD in the United States, pointing to disproportionate incidence of individuals with FASD being incarcerated. Streissguth et al. (2004) found 60% of the individuals with FASD in their study had encountered trouble with the law. Legislators and criminal justice system professionals in Alaska need additional training on FASD and how to accommodate individuals with FASD within the legal system. Numerous research studies have shown that

individuals with FASD are a vulnerable population with maladaptive behaviors that may increase their risk of criminal activity and victimization (Fast & Conry, 2009). Once individuals with FASD become involved in the criminal justice system, they are disadvantaged due to their lack of understanding of court procedures and inability to self-advocate. In September 2012, Alaska became the first state to pass a statute that allows judges to reduce a felony sentence when there is clear and convincing evidence that the defendant committed the offense because they are disabled by FASD. This is an important first step. Yet a study by Tibbett and Jeffery (2016) showed that the law has never been applied in Alaska. The law includes no provision for obtaining an FASD evaluation if either the judge or the attorney suspects the defendant is affected by prenatal alcohol exposure. Because awareness of FASD has developed relatively recently, many affected adults in Alaska are not diagnosed. The study reported concerns expressed by judges and state personnel including a lack of knowledge about FASD by both attorneys and judges and a lack of remedial services available to individuals with FASD if they are not incarcerated following a criminal act. Additional research, including consideration of alternative services to assist individuals with FASD in staying out of the correctional system could improve quality of life for both affected individuals and families.

FASD is a life-long disability, and affected individuals need various forms of support into adulthood, many throughout their lives. Providing individuals with FASD the help and support they need to live their lives as productively as possible within their home communities will reduce the need for other costly services such as hospitalization for mental health problems, in-patient substance abuse facilities, or incarceration for criminal activities. It seems prudent for Alaska to assist these individuals and their families to thereby reduce the likelihood of institutionalization.

I conclude with some thoughts from an article by Erin Dej, a professor at the University of Ottawa entitled, “What Once was Sick is Now Bad: The Shift from Victim to Deviant Identity for those Diagnosed with Fetal Alcohol Spectrum Disorder” (2011). Dej writes that society views children with FASD as innocent victims, seeing them as having a lifelong disability imposed on them by their prenatal exposure to alcohol. Society embraces the children, providing the very best supports possible. As the children develop into adolescence, however, societal views change. Actions and behaviors accepted when the children are young become unacceptable as they grow older. Society seemingly expects the children to outgrow their lifelong disability and the problems it engenders. Supports and services diminish as individuals with FASD become adults whom society holds responsible for their poor choices and undeserving of services - interventions that could help them maintain stability within the community and enjoy optimal quality of life. Thus, from a societal perspective, individuals with FASD has transformed from innocent child victims deserving of support to hopeless degenerates responsible for their problems.

My research aligns with other published studies in affirming that FASD is a life-long disability that greatly affects quality of life for affected individuals and for their families. We know that early diagnosis and interventions lead to the most effective forms of support for individuals with FASD and that such services remain essential throughout the lifespan. In my study on quality of life for individuals with FASD and their families, I sought *their* perspectives, anticipating that their experiences and insight could enlighten others and inform practices and policies that could mitigate many of the difficulties these individuals face and improve their quality of life, as well as that of their family members. Implementation of suggestions arising from this research will produce myriad benefits, not only to these individuals and their families,

but to society as a whole, with the reduction of far-reaching negative implications of the neglect of this largely overlooked segment of the population.

References

- AK Stat. §§ 4 AAC 52.130 (k), 2016.
- AK Stat. §§ 12.55.155(d)(20)(A). 2012.
- Amendah, D. D., Grosse, S. D., & Bertrand, J. (2011). Medical expenditures of children in the United States with fetal alcohol syndrome. *Neurotoxicology and Teratology*, 33(2), 322-324.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: American Psychiatric Publishing.
- Ase, F., Ilona, A. R., Mirjam, K., Pekka, S., Eugene, H. H., Sarah, M. N., & Marit, K. (2012). Adaptive behaviour in children and adolescents with foetal alcohol spectrum disorders: a comparison with specific learning disability and typical development. *European Child & Adolescent Psychiatry*, 21(4), 221-231. Retrieved from <http://dx.doi:10.1007/s00787-012-0256-y>
- Astley, S. J. (2004). *Diagnostic guide for fetal alcohol spectrum disorders: The 4-digit diagnostic code*. Seattle, WA: University of Washington.
- Babbie, E. R. (2011). *The basics of social research* (fifth edition). Belmont, CA: Wadsworth Cengage Learning.
- Baladerian, N. J. (1999). *Abuse of children and adults with disabilities: A risk reduction and intervention guidebook for parents and other advocates*. Disability, Abuse & Personal Rights Project. Culver City, CA.

- Barkley, R. A. (1997). *Defiant children: A clinician's manual for assessment and parent training* (second edition). New York, NY: Guilford Press.
- Beail, N., & Williams, K. (2014). Using qualitative methods in research with people who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 27(2), 85-96.
- Bertelli, M., Bianco, A., Rossi, M., Scuticchio, D., & Brown, I. (2011). Relationship between individual quality of life and family quality of life for people with intellectual disability living in Italy. *Journal of Intellectual Disability Research*, 55(12), 1136-1150.
- Bertrand, J. (2009). Interventions for children with fetal alcohol spectrum disorders (FASDs): Overview of findings for five innovative research projects. *Research in Developmental Disabilities*, 30(5), 986-1006. Retrieved from <https://doi.org/10.1016/j.ridd.2009.02.003>
- Blackburn, C., Carpenter, B., & Edgerton, J. (2010). Shaping the future for children with foetal alcohol spectrum disorders. *Support for Learning*, 25(3), 139-145.
- Bloomberg, L. D., & Volpe, M. (2016). *Completing your qualitative dissertation: A road map from beginning to end*. Thousand Oaks, CA: Sage Publications.
- Bobbitt, S. A., Baugh, L. A., Andrew, G. H., Cook, J. L., Green, C. R., Pei, J. R., & Rasmussen, C. R. (2016). Caregiver needs and stress in caring for individuals with fetal alcohol spectrum disorder. *Research in Developmental Disabilities*, 55, 100-113.
- Booth, T., & Booth, W. (1996). Sounds of silence: narrative research with inarticulate subjects. *Disability & Society*, 11(1), 55-70.

- Brems, C., Boschma-Wynn, R. V., Dewane, S. L., Edwards, A. E., & Robinson, R. V. (2010). Training needs of healthcare providers related to centers for disease control and prevention core competencies for fetal alcohol spectrum disorders. *Journal of Population Therapeutics and Clinical Pharmacology*, 17(3), e405-e417.
- Brown, N. N., Gudjonsson, G., & Connor, P. (2011). Suggestibility and fetal alcohol spectrum disorders: I'll tell you anything you want to hear. *Journal of Psychiatry and Law*, 39(1), 39-71.
- Brown, R. I., MacAdam-Crisp, J., Wang, M., & Iarocci, G. (2006). Family quality of life when there is a child with a developmental disability. *Journal of Policy and Practice in Intellectual Disabilities*, 3(4), 238-245.
- Burd, L., Cotsonas-Hassler, T. M., Martsolf, J. T., & Kerbeshian, J. (2003). Recognition and management of fetal alcohol syndrome. *Neurotoxicology and Teratology*, 25(6), 681-688.
- Burd, L., Fast, D. K., Conry, J., & Williams, A. (2010). Fetal alcohol spectrum disorder as a marker for increased involvement with correction systems. *Journal of Psychiatry & Law*, 38(4), 559-583. Retrieved from <http://dx.doi.org/10.1177/009318531003800408>
- Burd, L., Selfridge, R. H., Klug, M. G., & Bakko, S. A. (2004). Fetal Alcohol Syndrome in the United States corrections system. *Addiction Biology*, 9(2), 169-176.
- Cadman, D., & Goldsmith, C. (1986). Construction of social value or utility-based health indices: the usefulness of factorial experimental design plans. *Journal of Chronic Diseases*, 39(8), 643-651.
- Carpenter, B. (2011). Pedagogically bereft! Improving learning outcomes for children with fetal alcohol spectrum disorders. *British Journal of Special Education*, 38(1), 37-43.

- Centers for Disease Control and Prevention (CDC) (2000). Measuring Healthy Days: Population assessment of health-related quality of life. Atlanta, Georgia: Centers for Disease Control and Prevention.
- Centers for Disease Control and Prevention (CDC) (2002). Alcohol use among women of childbearing age – United States, 1991-1999. *MMWR. Morbidity and mortality weekly report*, 51(13), 273.
- Centers for Disease Control and Prevention (CDC) (2011). Health related quality of life concepts. Retrieved from www.cdc.gov/hrquol/concept.htm.
- Centers for Disease Control and Prevention (CDC) (2015). Alcohol use and binge drinking among women of childbearing age. United States. Retrieved from www.cdc.gov/preview/mmwe.html.
- Chamberlain, K., Reid, N., Warner, J., & Shelton, D. (2017). A qualitative evaluation of caregivers' experiences, understanding and outcomes following diagnosis of FASD. *Research in Developmental Disabilities* 63(2017), 99-106. Retrieved from <http://dx.doi.org/10.1016/j.ridd.2016.06.007>
- Charlton, J. I. (2000). *Nothing about us without us: Disability oppression and empowerment*, Berkeley, CA: University of California Press.
- Chasnoff, I. J., Wells, A. M., & King, L. (2015). Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics*, 135(2), 264-270. Retrieved from <http://dx.doi:10.1542/peds.2014-2171>
- Clarren, S. K., & Smith, D. W. (1978). The fetal alcohol syndrome. *New England Journal of Medicine*, 298(19), 1063-1066.

- Coles, C. D. (2011). Discriminating the effects of prenatal alcohol exposure from other behavioral and learning disorders. *Alcohol Research & Health, 34*(1), 42.
- Collaborative Institutional Training Initiative (CITI) (2000). Retrieved from <https://citiprogram.org>.
- Corcoran, M., & McNulty, M. (2018) Examining the role of attachment in the relationship between childhood adversity, psychological distress and subjective well-being. *Child Abuse & Neglect, 76*, 297-309.
- Dej, E. (2011). What once was sick is now bad: The shift from victim to deviant identity for those diagnosed with fetal alcohol spectrum disorder. *Canadian Journal of Sociology, 36*(2), 137-160.
- Denys, K., Rasmussen, C., & Henneveld, D. (2011). The effectiveness of a community-based intervention for parents with FASD. *Community Mental Health Journal, 47*(2), 209-219.
- Dukes, C. H. (1989). Alcohol manufacturers and the duty to warn: an analysis of recent case law in light of the alcoholic beverage labeling act of 1988. *Emory Law Journal, 38*, 1189.
- Duquette, C., Stodel, E., Fullarton, S., & Hagglund, K. (2006). Persistence in high school: Experiences of adolescents and young adults with fetal alcohol spectrum disorder. *Journal of Intellectual and Developmental Disability, 31*(4), 219-231.
- Dybdahl, C. S. & Ryan, S. (2009). Inclusion for students with fetal alcohol syndrome: Classroom teachers talk about practice. *Preventing School Failure: Alternative Education for Children and Youth, 53*(3), 185-196.
- Ehrlander, M. (2010). The historical roots of a frontier alcohol culture: Alaska and northern Canada. *Northern Review, (32)*.

- Eyberg, S. M., & Boggs, S. R. (1998). Parent-child interaction therapy: A psychosocial intervention for the treatment of young conduct-disordered children. In J. M. Briesmeister & C. E. Schaefer (Eds.), *Handbook of parent training: Parents as co-therapist for children's behavior problems* (pp.61-7). Hoboken, NJ: John Wiley.
- Fast, D. K. & Conry, J. (2009). Fetal alcohol spectrum disorders and the criminal justice system. *Developmental Disabilities Research Reviews, 15*, 250-257.
- Federal Drug Administration (1981). *Surgeon general advisory on alcohol and pregnancy: FDA Drug Bulletin 11(2) 9*. Washington, DC: Federal Drug Administration.
- Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, Am M., Edwards, V. ... & Marks, J. S. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The Adverse Childhood Experiences (ACE) Study. *American Journal of Preventive Medicine, 14(4)*, 245-258.
- Flick, U. (Ed.). (2014). *The SAGE handbook of qualitative data analysis*. Los Angeles, CA: Sage Publications.
- Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatry, 36(6)*, 717-732.
- Geertz, C. (1973). *The interpretation of cultures: Selected essays*. New York, NY: Basic Books.
- Goldsmith, S., Angvik, J., Howe, L., Hill, A., & Leask, L. (2004). *Status of Alaska Natives 2004 Report, Section Two Social & Cultural Issues & the Alcohol Crisis*. Retrieved from <http://www.alaskool.org/resources/anc2/ANC2Sec2/html>
- Grant, T., Huggins, J., Connor, P., Pedersen, J. Y., Whitney, N., & Streissguth, A. (2004) A pilot community intervention for young women with Fetal Alcohol Spectrum disorders. *Community Mental Health Journal, 40(6)*, 499-511.

- Green, J. H. (2007). Fetal alcohol spectrum disorders: understanding the effects of prenatal alcohol exposure and supporting student. *Journal of School Health, 77*(3), 103-108.
- Green, C. R., Mihic, A. M., Nikkel, S. M., Stade, B. C., Rasmussen, C., Munoz, D. P., & Reynolds, J. N. (2009). Executive function deficits in children with fetal alcohol spectrum disorders (FASD) measured using the Cambridge Neuropsychological Tests Automated Battery (CANTAB). *Journal of Child Psychology and Psychiatry, 50*(6), 688-697. Retrieved from <http://dx.doi.10.1111/j.1469-7610.2008.01990.x>
- Greenbaum, R. L., Stevens, S. A., Nash, K. Koren, G. & Rovet, J. (2009). Social cognitive and emotion processing abilities of children with fetal alcohol spectrum disorder: a comparison with attention deficit hyperactivity disorder. *Alcoholism: Clinical and Experimental Research, 33*(10), 1656-1676. Retrieved from <http://dx.doi.10.1111/j.1530-0277.2009.01003.x>
- Gudjonsson, G. H., & Clark, N. K. (1986). Suggestibility in police interrogation: A social psychological model. *Social Behavior, 1*, 83-104.
- Harwood, H. (2003). Economic costs of fetal alcohol syndrome [Power Point Presentation]. Prepared for the Lewin Group. Bethesda, MD: National Institute on Alcohol Abuse and Alcoholism.
- Indrus, N. M., & Thomas, J. D. (2011). Fetal alcohol spectrum disorders: experimental treatments and strategies for intervention. *Alcohol Research & Health, 34*(1), 76-85.
- Ipsiroglu, O. S., McKellin, W. H., Carey, N., & Loock, C. (2013). "They silently live in terror..." why sleep problems and night-time related quality-of-life are missed in children with a fetal alcohol spectrum disorder. *Social Science & Medicine 79*(2013), 76-83.

- Johnson, M. E., Robinson, R. V., Corey, S., Dewane, S. L., Brems, C., & Casto, L. D. (2010). Knowledge, attitudes, and behaviors of health, education, and service professionals as related to fetal alcohol spectrum disorders. *International Journal of Public Health, 55*(6), 627-635.
- Jones, K. L., & Streissguth, A. P. (2010). Fetal alcohol syndrome and fetal alcohol spectrum disorders: a brief history. *Journal of Psychiatry & Law, 38*(4), 373-382.
- Kable, J. A., O'Connor, M. J., Olson, H. C., Paley, B., Mattson, S. N., Anderson, S. M., & Riley, E. P. (2016). Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE): proposed DSM-5 diagnosis. *Child Psychiatry & Human Development, 47*(2), 335-346.
- Khan, B. A., Robinson, R. F., Smith, J. J., & Dillard, D. A. (2013). Prenatal alcohol exposure among Alaska Native/American Indian infants. *Circumpolar Health Supplements, 72*147-152. Retrieved from <http://dx.doi:10.3402/ijch.v72i0.20973>
- Kulp, J. (2012). *Our FAScinating Journey*. Brooklyn Park, MN: Better Endings New Beginnings.
- Leavy, P. (2011). *Oral history: Understanding qualitative research*. Oxford, England: Oxford University Press.
- Leenaars, L. S., Denys, K., Henneveld, D., & Rasmussen, C. (2012). The impact of fetal alcohol spectrum disorders on families: evaluation of a family intervention program. *Community Mental Health Journal, 48*(4), 431-435.

- Lincoln, Y. S., & Guba, E. G. (2000). The only generalization is: There is no generalization. In *Case study method*, 27-44, Thousand Oaks, CA: Sage Publications.
- Llewellyn, G., McConnell, D., Honey, A., Mayes, R., & Russo, D. (2003). Promoting health and home safety for children of parents with intellectual disability: A randomized controlled trial. *Research in Developmental Disabilities*, 24, 405-431.
- Lupton, C., Burd, L., & Harwood, R. (2004). Cost of fetal alcohol spectrum disorders. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, 127C(1), 42-50.
Retrieved from <http://dx.doi:10.1002/ajmg.c.30015>
- Malbin, D. (2002). *Fetal Alcohol Syndrome and Fetal Alcohol Effects: Trying Differently Rather Than Harder* (Second ed.). Portland, OR: FASCETS.
- Marshall, C., & Rossman, G. (1989), B. (1999). *Designing qualitative research*. Newberry Park: London, New Delhi: Sage Publications.
- Mattson, S. N. & Riley, E. P. (2000). Parent ratings of behavior in children with heavy prenatal alcohol exposure and IQ-matched controls. *Alcoholism: Clinical and Experimental Research*, 24(2), 226-231.
- Mattson, S. N. & Riley, E. P. (2011). The quest for a neurobehavioral profile of heavy prenatal alcohol exposure. *Alcohol Research & Health*, 34(1), 51.
- May, P. A., Gossage, J. P., Kalberg, W. O, Robinson, L. K., Buckley, D., Manning, M., & Hoyme, H. E. (2009). Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies. *Developmental Disabilities Research Reviews*, 15(3), 176-192.
- McDowell Group (2017). *Economic costs of alcohol abuse in Alaska, 2016 update*. Retrieved from www.mcdowellgroup.net

- Miller, D. (2006). Students with fetal alcohol syndrome: Updating our knowledge, improving their programs. *Teaching Exceptional Children*, 38(4), 12-18.
- Morisse, F., Vandermaele, E., Claes, C., Claes, L., & Vandeveld, S. (2013). Quality of life in persons with intellectual disabilities and mental health problems: an explorative study. *The Scientific World Journal*. Retrieved from www.hindawi.com/journals/tswj/2013/491918/
- Morrisette, P. J. (2001). Fetal alcohol syndrome: parental experiences and the role of family counselor. *The Qualitative Report*, 6(2). Retrieved from <http://www.nova.edu/ssss/OR/OR6-2/morrisette.html>
- Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of counseling psychology*, 52(2), 250.
- Myhra, L. (2011). "It runs in the family: intergenerational transmission of historical trauma among urban American Indians and Alaska Natives in culturally specific sobriety maintenance programs. *American Indian and Alaska Native Mental Health Research*, 18(2), 17-40.
- O'Connor, M. J. (2014). Mental health outcomes associated with prenatal alcohol exposure: Genetic and environmental factors. *Current Developmental Disorders Reports*, 1(3), 181-188.
- Olson, H. C., Oti, R., Gelo, J., & Beck, S. (2009). "Family matters:" Fetal alcohol spectrum disorders and the family. *Developmental Disabilities Research Reviews*, 15(3), 235-249.

- Olswang, L. B., Svensson, L., & Astley, S. (2010). Observation of classroom social communication: do children with fetal alcohol spectrum disorders spend their time differently than their typically developing peers? *Journal of Speech, Language, and Hearing Research, 53*(6), 1687-1703.
- Paley, B., O'Connor, M. J., Kogan, N., & Findlay, R. (2005). Prenatal alcohol exposure, child externalizing behavior, and maternal stress. *Parenting: Science and Practice, 5*(1), 29-56.
- Paley, B., & O'Connor, M. J. (2011) Behavioral interventions for children and adolescents with fetal alcohol spectrum disorders. *Alcohol Research & Health, 34*(1), 64.
- Pei, J., Job, J., Kully-Martens, K., & Rasmussen, C. (2011). Executive function and memory in children with Fetal Alcohol Spectrum Disorder. *Child Neuropsychology, 17*(3), 290-309. doi:10.1080/09297049.2010.544650
- Popova, S., Stade, B., Bekmuradov, D., Lange, S., & Rehm, J. (2011). Policy: what do we know about the economic impact of fetal alcohol spectrum disorder? A systematic literature review. *Alcohol and Alcoholism, 46*(4), 490-497.
- Popova, S., Lange, S., Burd, L., & Rehm, J. (2015). Cost attributable to Fetal Alcohol Spectrum Disorder in the Canadian correctional system. *International Journal of Law Psychiatry, 41*, 76-81. Retrieved from <http://dx.doi.10.1016/j.ijlp.2015.03.010>
- Rasmussen, C. (2005). Executive functioning and working memory in fetal alcohol spectrum disorder. *Alcohol Clinical Experimental Research, 29*(8), 1359-1367.
- Rasmussen, C., Becker, M., McLennan, J., Urichuk, L. & Andrew, G. (2010). An evaluation of social skills in children with and without prenatal alcohol exposure. *Child: care, health and development, 37*(5), 711-718.

- Rasmussen, C., & Bisanz, J. (2009). Executive functioning in children with fetal alcohol spectrum disorders: profiles and age-related differences. *Child Neuropsychology, 15*(3), 201-215.
- Rubin, H. J., & Rubin, I. S. (2005). *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: Sage.
- Ryan, S., & Ferguson, D. L. (2006). The person behind the face of fetal alcohol spectrum disorder: Student experiences and family and professionals' perspectives on FASD. *Rural Special Education Quarterly, 25*(1), 32-40.
- Schalock, R. L. (2004). The concept of quality of life: what we know and do not know. *Journal of Intellectual Disability Research, 48*(3), 203-216.
- Schalock, R. L., Verdugo, M. A., & Braddock, D. L. (2002). *Handbook on Quality of Life for Human Service Practitioners*. Washington DC: American Association on Mental Retardation.
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., & Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: report of an international panel of experts. *Mental Retardation, 40*(6), 457-470. Retrieved from [http://dx.doi.10.1352/0047-6765\(2002\)040<0457:CMAAOQ>2.0.CO;2](http://dx.doi.10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.CO;2)
- Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. from *Handbook of qualitative research*, 118-137, Thousand Oaks, CA: Sage Publications.
- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information, 22*(2), 63-75.

- Stade, B. C., Stevens, B., Ungar, W. J., Beyene, J., & Koren, G. (2006). Health-related quality of life of Canadian children and youth prenatally exposed to alcohol. *Health Quality Life Outcomes*, 4, 81. Retrieved from <http://dx.doi.10.1186/1477-7525-4-81>
- Stade, B., All, A., Bennett, D., Campbell, D., Johnston, M., Lens, C., Tran, Sofia, & Koren, G. (2009). The burden of prenatal exposure to alcohol: revised measurement of cost. *Canadian Journal of Clinical Pharmacology*, 16(1), e91-e102.
- State of Alaska Division of Behavioral Health (DBR). (2006). *FAS knowledge, attitudes, beliefs and behaviors*. Retrieved from http://bhhs.uaa.alaska.edu/pdf/reports/FAS/FAS_KABB_FINAL_Report.pdf
- Streissguth, A. P. (1994). A long-term perspective of FAS. *Alcohol Health and Research World*, 18(1), 74-81.
- Streissguth, A. P., Barr, H. M., Kogan, J., & Bookstein, F. L. (1996). Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). *Final report to the Centers for Disease Control and Prevention (CDC)*, 96-106.
- Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics*, 25(4), 228-238.
- Streissguth, A. P., Clarren, S. K., & Jones, K.L. (1985). Natural history of the Fetal Alcohol Syndrome: A ten-year follow-up of eleven patients. *Lancet* 2: 85-91.

- Thiel, K. S., Baladerian, N. J., Boyce, K. R., Cantos, O. D., Davis, L.A., Kelly, K., ... & Stream J. (2011). Fetal alcohol spectrum disorders and victimization: implications, social services, law enforcement, and the judicial system. *Journal of Psychiatry and Law*, 39(1), 121-157.
- Thomson, P., & Jaque, S. V. (2017). Adverse childhood experiences (ACE) and adult attachment interview (AAI) in a non-clinical population. *Child Abuse & Neglect*, 70, 255-263.
- Tibbett, T., & Jeffery, M. I. (2016). Smart Justice and FASD in Alaska: From Prevention to Sentence Mitigation. In *Fetal Alcohol Spectrum Disorders in Adults: Ethical and Legal Perspectives*, 169-189. Cham, Switzerland: Springer Publications.
- Toutain, S., & Lejeune, C. (2008). Family management of infants with fetal alcohol syndrome or fetal alcohol spectrum disorders. *Journal of Developmental and Physical Disabilities*, 20(5), 425. Retrieved from: <https://doi.org/10.1007/s10882-008-9110-z>
- Verdugo, M. A., Schalock, R. L., Keith, K. D. & Stancliffe, R. J. (2005). Quality of life and its measurement: important principles and guidelines. *Journal of Intellectual Disability Research*, 49(10), 707-717.
- Verdugo, M. A., Navas, P., Gomez, L. E., & Schalock, R. L. (2012) The concept of quality of life and its role in enhancing human rights in the field of intellectual disability. *Journal of Intellectual Disability Research*, 56(11), 1036-1045.
- Warren, K. R., & Hewitt, B. G. (2009). Fetal alcohol spectrum disorders: when science, medicine, public policy and laws collide. *Development Disabilities Research Reviews*, 15(3), 170-175.
- Warren, K. R., Hewitt, B. G., & Thomas, J. D. (2011). Fetal alcohol spectrum disorders: research challenges and opportunities. *Alcohol Research & Health*, 34(1), 4-14.

Webster-Stratton, C. (2001). The incredible years: Parents, teachers, and children training series.

Special issue: Innovative Mental Health Interventions for Children: Programs That Work, 18, 31-45.

Whitehurst, T. (2012). Raising a child with foetal alcohol syndrome: hearing the parent voice.

British Journal of Learning Disabilities, 40(3), 187-193.

Williamson, K. (2006). Research in constructivist frameworks using ethnographic techniques.

Library Trends, 55(1), 83-101.

World Health Organization (WHO) (1997). *WHOQOL Measuring Quality of Life*. Geneva:

World Health Organization.

APPENDIX A

Individual Informed Consent Form

Quality of Life for Alaskan Adults with Fetal Alcohol Spectrum Disorder

IRB #829897-1

Date Approved: April 6, 2017

Description of the Study:

You are being asked to take part in a research study about Fetal Alcohol Spectrum Disorder (FASD). The goal of this study is to learn how FASD affects an individual's quality of life and the lives of family members. Please read this form carefully. Please feel free to ask questions and discuss the study before deciding on whether or not to participate.

If you decide to take part, you will be asked to talk about your life. You will be asked to discuss your childhood, memories about going to school, jobs you may have worked, your relationships with friends and family, your health, and any other concerns or positives you may want to share about your life. The interview will take approximately 1-2 hours.

Information that you share will be kept confidential. However, you must understand that as a mandated reporter, I would have to make a report if you told me you wanted to hurt yourself or someone else.

I expect that the majority of my interviews with individuals that have FASD will be in person. This allows me to establish rapport and make sure they understand the consent form, as well as the questions. In the unlikely event I do a telephone interview, I will e-mail the consent to the person and have them send an e-mail back saying they agree to participate. I will also discuss the consent with them on the phone to make sure they understand. Telephone interviews will be completed from my home office where I have complete privacy.

Risks and Benefits of Being in the Study:

The risk to you, if you take part in this study, is that you may find some memories painful. Please remember that you may ask to change the subject or stop the interview at any time.

The benefit to you for taking part in this study is that you may enjoy telling your own personal story so that other people have a better understanding of what it is like to live with FASD. We cannot guarantee that you will benefit from taking part in this study but hope that this study will give others a better understanding of FASD. I hope that this research may help families, educators and legislators to understand what supports and services could help individuals and families living with FASD.

Compensation:

At the end of the interview you will receive a \$15 I-Tunes gift card. If the interview is over the phone, I will ask for your mailing address and mail the card to you.

Confidentiality:

- Any information obtained about you from the research will be kept confidential.
- Any information with your name attached will not be shared with anyone outside the research team.
- We will code your information with a number so no one can trace your answers to your name.
- We will properly dispose paperwork and securely store all research records.
- Your name will not be used in reports, presentations, and publications.

Voluntary Nature of the Study:

Your decision to take part in the study is voluntary. You are free to choose whether or not to take part in the study. If you decide to take part in the study you can stop at any time or change your mind and ask to be removed from the study.

Contacts and Questions:

If you have questions now, feel free to ask me now. If you have questions later, you may contact myself, Brenda Dow at 907-388-6642 or my Graduate Advisory Committee Chair Mary Ehrlander at 907-474-6556.

The UAF Institutional Review Board (IRB) is a group that examines research projects involving people. This review is done to protect the rights and welfare of people involved the research. If you have questions or concerns about your rights as a research participant, you can contact the UAF Office of Research Integrity at 474-7800 (Fairbanks area) or 1-866-876-7800 (toll-free outside the Fairbanks area) or uaf-irb@alaska.edu.

Statement of Consent:

I understand the procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I am 18 years old or older. I have been provided a copy of this form.

Signature of Participant &
Date

Signature of Person Obtaining Consent & Date

APPENDIX B

Family Informed Consent Form

Quality of Life for Alaskan Adults with Fetal Alcohol Spectrum Disorder

IRB #829897-1

Date Approved: April 6, 2017

Description of the Study:

You are being asked to take part in a research study about Fetal Alcohol Spectrum Disorder (FASD). The goal of this study is to learn how FASD affects an individual's quality of life and the lives of family members. Please read this form carefully. Please feel free to ask questions and discuss the study before deciding on whether or not to participate.

If you decide to take part, you will be asked to discuss living with an individual that has FASD. You will be asked to discuss your memories of their childhood, going to school, jobs they may have worked, their relationships with friends and family, health problems, and any other concerns or positives you may want to share. The interview will take approximately 1-2 hours.

Information that you share will be kept confidential. However, you must understand that as a mandated reporter, I would have to make a report if you told me you wanted to hurt yourself or someone else.

If the interview is telephonic, I will e-mail the consent form to the individual, have them read it and send a written note that they agree to participate. At the beginning of the interview, I will ask if they have questions regarding the consent and go over it once again.

Risks and Benefits of Being in the Study:

The risk to you, if you take part in this study, is that you may find some memories painful. Please remember that you may ask to change the subject or stop the interview at any time.

The benefit to you for taking part in this study is that you may enjoy telling your family's story so that other people have a better understanding of what it is like to live with FASD. We cannot guarantee that you will benefit from taking part in this study but hope that this study will give others a better understanding of FASD. I hope that this research may help families, educators and legislators to understand what supports and services could help individuals and families living with FASD.

Compensation:

There is no financial compensation for this interview.

Confidentiality:

- Any information obtained about you or your family from the research will be kept confidential.
- Any information with your name attached will not be shared with anyone outside the research team.
- We will code your information with a number so no one can trace your answers to your name.
- We will properly dispose paperwork and securely store all research records.
- Your name will not be used in reports, presentations, and publications.

Voluntary Nature of the Study:

Your decision to take part in the study is voluntary. You are free to choose whether or not to take part in the study. If you decide to take part in the study you can stop at any time or change your mind and ask to be removed from the study.

Contacts and Questions:

If you have questions now, feel free to ask me now. If you have questions later, you may contact myself, Brenda Dow at 907-388-6642 or my Graduate Advisory Committee Chair Mary Ehrlander at 907-474-6556.

The UAF Institutional Review Board (IRB) is a group that examines research projects involving people. This review is done to protect the rights and welfare of people involved the research. If you have questions or concerns about your rights as a research participant, you can contact the UAF Office of Research Integrity at 474-7800 (Fairbanks area) or 1-866-876-7800 (toll-free outside the Fairbanks area) or uaf-irb@alaska.edu.

Statement of Consent:

I understand the procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I am 18 years old or older. I have been provided a copy of this form.

Signature of Participant &
Date

Signature of Person Obtaining Consent & Date

APPENDIX C

Individual Interview Questions

1. Let's start by talking about your childhood. What was life like for you growing up?
 - a. Where did you grow up?
 - b. Where did you go to school?
 - i. Favorite subjects?
 - ii. Difficult subjects?
 - iii. Did you complete high school?
 - iv. Did you get any additional training or schooling?
2. Tell me about your family and friends
 - a. Who is in your immediate family?
 - b. Who are you close to in your family?
 - c. Who are your friends?
 - d. What sorts of activities do you do with friends?
 - e. Overall, who are your best supports?
3. Do you work?
 - a. If yes, what do you do?
 - i. How long have you worked there?
 - ii. Have you worked other jobs?
 - iii. What do you enjoy about your job?
 - iv. What do you not like about your job?
 - b. If no, have you ever worked before?
 - i. What did you enjoy about your job?
 - ii. What did you not like about your job?
4. How about your health – what can you tell me about your health?
 - a. Any problems at birth
 - b. During childhood?
 - c. Mental health or substance abuse issues in the past?
5. Are you having any current struggles?
 - a. Do you have any health problems?
 - b. Have you had any interactions with the law?
 - c. Do you feel that you could use any kind of help that you're not getting now?
6. If you could share how FASD has affected your life, what would you say?

APPENDIX D

Family Questionnaire

1. Please tell me about _____'s health.
 - a. Any problems at birth
 - b. During childhood?
 - c. Are you aware of any mental health or substance abuse issues in the past?
 - d. Does _____ have any current health problems?
2. What was life like for _____ growing up?
 - a. Where did _____ grow up?
 - b. Where did _____ go to school?
 - i. Favorite subjects?
 - ii. Difficult subjects?
 - iii. Other struggles at school?
 - iv. Did _____ complete high school?
 - v. Did _____ get any additional training or schooling?
3. Tell me about your family
 - a. Who is in your immediate family?
 - b. Who is _____ close to in your family?
 - c. How do think having an individual with FASD affected your family?
 - i. Positives?
 - ii. Struggles?
4. Who are _____'s friends?
 - a. How often does _____ do activities with friends?
 - b. What sorts of activities does _____ do with friends?
 - c. Overall, who are _____'s best supports?
5. Does _____ work?
 - a. If yes, what does _____ do?
 - i. How long has he/she worked there?
 - ii. Has he/she worked other jobs?
 - iii. What does he/she enjoy about their job?
 - iv. What does he/she not like about their job?
 - b. If no, has he/she ever worked before?
 - i. What did he/she enjoy about their job?
 - ii. What did he/she not like about their job?
6. Is _____ having any current struggles?
 - a. Health?
 - b. Interactions with the law?
 - c. Other?
7. If you could share how FASD has affected _____'s life, what would you say?

8. Is there any kind of support that you wish you could have received that might have made life easier for your family?
9. Is there any kind of support that you think _____ would have benefitted from?
10. If you could share how FASD has affected you or your family's life, what would you say?