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# Obtaining a Diagnosis of Fetal Alcohol Spectrum Disorder: Experiences of Caregivers and Professionals

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

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OBTAINING A DIAGNOSIS OF FETAL ALCOHOL SPECTRUM DISORDER:  
EXPERIENCES OF CAREGIVERS AND PROFESSIONALS

(Thesis format: Monograph)

by

Erica R. Lundberg

Graduate Program in Education

Submitted in partial fulfillment of the requirements of for the degree of

Master of Arts

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London, Ontario, Canada

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## **Abstract**

The current study describes the lived experiences of stakeholders in a community-based fetal alcohol spectrum disorders assessment clinic. A qualitative methodology was used. Five participants, one caregiver and four professionals, were interviewed about their experiences. Six themes emerged from this process including: clinic organization: systemic strengths and challenges; attitudes and approach: laying the foundation; beyond yes or no: assessment and diagnosis; the moment of truth: delivering the diagnosis; outcomes: what happens after the diagnosis?; what does the future hold? next steps and needs. These themes formed a sequential story-telling of participant experience. Study results are critiqued and practical implications are discussed.

Keywords: FASD, fetal alcohol spectrum disorders, diagnosis, lived experience, professionals, caregivers, families.

## **Dedication**

For my parents, who have been the best parents I could ever ask for and have provided me with every ounce of love and support I could ever need

## **Acknowledgments**

Infinite thanks go out to my wonderful family and friends. Thank-you for cheering me on, sharing your wisdom with me, and patiently listening to me throughout the thesis-writing process.

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To my interview participants, I extend my sincerest thanks for your time, contributions to research, and sharing your inner experiences with me.

To the service providers who have dedicated their work to helping individuals with FASD live life to the fullest.

And, last but not least, a tip-of-the-hat goes out to all the people affected by FASD, doing their best to live and thrive in a world that just wasn't quite built for them. You can do it!

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## **Chapter 1: Introduction**

This study explores the lived experiences of caregivers and professionals during the process of diagnosing children with fetal alcohol spectrum disorder (FASD). Chapter one provides the reader with general background information about FASD, FASD diagnosis, and FASD in the context of the family. Chapter one also introduces the researcher's aims for the present study.

### **Fetal Alcohol Spectrum Disorder**

FASD is an array of developmental disabilities caused by teratogenic effects of prenatal consumption of ethyl alcohol (Riley, Infante, & Warren, 2011). FASD, first conceptualized in the 1970's, is characterized by facial malformations, growth deficits, and neurological abnormalities. These characteristics are conceptualized across a continual spectrum because they are highly variable in their severity and presentation clusters across individuals (Lyons & Streissguth, 2010). Labels for different types of problems on the FASD spectrum are: fetal alcohol syndrome (with and without confirmation of maternal drinking), partial fetal alcohol syndrome, fetal alcohol effects, alcohol-related neurodevelopmental disorder, and alcohol-related birth defects (O'Leary, 2004).

FASD is associated with a broad spectrum of medical complications and neurological impairment caused by direct structural and functional alterations of tissue; some examples of this impairment include hyperactivity and attentional problems. FASD is also associated with a wide variety of secondary disabilities, which are not directly caused by teratogenic damage, but rather are thought of as the more distal psychosocial antecedents of the direct damages; some examples of common secondary disabilities



include mental illness, employment problems, and involvement in the justice system (Boland, Burrill, Duwyn, & Karp, 1998; Streissguth, Bookstein, Barr, Sampson, O'Malley, & Young, 2004).

The pathways to the development of FASD are not well understood and the literature suggests that there is a broad range of variance in amount, frequency, and timing of prenatal alcohol consumption that can contribute to a wide range of effects on offspring (Maier & West, 2001). Prenatal alcohol consumption is also associated with prenatal use of other teratogenic substances (Hans, 1999) and adverse psychosocial conditions, such as poverty and malnutrition (Cannon, Dominique, O'Leary, Sniezek, & Floyd, 2012), both of which may have further detrimental effects on a child's health.

FASD remains a leading cause of preventable disability, with Canadian prevalence estimates ranging from one in 2,000 live births in the general population and as high as one in four live births in certain high-risk sociocultural groups (Kyskan & Moore, 2005). Popova and colleagues report that in Canada, the estimated cost of FASD to society is approximately seven-million dollars annually (Popova, Lange, Burd & Rehm, 2012). Other reports indicate that seven-million dollars annually might represent FASD screening and diagnosis alone (Lange, Burd, Chudley, Clarren, Rehm, & Popova, 2013). However, due to the diagnostically-complex nature and the psychosocial stigma associated with FASD, these reports could easily under-estimate the magnitude of FASD prevalence in and cost to society.

### **Diagnosis**

One of the best strategies to manage FASD and lessen potential morbidity is early screening children who are alcohol-exposed to determine whether or not they meet

criteria for a FASD diagnosis (Olson, Jirikowic, Kartin, & Astley, 2007). FASD diagnosis is exceedingly complex due to a wide syndromal variability (Burd & Mardslof, 1989) and symptom overlap with many other neurodevelopmental disorders (O’Leary, 2004). One of the most widely accepted methods for FASD diagnosis is the four-digit diagnostic system (Astley & Clarren, 2000), described in further detail in chapter two. FASD diagnosis can place a large professional and emotional load on the shoulders of health care professionals, alcohol-exposed children who are under assessment, and their families (Dewane, 2010). This lengthy and stressful diagnostic process also affects family caregivers’ emotional wellbeing (Anderson, 2010).

### **Families Raising Children with FASD**

Families raising children with FASD encounter numerous problems. Caregivers struggle to manage problem behaviour and experience a high level of psychological distress compared to parents of typically-developing and non-alcohol exposed children (Derogatis, 1994, c.f. Olson et al., 2009). Families, both biological and non-biological encounter and feel the negative effects of stigma against fetal-alcohol exposure. Caregivers often report experiencing difficulties accessing appropriate services. Caregivers also report troubling difficulties accessing knowledgeable and understanding professionals, often citing communication problems as a major barrier to service access (Olson, Oti, Gelo, & Beck, 2009).

### **Thesis Aims**

The aim of the present study is to better understand the subjective, lived experiences of familial caregivers and professionals involved in a local FASD diagnostic clinic. The results of this study may help improve FASD diagnostic services and

supports, increasing the speed and accuracy of the diagnosis, leading to increased access to appropriate services, and, thus, reduction of secondary disability among children and adults with FASD. The discussion of study results indicate specific recommendations to FASD service providers that may help improve the psychosocial tensions between caregivers and professionals.

### **Thesis Structure**

Chapter two is a review of the literature relevant to this research. The review includes the current findings on FASD and the family, FASD diagnosis, FASD diagnosis and the family, and FASD diagnosis and healthcare professionals. Also included in Chapter two is a critique of the existing literature and synthesis of the current research question.

Chapter three describes the methodology that was employed in the current study. This includes participant sampling and recruitment, study procedures, ethical review, and plans for analysis.

Chapter four describes the results of the study. Results are presented as qualitative themes. To elucidate themes for the reader, exemplar quotes are included.

Chapter five houses the discussion of the results. Within this section, the reader will find a summary of the results, a critique of the current study, and a discussion of study result implications.

## **Chapter 2: Literature Review**

As discussed in chapter one, FASD is a spectrum of diagnoses caused by the direct teratogenic effects of prenatal alcohol consumption. It is a leading cause of preventable disability and is often associated with devastating secondary disabilities. One major defense against the development of secondary disability is early diagnosis and intervention through biomedical and/or psychosocial services and family supports and strategies. In chapter two, the reader will find an overview of the interplay between FASD and the family. Also presented is an overview of FASD diagnosis and the existing literature on the subjective experience of FASD diagnosis, from both the professional and family caregiver perspective.

### **FASD and the Family**

The literature indicates that children with FASD can be greatly affected by their family environment, that some traits of children with FASD can affect the health and wellbeing of their caregivers, and that there is a need for improvement in the relationships between FASD families and health and social service professionals (Dewane, 2010; Hess, 1996).

Themes from the informal literature, such as online peer support networks, chat rooms and FASD information pamphlets, shed light on the positive aspects of raising children with FASD, like personal fulfillment and enjoyment of the children, as well as the negative aspects of raising children with FASD, like coping with behavioural problems and fears about childrens' futures. Caregivers of children with FASD emphasize struggles such as feeling emotional pain and stress, the financial strain of raising a child with special needs, and frustration with the lack of knowledge about FASD among professionals. Families also note the importance of supportive services,

such as respite care, camps, and peer support networks, that help them cope with the struggles they face raising children with FASD (Olson, et al., 2009).

The formal, empirical literature also indicates that caring for children with FASD can be very challenging and negatively impact the wellbeing of family members (Olson et al., 2009). Most of the literature focusses on stress and wellbeing among primary or parental caregivers. Many such caregivers experience stress levels and psychiatric symptoms that would indicate the need for therapeutic intervention (e.g. Derogatis, 1994, c.f. Olson et al., 2009). Studies show that variability in caregiver stress can be attributed not to a child's diagnostic status, but rather to the differences in a child's externalizing behaviours, internalizing problems, and difficulties with executive and adaptive functioning (e.g., Paley, 2005). It is also important to note that many parenting experiences of caregivers with children who have FASD are positive and that some child characteristics are associated with a lower parental stress. Some examples of traits that are associated with increased wellbeing are: children who take pride in independent accomplishments, take on household responsibilities, and those who seek and take help from their caregivers (Hodges, 1999, c.f. Olson, 1999).

The home environment can greatly impact wellbeing of children with FASD. The home environment and quality of parenting experiences are especially important with respect to the development and severity of secondary disabilities that are often associated with FASD, such as mental illnesses, criminal involvement, academic struggles, and employment problems (Olson et al., 2009). The more stable and positive a child's home environment is, the less likely he or she is to develop severe secondary disabilities. However, children who are prenatally exposed to alcohol are at a disproportionate risk for

negative and unpredictable caregiving environments and are not likely to experience a warm, stable, and positive caregiving environment that could ward off negative outcomes (Olson, Jirikowic, Kartin, & Astley, 2007). This research underscores how important it is to understand family functioning so that health and social services can target key areas that are in need of improvement in order to minimize potential risks to developing children.

Caregiver-related variables are also known to impact child outcomes. For example, expressed emotion and attitudes towards children contribute to outcomes for children with developmental disabilities. Children who are cared for by individuals who engage in frequent expressed emotion and those who show negative attitudes towards their children are less likely to thrive and succeed (Bailey, 2007). Intervention studies have found that psycho-educational programs that increased caregivers' knowledge about FASD led to changes in attitudes and behaviour; these parental changes were thusly associated with improvements in child-outcomes (Olson et al., 2009).

Qualitative literature suggests that there are systematic differences between various *types* of families raising children with FASD, namely birth-, adoptive-, and foster-families. Birth parents report themes such as: fearing for their child's future, feeling abandoned by health professionals, lacking sufficient supports in the education system, being seen as the cause of their children's poor behaviours (Salmon, 2008), and feeling stigmatized by and isolated from other people (Brown, 2004). Adoptive parents report concerns about the impact on partnerships, concerns over child management, parental insecurities and adjustment issues, difficulty with professionals, medical

complications, and concerns for their children's eventual independence (Morrissette, 2001).

Research on foster families of children with FASD has focused on families' motivation for wanting to foster a child with FASD, such as wanting to help children and seeing positive change in previous children. This research also investigates foster parents' opinions about potential events that could dissolve the foster placement, such as if the child became unmanageable or risked harm to self/others (Brown & Bednar, 2007).

Researchers and families argue that special interventions must be designed for biological and non-biological caregivers of children with FASD due to variable family dynamics (for review, see Rowbottom, Merali, & Pei, 2010). At the current time, most children with FASD do not reside with their birth parents; however, there is a trend towards keeping biological families intact when possible and appropriate through parental care and/or kinship care (Brown, 2004). Note that no research to date has specifically focused on kinship care caregivers of children with FASD; however, in some jurisdictions, foster care includes kinship caregiving, so the literature on foster parents may be applicable.

### **Family Supports**

The research literature indicates that families raising children with FASD need extensive supports in order to maintain physical, psychological, and social wellness (Brown, 2004). The benefits of social support are universal to all people, but of particular help to caregivers of children with FASD. Families need a variety of informal instrumental and emotional supports, such as helpful and understanding friends and family within the community. Caregivers benefit from the support of compassionate social contacts who understand the common medical, behavioural, and psychosocial

problems that they encounter while raising their alcohol-affected children (Guinta, & Streissguth, 1988).

Families often require formal supports for their children, health and social service from professionals in the community, such as doctors, psychotherapists, justice professionals, special education teachers, and occupational therapists. Families need to have access to understanding professionals who are knowledgeable about FASD and FASD-related issues and competent in treating these issues (McCarty, Waterman, Burge, & Edelstein, 1999). If a child's medical and/or behaviour problems are not recognized as FASD-related, a professional may not be able to select an appropriate intervention, and employ techniques that have no relevance of efficacy to treat a child with teratogenic neurological damage (Brown, 2004). In addition to requiring supports for their children, most professionals can recognize that families raising children with FASD require support themselves; however, the research literature has yet to establish evidence-based best practices for family supports for FASD, an obvious barrier to the provision of family supports (Olson, Rudo-Stern, & Gendler, 2011). One can easily imagine the frustration and isolation a family might feel if they do not have reasonable access to knowledgeable and approachable professionals.

Another hurdle to receiving supports for children with FASD and their families is diagnosis. In order to activate or qualify for most health, social, and financial supports for FASD, a child must first obtain a diagnosis of FASD. One could look upon diagnosis as a gateway to services and one of the crucial first steps to management of the disorders and prevention of debilitating secondary disabilities. However, the differential diagnosis of FASD is difficult and complex, even if willing and able diagnosticians are accessible



in the community. If appropriate diagnostic services are not available, a child might miss-out on important assistive services.

### **FASD Diagnosis**

FASD is an extremely heterogeneous syndrome spectrum (Burd & Matsof, 1989) and shares symptomatology with many other neurodevelopmental and behavioural disorders, which can make the diagnosis process difficult and complex (O’Leary, 2004). The process will involve caregivers as informants of alcohol use history and the child’s health and behaviour, as well as professionals from many different disciplines, such as neurology, genetics, and psychiatry (O’Leary, 2004). While the FASD diagnosis was an entirely subjective experience at one point in history, there are now several systematic diagnostic methods developed to aid the differential diagnosis process.

**Canadian diagnostic guidelines.** Different geopolitical regions approach FASD diagnosis different; as the present study was conducted in Canada, the discussion of diagnostic strategy presented herein is limited to the Canadian diagnostic guidelines. At current, these guidelines are based on the recommendations synthesized by Chudley and colleagues (Chudley, Conry, Cook, Loock, Rosales, & LeBlanc, 2005).

***4-digit diagnostic code.*** A widely-used diagnostic system for evaluating the presence or absence of FASD characteristics is the “4-Digit Diagnostic Code (4-DDC; Astley & Clarren, 2000). The 4-DDC allows for a range of scores one-to-four on four different traits that are characteristics of FASD: growth deficiency, FASD-phenotype craniofacial features, central nervous system damage, and risk for prenatal alcohol exposure. Each individuals’ four-digit score, ranging from 1-1-1-1, which represents no alcohol exposure and no FAS-typical traits, to 4-4-4-4, which represents high risk for

alcohol exposure and severe expression of FAS-typical traits, corresponds to a diagnosis along the FASD spectrum (see Table 1 for further details about 4-DDC criteria).

**Table 1: 4-DDC criteria for FASD diagnosis**

<i>Rank</i>	<i>Growth deficiency</i>	<i>FAS facial phenotype</i>	<i>CNS damage/dysfunction</i>	<i>Gestational alcohol exposure</i>
4	Significant (height <i>and</i> weight <3 <sup>rd</sup> %ile)	Severe (all 3 features: palpebral fissure length 2 SD's <M, thin lip rank 4-5, smooth philtrum rank 4-5)	Definite (structural or neurological evidence)	High risk (confirmed exposure to high levels)
3	Moderate (height <i>and</i> weight < 10 <sup>th</sup> %ile)	Moderate (generally 2/3 features)	Probably (significant dysfunction across 3 + domains)	Some risk (confirmed exposure, rank 4 or exposure level unknown)
2	Mild (height <i>or</i> weight <10 <sup>th</sup> %ile)	Mild (1/3 features)	Possible (evidence of dysfunction, but less than rank 3)	Unknown (not confirmed present or absent)
1	None (height <i>and</i> weight ≥ 10 <sup>th</sup> %ile)	Absent (0/3 features)	Unlikely (no structural, neurological, or functional impairment)	No risk (confirmed absence from conception to birth)

\*4-DDC criteria table adapted from Chudley et al., 2005.

%ile= percentile

'rank' refers to systematic scoring guidelines and standardized exemplars for the 4-DDC

***Institute of Medicine terminology.*** The Canadian diagnostic guidelines recommend merging the 4-DDC scoring system, to assess the level of FAS-typical traits, with the Institute of Medicine (IOM) terminology to describe the diagnosis (Chudley et al., 2005). Acceptable diagnostic terminology for diagnoses on the fetal alcohol spectrum

are: fetal alcohol syndrome, with and without confirmed exposure, partial FASD, and alcohol-related neurodevelopmental disorder (ARND).

**Table 2: IOM diagnostic labels with 4-DDC score criteria**

<i>IOM terminology</i>	<i>4-DDC ranks</i>			
	<i>Growth deficiency</i>	<i>FAS facial phenotype</i>	<i>CNS damage/dysfunction</i>	<i>Gestational alcohol exposure</i>
FAS (with confirmed exposure)	2, 3, or 4	3 or 4	3 or 4	3 or 4
FAS (without confirmed exposure)	2, 3, or 4	3 or 4	3 or 4	2
Partial FASD (with confirmed exposure)	1, 2, 3, or 4	2, 3, or 4	3 or 4	3 or 4
ARND (with confirmed exposure)	1, 2, 3, or 4	1 or 2	3 or 4 (2 if ≤ 6 years)	3 or 4

*\*Adapted from Chudley et al., (2005).*

**Assessment.** The Canadian guidelines for FASD diagnosis suggest strategies for physical examinations, in order to confirm FASD-typical morphology and evaluate the presence of medical syndromes that mimic or overlap with FASD, such as Dubowitz Syndrome and Noonan Syndrome (Chudley et al., 2005). The guidelines also suggest a large number of standardized tests to assess for deficits in various neurodevelopmental domains, such as: the *Dunn Sensory Profile* to evaluate sensory function, the *Weschler Intelligence Scale for Children* to assess intellectual functioning, and the *Expressive Vocabulary Test* to help assess communication skills and deficits (Chudley et al., 2005).

**Multidisciplinary teams.** Interestingly, the Canadian guidelines presented by Chudley et al. (2005) also suggest the use of multidisciplinary teams for an accurate and

comprehensive assessment. Their recommendations for team membership are: a case manager or coordinator, such as a nurse or social worker, a physician, a psychologist, an occupational psychologist, and a speech and language pathologist. Critics of this multidisciplinary team model argue that such a comprehensive assessment is unrealistic, exceedingly expensive, and unsustainable and that a FASD assessment could be executed by any competent professional (e.g. Goulden, 2005). However, regional needs assessments in Ontario suggest that the multidisciplinary approach is preferred by professionals (Chera, 2010). Similarly, the availability of independent, qualified professionals *willing* and able to make an FASD diagnosis may not be enough to meet the needs of every community (Chera, 2010; Wedding, 2007). Chudley and colleagues also express doubt that a single clinician, in isolation, may be able to provide the comprehensive assessment that one needs to make an FASD differential diagnosis, particularly due to the lack of an objective biomarker or medical test to conclusively detect the presence or absence of an FASD (Loock, Chudley, Conry, Cook, Rosales, & LeBlanc, 2005).

***Diagnostic settings.*** The Canadian diagnostic guidelines suggest that a number of different clinic formats are acceptable and appropriate for a comprehensive assessment; these formats include regional clinics, virtual clinics, and teleclinics. Teleclinics are noted as particularly useful for rural and remote communities (Chudley et al., 2005).

While much literature exists on the mechanics of the FASD diagnosis, there is limited information about the subjective experience of the FASD diagnostic process and how best to support caregivers and professional participants during this difficult and complex process.

## **Families and FASD Diagnosis**

Few studies focus on caregiver experiences of the FASD diagnostic process. Anderson (2010) qualitatively interviewed birth mothers of children with FASD about their experiences of discovering their child's diagnosis. The researcher found themes such as: "something is not right", "this can't be happening", and "I can't fix it". Although the study was about the reaction to a child's diagnosis, only one mother in this sample retained custody of their child, so the lived experience of these birth mothers may not generalize to caregivers who are actively raising a child with FASD during the diagnosis process.

Hess (1996) compared phenomenological interviews with care-giving parents of children with a formal FASD diagnosis with parents whose children had a non-confirmed, probable FASD diagnosis. Analysis of survey responses revealed that the two groups both felt that diagnosis was necessary for access to services, both groups felt more negatively about teachers than they did about other nurses and social workers, both groups felt similarly about their interactions with health and education professionals, and both groups felt that their children were more stigmatized than they were as parents. Both of the groups surveyed were similar in experiences and attitudes; these findings bolster the findings of Paley (2005), that the distress felt by caregivers is driven by problematic behaviours of their children and may not be, not necessarily, anguish over the diagnosis itself. However, it is important to note that these reports were about how caregivers felt *during* data collection and they may not necessarily reflect subjective experience and psychological wellbeing during and directly following the FASD diagnostic process.

Research about families raising children with FASD in general might help fill in the gaps in the limited evidence about caregivers' experiences of the diagnostic process. One could extrapolate that caregiver experiences during the process might be uniquely stressful. Stress may heighten due to increased demands on the family, such as having to travel to many different clinics for each piece of the diagnostic puzzle. It might be very stressful to interact with many new professionals, who are likely to be authoritarian, high socioeconomic figures and who ask about their struggles raising their child. Families may feel heightened stigma if attention is drawn to the fact that they are struggling to control problem behaviours in their child; birth mothers may feel even more stigmatized than usual, as the diagnostic process is apt to involve questioning about their prenatal alcohol consumption habits.

### **Professionals and FASD Diagnosis**

A substantial literature exists, written by and for professionals regarding FASD knowledge and clinical competencies (e.g. Memo et al, 2011; Morse, Idelson, Sachs, Weiner, & Kaplan, 1992) and the mechanics of the diagnosis process itself (e.g. Astley, 2006; Burd & Marsolf, 1989). However, less is known about the subjective experience of working professionally with children who have FASD. Many researchers that describe the diagnostic process report objective, quantitative measures, such as how many diagnoses participants completed and what diagnoses were assigned to patients (Zoorob, Aliyy, & Hayes, 2010), but this does not provide the rich description needed to intimately understand what the diagnostic process feels like, subjectively, to a professional. Research knowledge about this phenomenon comes from information professionals have

voluntarily reported on their subjective perceptions of diagnosis within the context of larger studies about FASD knowledge, treatment, and education.

The results from a survey of psychologists (Wedding et al., 2007) indicate that this population is generally knowledgeable about characteristics and outcomes of FASD. However, they felt ill-prepared to diagnose FASD and identified the barriers to diagnosis as: lacking relevant training on FASD diagnosis, not believing that a diagnosis would make any difference, and not having time to make the diagnosis. Although it was not elaborated on, it would be of particular interest to know why these professionals did not feel a FASD diagnosis would make any difference in a child's life or outcomes.

Dewane (2010) studied the knowledge, attitudes, and behaviours related to FASD among physicians in Alaska, a region with a very high FASD prevalence, akin to some sociocultural pockets in Canadian society with high FASD rates. Participants reported barriers to FASD-related practice within the healthcare system and social context, noting many gaps in knowledge about the disorder and FASD treatment and support services. Participants also commented on barriers to screening and diagnosis, like the prohibitive nature of the complex diagnosis process and lack of objective tests for FASD, often needing to refer to or confer with specialized professionals for diagnosis, and lack of standardized charting practices for prenatal alcohol exposure. Physicians also noted several caregiver-related issues that pose barriers to diagnosis. These include: frequently missed appointments, reluctance to recognize the effects of prenatal alcohol use on the child, and difficulties dealing with emotional reactions. Perhaps professionals' perceptions of barriers to FASD diagnosis such as these could help explain the lack of professionals who are able and willing to participate in an FASD diagnosis (Brown,

2004). Just as caregivers report problems collaborating with professionals, it seems that professionals experience problems collaborating with caregivers. These collaboration and communication barriers could seriously hinder the diagnostic process, and therefore a child's access to services, and warrants serious research attention.

### **Literature Critique**

A common theme across the literature is the impact of social desirability on research results; due to the known risk to fetuses, drinking during pregnancy is taboo in many cultures, thus some birth parents feel shame or guilt for causing a preventable disability in their child. Likewise, foster and adoptive parents in the informal literatures report feeling guilty for not being able to help their child as much as intended. These forces could certainly affect responses in a research setting, perhaps leading caregivers to downplay family problems relating to their children's disability. The researcher was mindful of this when collecting and interpreting the data, and made every effort to remain sensitive and understanding of the competing pressures for participants to contribute truthfully to research and wanting to present themselves in a positive light.

The applicability of this small literature may be a problem in this literature due to sampling biases. Many studies sample from high risk populations and patients currently having the worst problems, versus others from general clinic samples, versus other prospective studies sampling prospectively from children identified with FASD at birth. The existing literature may not be transferable to the current study's context, as the clinic sample and samples in previous literature may not be similar enough to consider them equivalent. As there is insufficient evidence from generalizable sources to do so, the researcher cannot pre-suppose any specific theory or predict thematic outcomes.



The literature suggests that different types of caregivers of children with FASD, such as biological, adoptive, and foster parents, and kinship caregivers, may need different types of supports from the medical and mental health care communities. This suggests that their experiences are phenomenologically different; this may well indicate that their subjective experiences of the FASD diagnostic process may also be phenomenologically different. Thus, within the current study, the researcher invited any type of primary caregiver to participate.

Although caregivers and professionals have reported on their own subjective experiences in separate studies (e.g. Dewane, 2010; Wedding et al., 2007), these groups have never described their own experiences of the diagnostic process within the same study, to the researcher's knowledge. Diagnostic processes can be quite different across individuals and sociocultural contexts. A clearer, less confounded picture of both sides of the phenomenon—the caregivers' and the professionals'—was obtained by sampling both caregivers and professionals from the *same* clinic setting; thereby, informants reflected on a more homogenous diagnostic experience.

Caregivers of children with FASD within the formal research literature and the informal public domain literature often report that relationships and interactions with health and social service providers can be difficult. Because caregivers are often informants on maternal drinking habits and are almost always the main informants on children's behaviour and wellbeing, they must work very closely with professionals in order for the professionals to discern a differential diagnosis and conduct ongoing care. Professionals also report some difficulties working with caregivers at the time of diagnosis, some characteristics of the caregivers themselves, while other difficulties stem

from problems in caregiver-professional interactions. There is a logical role for counselling researchers and practicing counsellors to address the psychosocial issues between caregivers and health and social service professionals that have been described in the literature. The researcher strove to address this issue by describing the phenomenon more elaborately, in a way that could help identify strategies to support caregivers and professionals.

### **Chapter 3: Methodology**

As discussed in chapter two, in order to improve FASD diagnostic services, more information about the subjective experience of diagnosis is needed. Chapter three describes the research methodology employed in the present study. The researcher created the study to answer the research question “what are the experiences of caregivers and professionals during the FASD differential diagnosis process?” The chapter describes the research setting, a community-based FASD assessment clinic, and the research participants, caregiving and professional stakeholders within that clinic. Also discussed are the study procedures, mainly qualitative, phenomenological interview, and materials. Lastly, the reader will find an overview of the data analysis protocol.

#### **Research Question**

This research was exploratory and descriptive in nature. The researcher intended to address the overarching question: what are the experiences of caregivers and professionals during the FASD differential diagnosis process? From these results, the researcher hoped to propose strategies to improve the FASD diagnostic process within the specific clinic and, generally, in the professional community.

#### **Research Design**

This descriptive field study involved a single observation of each participant, following the experiences of collaborating on a FASD differential diagnosis. Participants were a caregiver involved in a FASD differential diagnosis and clinic professionals who complete FASD diagnoses. The study was primarily qualitative and focused on lived experiences of participants. Participants completed a qualitative interview about their experiences. The methodology was an appropriate design for a descriptive field study,

such as this. The methodology also had the ability to answer the research questions and was an appropriate design considering the limited number of potential research participants available.

### **Setting**

The research setting was a community-based FASD diagnostic assessment clinic in a medium-sized city in Ontario specializing in differential diagnoses of children with suspected fetal alcohol spectrum disorders. This clinic is a virtual clinic, meaning that professionals operate out of various host agencies, connected together by a coordinator. Referrals come from professionals within and outside of the partner agencies. Typically, caregivers and the child or youth first meet with the clinic coordinator, followed by assessment appointments with the diagnostic team—a physician, psychologist, occupational therapist and speech and language pathologist. The findings of these assessments are compiled, the team meets and a decision about diagnosis is made. The team then meets with the family, and a follow up appointment with the coordinator is scheduled. The clinic operates at no cost to children and families. Henceforth, this clinic setting is referred to as ‘the clinic.’

### **Participants**

**Recruitment.** Participants were a convenience sample of five stakeholders from the clinic. The clinic coordinator made the initial contact with potential participants, informed them of the study and their eligibility to take part in the research, and provided the researcher’s recruitment poster (see Appendices A and B). To ensure participant comfort, no time limit was set for how long after a diagnosis a participant can be

interviewed, to accommodate busy schedules and the potential need for a ‘cooling off period’ following diagnosis.

All caregivers involved with the clinic since its opening approximately 1.5 years earlier were invited to participate. Any primary caregiver was invited to participate; this included male and female caregivers, biological, step, foster, adoptive parents, other extended family members, and/or institutional caregivers (e.g. group home workers). It was hoped that a variety of caregivers would participate in order to capture their divergent and common experiences. One caregiver participated in the research study.

All professionals who had participated in a diagnosis at the clinic were invited to participate. Professionals from a variety of specialties—medicine, social work, occupational therapists, and psychologists—were invited to participate. It was hoped that a variety of health and social service professionals would participate to represent the breadth of experience from the multidisciplinary team. Four professionals from three different specialties completed the research study.

**Demographics.** All participants were female ( $M_{age}=46.8$ ,  $SD=8.5$ .) The caregiver participant was a biological relative providing kinship care of a male, school-aged child. The four professional participants represented three specialties: medicine, psychology, and social work. All professional participants had significant previous experience with clients with FASD.

### **Procedure**

Participants completed one research session, 45-90 minutes in duration, in which they completed study questionnaires and a phenomenological, qualitative interview. All interviews were audio-recorded. The interview with the caregiver participant was

conducted at Western University. The caregiver participant was compensated \$20.00 to reimburse for incidental expenses (e.g. travel, childcare, etc.; receipt displayed in Appendix C). Research sessions with professionals were conducted at their place of work, for their convenience. Professionals were not compensated.

### **Instrumentation.**

**Consent Documentation.** A letter of information and informed consent form was provided to every participant. The letter of information and informed consent form for caregivers can be viewed in Appendix D. The letter of information and informed consent form for professionals can be viewed in Appendix E.

**Demographic form.** Basic demographic information about participants, such as age, gender, occupation was collected. The demographic form for caregivers can be viewed in Appendix F. The demographic form for professionals can be viewed in Appendix G.

**Interview guides.** The caregivers' interview guide and professionals' interview guide were newly authored, semi-structured interview guides designed to explore participants' experience of the diagnosis process. The interview guides were two parallel forms—for caregivers and professionals—of the same interview. The primary question is: “could you please tell me about your experiences going through the diagnosis process?” Eleven subsequent prompts were developed in order to elicit more detailed information. Prompts included questions like “what feelings or emotions did you have through the diagnosis process?”, “in your opinion, what things made it harder to work with the caregivers/clinic professionals?”, and “what advice do you have for professionals/caregivers who will go through this process in the future?” The interview

guides can be viewed in appendices G and I, for caregivers and professionals, respectively.

**Additional questionnaires.** Additional quantitative measures were completed by participants during data collection, however, due to the limited sample size, the researcher felt that the information gathered would be too identifiable to display within this manuscript. The researcher also felt that the data would be practically and statistically insignificant due to the limited sample size.

### **Analysis**

Data analysis followed Creswell (2003)'s procedure for qualitative data analysis. First, data was organized and prepared for analysis. Second, all transcripts were reviewed to gather a general impression of their content and meaning. Thirdly, utterances were segmented into meaning units and each meaning unit was labelled with a short code. Codes were summative labels that captured the sentiment of the statement. Fourth, codes were listed and meaning units across participant transcripts were re-organized according to code. Redundant codes were collapsed. Next, codes that were similar in topic were grouped together into themes. Lastly, thematic analysis was interpreted (see Chapter 5).

**Transcripts.** Qualitative data from interview recordings were transcribed verbatim. Identifying details were blinded; for example, if a participant mentioned a specific doctor, the transcript would read "*Dr. [name of doctor].*"

**Meaning units.** Transcripts were segmented into meaning units, that is, statements (or a series of successive statements) that represented a single idea. All statements that did not hold any semantic meaning were discarded. For example, interviewer "Mhm" statements and statements that only served to summarize

participants' responses, were not included as meaning units. Interviewer questions are not presented as meaning units, unless the question is crucially necessary to understand the subsequent participant response. Likewise, summative, but semantically void participant statements such as "so, that's what I think about that", were also discarded.

**Coding strategies.** All meaning units were then assigned a qualitative code to summarize the content of the meaning unit. Codes were collapsed when they were judged to have similar content in order to reduce duplicate codes and irrelevant codes. All meaning units were assigned one and only one code. In the case that a meaning unit could be judged to have more than one applicable code, the meaning unit was further segmented, or, if segmenting was impossible due to the syntactic structure of the statement, the meaning unit was assigned the code that best spoke to the research question. By the end of the data reduction process, 44 codes were used to describe 321 meaning units.

**Thematic reduction strategies.** The codes were grouped in a way that best addressed the research question: what were experiences of caregivers and professionals during the FASD differential diagnosis process? Codes hung in themes that, generally, represented different temporal stages in the retelling of experience: how the clinic was formed, pre-existing attitudes that influenced clinic operations, what happened during the diagnostic process and how this happened, how the diagnosis was delivered, what happened afterwards, and future directions. Six themes emerged; these themes are discussed in further detail below.

### **Trustworthiness**



The researcher employed several strategies to increase trustworthiness of the data and analysis. First, all meaning units used in the analysis are displayed, as transcribed verbatim in Appendix J. Each meaning unit is labelled according to the participant who made the utterance. For clarity, the meaning units are presented grouped according to the qualitative code to which it has been assigned.

Second, the researcher engaged in ongoing consultation with her supervisor, Dr. Jason Brown, who is well versed in qualitative analysis. Through this consultation, the researcher aimed to ensure logical, succinct, and streamlined coding of meaning units and thematic reduction of codes.

To increase trustworthiness and transparency, the researcher involved the clinic (from which the participants were recruited) in the study planning. For example, clinic staff indicated what types of information would be helpful to improve operations and what types of data collection they thought caregiving and professional participants would be willing to undergo.

Also to increase trustworthiness of the researcher in this setting, prior to data collection, the researcher attended many public events associated with the FASD assessment clinic, such as conferences, workshops, and the clinic's opening ceremony. This attendance was intended to better understand the nature of FASD from different stakeholders' viewpoints, better understand the culture of the clinic, and make herself genuinely known to the clinic community.

## **Ethics**

All study procedures and materials were approved by the Western University, Faculty of Education Research Ethics Board, which adheres to the Tri-Council Policy Statement on research ethics. Subsequently, this research protocol was also approved by a research ethics board at a community organization associated with the clinic. All participants were provided with detailed information about the study prior to providing explicit, written consent. Every effort was made to maintain the safety and dignity of research participants.

### **Summary of the Methodology**

Individuals who participated, either as a caregiver or a professional, in a differential diagnosis at the clinic were invited to participate. Five participants completed a qualitative interview describing their lived experiences throughout the diagnostic process. Interview recordings were transcribed verbatim; the content was coded and reduced to qualitative themes.

## Chapter 4: Results

FASD is a spectrum of disorders caused by prenatal alcohol exposure. Alcohol damage causes craniofacial malformations, growth delay, and/or neurological problems. Diagnosis can open doors to services and supports for children and families to manage existing symptoms and prevent additional, secondary disabilities. However, the process of diagnosis is exceedingly complex and can be difficult for both professionals completing the diagnosis and families participating in the diagnosis. Five participants from a community-based FASD diagnostic clinic completed a qualitative interview about their experiences during the FASD diagnostic process. All interview data was subject to qualitative analysis. The study results are presented below.

### Themes

**Clinic organization: systemic strengths and challenges.** This theme described the manner in which the clinic was set up. This theme contains 11 codes: planning clinic, organizational structure, team approach, caregivers feeling like part of the team, coordination, professional development, distribution of labor, staffing issues beyond typical work activities, referral procedure, and capacity building. The participants viewed some aspects of the organizational structure as facilitative of diagnoses and general ease of work, while other aspects seemed to pose challenges.

Participants commented on the planning stages of the clinic, when the need for a clinic of this nature was identified, planned for, and formulated.

*P3- Like before the diagnostic clinic even started, like 2 or 3 years before that, um, during the process of, like, capacity building, and trying to get people on board, and trying to^ trying to convince people that there was a systems gap,*

*and^ um, so, uh, I've been in it, like, since the very, very beginning. So~ um, there's been a lot of bumps in the road*

Participants explained the organizational framework of the clinic, which involved many different community agencies working together to refer and assess children suspected to have an FASD. Participants commented about the inherent strengths and weaknesses of involving so many partnering agencies.

*P2~...Uh, certainly um, the commitment of all the stakeholders to be involved and participate. Um, the clinic is running on a [granting agency]grant right now, so all the work we do as professionals is in kind. Um, and uh, so, I think that it's amazing that, I forget now where we're at, I think it's [number] stakeholders can come together in a community as large as [city] and provide this type of service that has never been available here, you know, according to how, um, it probably should be diagnosed. Um, and, I think, initially, with any new endeavor there's growing pains.*

All professional participants commented on the importance and success of the team approach throughout their interviews. They discussed the diagnostic confidence that the team approach allows, the collegial support, as well as some of the pitfalls of coordinating so many different professionals across agencies and specialties.

*P1-I think the best part about the clinic is, uh, that opportunity to sit down with the team and discuss the findings. And that's the experience of people across the country as well. Um, that is is that discussion that is the most helpful and that it's the group's opinion in the end that sortof makes a diagnosis happen or not. And that doesn't happen very much anywhere else*

*P3-Um, I think good teamwork between professionals, I think mutual respect for each other's disciplines and um, being willing to listen and hear what the other people are saying. It's quite a collaborative process when we come together on clinic day. Um, you know, everyone says their part and them, um, and then we sortof come together to figure out, like we rate, you know the 4-point diagnostic code is?*

The professional participants noted the strength of the team approach and identified a sense of group belonging, but it is also important to note that the caregiver also felt like she was a part of the team, rather than simply an afterthought.

*C-I guess it made me feel more a part of the process, rather than, um, I'm way over here [gestures off to the side], sometimes when you are involved with professionals it feels like they are way over here [gestures] and they are going to decide everything over here and they kindof just let you in in as an afterthought, kindof thing. And I never felt that at all during this process.*

Participants discussed the importance and helpfulness of the clinic's coordination. From the comments collected, it seems that the virtual clinic format would be near to impossible without a centralized person pulling all the information together and coordinating schedules of all the clinicians and families.

*C- giving me the dates and times and if there was any kind of support available.*

*P1-certainly, the service coordination is essential, like pulling everything together to find, to be one person to talk to the family. And also to gather up all the information. I think that's^ that's very important.*

*P2- I would say that, uh, definitely you need to have a, uh, coordinator. Um, you need a central person who is going to assist the professionals all together and, yeah, as effective as possible.*

The professionals interviewed commented on the importance of high quality professional development to the proper conduct of the assessment clinic, particularly for diagnostic-specific knowledge and for keeping up with best practices.

*P2-and, um, for the diagnosticians, um, there's a couple of excellent conferences each year. World conferences where, um, you can certainly learn a lot about the various measures and what's, you know, in the last year, what's been tested and seems more valid in terms of, uh, the FASD population or, um, you know, various things like that.*

*P3-And then I think ongoing professional development, um, is really important. So there's not a lot of money. I think all the diagnostic professionals, all of them, would benefit from going to the conference. I can't see that happening, but*

*honestly, it's an amazing conference. Your knowledge just goes from 0 or 90 the whole time you're there. it's really, really a valuable experience. But there's, there's not a lot of money. But, I think anyone who wants to be a diagnostic professional, should have that opportunity, even though it's not available so I think those are some of the things that would work better.*

Problems with unequal distribution of labor were noted. Participating professionals noted the need to remain conscious of the workloads, both on an individual and agency level. Interview responses also indicated that it has been a really difficult balancing act to try to ensure than any one diagnostic professional is not overburdened by work from the clinic.

*P3-yeah, so I think...so, part of the difficulty, I think, of the actual clinic is getting the number of diagnostic professionals that you need to get the diagnosis done. And not over-weighting any one particular agency or one particular professional with the work.*

*P4- I just wish we could have clinicians who that dedicated to June, dedicated to you know whatever and we just put them in. and if they had an easy clinic 'cause a lot of the reports were done, terrific, then we just trust that that'll happen again, but right now, it's a matter of me. Ok, this one's been overworked, I need to make this an easy clinic for her. So, this is goin^ you know what I mean? So it's just a lot of, a lot of juggling right now.*

Many participants noted systemic challenges with staffing the clinic. Of significant concern to participants was the extensive time commitment required for the psychological assessment and the need for additional psychologists to meet this demand. Also noted was the lack of an occupational therapist for a portion of the clinic's operation.

*P3-the big gap is psychology, of course, because it's the main part of the assessment. it's the most time consuming and you can't do a diagnosis without it. So, you have to have it. Um, SLP and OT, um, you could, I mean they are essential as well, but there are clinics that run with just a physician and a psychologist. Um, but the more OT and SLP you have, the less a psychologist has to do So, it's re^ it is important to have them, but psychology is essential.*

*P4-- what factors help facilitate the diagnostic process? Well, we need to have clinicians, we need to have clinicians who have the appropriate time available in order to incorporate all the measures and to be flexible^ to meet the needs of the children who are coming in.*

Also of note, in terms of distribution of labor, was that some participants reported that the professionals' workload at their agency could be further reduced to compensate for FASD assessments.

*P3- So, the do^ the idea is that your agency is supposed to give you in kind and they do to some extent, but in a lot of cases, your in-kind is you providing your personal in in-kind time.*

Many participants noted that for some diagnostic professionals, their responsibilities at the clinic fall beyond their typical work activities, in terms of scope of practice. For many professionals, the clinic requires assessments that are not typically part of the professionals' usual routine.

*P1-some of the, um, professionals, so psychology, these assessments are just above and beyond what they normally do, so it's like an extra, which isn't really sustainable*

*P1-I guess, with the exception of myself, who might have made the diagnosis in the office using just what I can gather from other people. Um But, for the others, there was no clinic before so they weren't doing it. So, every^ for every agency, it's like an add-on, so, it becomes a bit lower priority than if it's your main business.*

Capacity building was a concern noted by several participants. Their comments focused on capacity to see a certain number of children as well as capacity in terms of professional competency in this highly specific area of practice.

*P1-Well, I think the biggest factor is capacity, so the lots of kids out there who could have a diagnosis, may who need a diagnosis, who are struggling and, you know, the clinic is seeing one patient per month. And, uh, that is just really a small number in comparison to, uh, all that are out there.*

Participants reflected on the complex nature of the referral process. Participants, despite being active participants in the clinic, had an unclear picture of how children are referred to the clinic and how the partnering referral agencies affected the priority of assessments.

*P1- I don't know that people sit here at [agency] know how to make a referral and I don't think we know how to prioritize those. So, in other words, if we get 10 referrals from [agency], and 10 from [other agency] and none from somewhere else, what^ do we just see those 20 or do we seek them out from other places?*

*P1- they have to be associated with one of the [number of partnering] agencies. Although, we've tried to be flexible. So I think the flexibility helps, but on the other hand it's because there's so many agencies, and there's reasons for that, um, it just makes the path not clear. But I have to say that applies to all of mental health and developmental services*

Taken together, the responses in this theme paint a picture of a very complex organization, but one that has improved over time as it addressed problems. These complexities and pitfalls are not unlike those experienced in many similar mental health or developmental services.

**Attitudes and approach: laying the foundation.** This theme describes what the stakeholders 'brought to the table' in terms of existing attitudes toward the clinic, the children, and the diagnosis, as well as their approach to the diagnostic process. This theme contained six codes: enjoyment and passion, rapport, empathy, dedicated caregivers, caregiver attitude, and stigma.

Participants commented on their enjoyment in and passion for working with children, in general, and children with FASD, in specific.

*P4- but everybody who's I^ who I've had the pleasure of working with is there because they really, really, want to do it. And they find the work both fascinating,*



*you know emotionally gratifying, challenging, all of the above, but they, they know that there's a need and that we're doing good things.*

*P3-yeah. Yeah, I think, you know FASD at this stage is run on passion. Like, the diagnostic of FASD and the capacity is run on passion. As opposed to money+++ So, you know, it's how long that passion will last before we start to get a bit burnt out.*

Participants discussed the importance of rapport between the clinicians and the children and families being seen at the clinic as a facilitator of the diagnostic process.

*P4-So, what makes it run well? Is, you know, our connection with families and I think the clinicians are amazing with families and how they are so, the way they deliver information is just so kind and so eloquent, but yet very pragmatic and and professional.*

*C-like they all sat down and talked to me, and this is what we're gonna do. I think the psychologist had some things for me to fill out and then she told me what she was gonna do when she took him in and interviewed him. I didn't have no^ I wasn't apprehensive about anything, like him going to a room with a strange woman, you know or anything like that.*

*C-She was really helpful. And...all the doctors were really nice. And down to earth people, I guess. Easy to talk to.*

Participants commented on the importance of empathy within their work.

Clinicians reported striving to truly understand the experiences of families and recognize that their experiences with the children may not be congruent with caregivers' day-to-day experiences.

*P3-So, I think really listening to the parents and trying to understand where they're coming from and giving them that chance has been a really, really helpful^ and I think that works for the workers too, especially CAS workers and stuff that are really having a lot of trouble with the kid. If you give them a chance to talk about and explain their frustrations, and what's been really difficult, I think that is helpful to get engagement from them, in terms of facilitating their support around getting through the diagnostic process, which is pretty onerous.*

Professional participants commented, in admiration, on how dedicated and committed to their children/charges the clinic's caregivers have been.

*P1-Well they've been fantastic. And, um, I think that's one thing that stands out is the just work and dedication and so on of, uh, parents and, I mean guess I didn't mention this at the beginning, but there's a lot of grandparents, great-grandparents who are doing a lot of the childcare and you have to really admire them for taking that on, often with their own^ they have their own illnesses and, uh, energy levels and so on.*

*P2-And so, for many of them [caregivers], they have been very motivated, like attending the appointments, even though it's been a struggle to get off work or get here or whatnot. They've been very, um, they've been excellent at returning questionnaires and completing those. Um, attending, you know the feedback sessions, asking great questions.*

There was a wide variety of caregiver attitudes towards diagnosis and the diagnostic process. Some caregivers are happy to have their child diagnosed and eager for the changes that could result from a diagnosis, while other caregivers are less than eager to have their child involved in the diagnostic clinic, or any health or social service experience, for that matter. These differential attitudes may help us understand differential reactions to diagnostic feedback described later on.

*P1- the rest kind-of depends a little bit on the caregivers that come, what they're um, attitude is. So sometimes they're here and they don't want to be here and somebody told them they had to come, so they are pretty angry, so you can kind-of feel that. Um, So, they may direct the anger toward um, me. Not overtly, but you can just kind-of feel that.*

*P4-yeah, they're grateful, grateful for the opportunity to be^ have their child diagnosed.*

Stigma is ubiquitous in the provision of FASD diagnostic services. Participants noted that stigma surrounding prenatal alcohol consumption might lead caregivers to be reluctant to disclose an accurate prenatal history or to feel diminished due to a FASD diagnosis.

*C-I think so. I don't think I worried about it that much [that a diagnosis would lessen herself/her child], maybe because he's not my birth-child or anything like that.*

*P3- and it's very, um, they're very reluctant to admit it because, of course, they didn't know at the time, but now it's all over billboards, it's^ it's you know, washrooms in bars and it's very, the public health has been pretty, um, open about it, so I think they know there's something wrong, but they're not as willing to admit it, but if they did it could really help.*

**Beyond yes or no: assessment and diagnosis.** This theme describes some of the procedural aspects of the FASD assessment. The theme contains six codes: comprehensive assessment, Canadian diagnostic system, assessment appointments, attending appointments, prenatal alcohol use history, and clinic day. These codes help us understand the complex process of assessment and arriving at a diagnosis.

Participants noted the comprehensiveness of the assessment, mostly noting the variety of different specialties involved and the different assessment activities used to evaluate a child's functioning in various domains. Some participants also compared the FASD assessment to other developmental assessments, noting the utility (or lack thereof) of some standardized measures in this differential diagnosis.

*P1-When there isn't a specified clinic, then we have to use assessments done by people who may or may not know about FASD, they may or may not know what tests we need to do to really clarify it. So, commonly used tests like IQ aren't particularly helpful, but might be helpful in giving you clues to what other tests might need to be done or to clarify.*

*P2-And, uh, also, background history and that kind of thing. We try to get as much of that up front through other, well we have a, a extensive questionnaire that our coordinator will do, so we get that background information, but then we also get a fair bit of collateral information, which is really helpful.*

*P3- because we have SLP [speech and language pathology], which we're really lucky with, we [psychology] just don't do any language whatsoever, so that takes away a huge chunk. I'm left with people who are, you know, who have gone to school for years to study that, so it's perfect.*

Several participants made mention of the clinic's use of Canadian guidelines. Although the reasons for this are obvious, there are practical implications in terms of comparison to other clinics and other research.

*P1-The Canadian guidelines are very useful, so I'd say, you know, make sure you read those and I'd say follow the Canadian guidelines, which are um very clear, very helpful, uh, in comparison to the Washington manual, the four-digit code. The Canadian guidelines takes that in, and just puts in in a slightly different format. That's what people across Canada are using.*

Participants commented on the format, content, frequency, and pitfalls of the assessment appointments themselves. Of frequent mention was the number of appointments necessary to arrive at a diagnosis and the potential strain this can put on individuals and families.

*C- Answer questions about his development.*

*P1- Um, this way it's all done in a month. So that's very efficient for the families, they kinda remember what we're doing and we all remember what it is that we're doing and we get a snapshot of the child at the same time as opposed to me seeing them now and then, you know, next spring they get an assessment And then, we try to get everybody back together. It's just very difficult to coordinate and I think it's very difficult to families to kindof follow along what the process is.*

*P3- So, I work mainly with teens. I think they're scared, first of all, because they don't want to be^ feel stupid. is that they're worried they're going to come out on the other end, being labelled "stupid", of course not that you were feeling that way or whatever, that's the exact word that they use. So, ~ um, there's a lot^ there's some anxiety around that. So sometimes getting them in, even in the first place, is difficult 'cause they're trying to avoid it a little bit.*

Several participants noted that some families experience difficulties attending appointments and attending *to* appointments, that is some difficulties actually getting to the appointments as well as some difficulties participating in the appointment activities.

*P4- 'cause sometimes they [the children] 're testable and sometimes they're not.*

*P4-well, simple things like transportation. simple things, like, um, yeah, if families can't get to all the appointments, it doesn't usually happen*

*P4-Um...uh, I, you know, mom and dad's mental health, as well. Whether they're able to, kindof remember. There's a lot of things, there's a lot of appointments over a very short period of time. I'd have a very hard time keeping it together for my family, so it's a lot. It's a lot of, um, lot of work for families to do in a quick turn around time.~*

Several participants noted that the clinic was able to provide some supports surrounding attendance, such as providing taxicabs, which were thought of as a helpful service.

*C-.....well, being able to take a cab to one appointment was helpful.*

Participants described some of the issues experienced surrounding unclear histories of alcohol units during a child's gestation. Some participants commented on the reluctance of birth mothers to disclose alcohol use, likely related to the stigma discussed in the *attitudes and approach* theme. Many of the children seen are not in the care of their birth mother and it often takes third-party reports and corroboration in order to ascertain this history with confidence.

*C-Some things were difficult because I didn't know...um...um...well the prenatal kind of stuff I didn't know about all that. Because the mother doesn't really, didn't stay in touch during the pregnancy*

*P1-so we're kindof relying on grandparents, adoptive parents and so on, to tell what they think happened and have to go get information from the CAS and so on. So that bit can be difficult, but it's not their fault, they're doing the best they can.*

*P4- And they don't really wanna readily admit that they've consumed alcohol or drugs, and most often in combination.*

*P4-previous reports, previous involvement. And um sometimes that clear history. Obviously, we need, um, documentation confirming prenatal exposure.*

The meaning units within this code describe how the clinicians on a given FASD assessment case all gather together, in person, for one day to review their individual findings and synthesize an agreed-upon diagnosis.

*P1- Um, I think the comprehensive assessments that people have done and the opportunity to sit down and discuss it has been very helpful in both understanding the child and how their problems are manifest and also making the diagnosis or not.*

*P1-And then I participate in the uh, feedback and conference session where all the team members get together, we discuss the various findings, we determine whether there is an FASD diagnosis or not*

Clinic day is when all the elements of the very comprehensive assessment are integrated into a single diagnostic result; this result may be a diagnosis on the fetal alcohol spectrum, another developmental or mental health diagnosis, or may be a decision of no diagnosis. In the case of no diagnosis, it is often the case that the diagnostic picture is not clear enough to make a definitive diagnosis, particularly if the child is very young.

**The moment of truth: delivering the diagnosis.** Once a diagnosis (or lack thereof) is determined, the child and his or her family must be informed. This theme describes how the diagnosis is communicated to families. As evidenced by participant responses, this is a delicate and complicated process. This theme involves five codes: feedback, ethical issues, reports, individual considerations, and follow-up. The content of this theme helps us understand what it is like to be in a feedback meeting, from both professional and caregiving perspectives.

Participants commented on the provision of feedback. This happens at the end of clinic day, after a diagnostic decision is rendered and the family is brought into the clinic.

*P1-Uh, so that we, we provide reports. So all the clinicians that see the child provide reports and then there is a summary diagnostic letter that says if they have FASD or not. And all of that goes as a package to the family. And, um, in addition, some information about FASD or whatever else they might have. Uh, and then there are recommendations for treatment for whatever we identify as the problem.*

*P3- I think from the professionals' standpoint, um, I, for me, it's always feedback is always a challenge to figure out the most humane way to deliver really bad news.*

*P4-We try not to I present the families with a layman's terms of reference, so that they and I can understand some of the lingo+++ that's used++ I'm not sure that, you know, when you go to a [professional] assessment, I'm not sure that [professionals] are always aware that sometimes the terminology is difficult for families. So I just normalize it across the board and throw myself into the group as well, because^ it's been quite a learning curve for me too, despite of the fact that I'm in this field.*

While ethical issues can arise at any given point or place in a diagnostic assessment, meaning units under this code are seated within this theme, as all of the ethical issues discussed by the participants centered on disclosure and feedback.

*P3- Like, um, you know the fact that the^ you know a child, especially the kids that I work with, have a right to know their diagnosis. And parents are very, sometimes reluctant to have that passed onto their kid. But, you know, ethically we had a big ethics thing about this at [partnering agency] it's really important, and even for my college, like^ the client has a right to feedback, right? So, um, and if the kids have capacity, they should get it. So, you know, just warning parents up to the fact that, that is an expectation. How it gets done is, you know, we'll coordinate with them, but it's not whether or not it gets done, it's how it gets done instead. And so, talking to them about that early is good*

Participants also discussed the comprehensive reports that accompany a diagnosis and feedback session. These reports contain information about a child's diagnosis and some suggestions and next steps; these reports are packaged and given to families.

*P3-Uh, I think probably people getting the reports out is difficult. It doesn't affect the diagnosis getting made, but it does affect, a little bit, what people can do with that diagnosis. So, I know there's still some outstanding reports that people are having a hard time getting done. That speaks to the^ you know, how busy people*

*and how over and above what they'd normally be doing outside of their mandates. so, um, I think that does have an impact, actually and probably does affect families.*

*P3-So there's^ they get the diagnostic letter as well as some recommendations to jumpstart them, to get them started. Um, and then they're supposed to get a report from each professional, together, like it's all together, like in one package. And then, um the clinic coordinator has a bunch of resources for them in a binder, it's pretty awesome actually. and then she hands the whole thing to them.*

Participants discussed some of the individualized approaches to feedback that were employed by clinic staff in order to make families more comfortable. These strategies centered around cultural and mental health needs of the families.

*P4-yeah, well, sometimes it's cultural, a number of our families have been Aboriginal. so, we recognize that the way we see groups and the way that they like to be in a group environment is sometimes different. so we're cognizant of that. But it's different for every one of them, too. So, it's just from our perspective, we ask and try to make sure that they are able to voice whatever needs they have*

*P4- we had one, you know, one [caregiver] who had significant anxiety and mental health issues, so the whole day was, was very difficult for her. Um, and so, we took breaks when needed. You know, we just try to make it as^ a very uncomfortable situation as comfortable as possible.*

Several participants discussed clinic-specific follow-up. While there is no formal follow-up built into the clinic operations (at least, not at the time of interview), participants discussed follow-up with schools, family members, and treating clinicians. Some participants also discussed the clinic's upcoming FASD group for caregivers.

*P1- We have had follow-up conferences with places like schools, so the [another professional] and I will go out to the school and give them the information. Uh, there was one child where there were a few diagnoses at^ at^ kindof on the table, so I had to conference with some other clinicians and the parents to discuss what, in the end, we determined was the diagnosis. So, I worked with the agency that would be taking care of the diagnosis the child had. Um, uh, so there's a limited amount of followup*



*P3-. Um, she [coordinator] 's also going to be doing some groups. Um, starting some groups, um starting some groups, which will be really good, she's got a couple of students that are gonna help her, um, set up some groups. She's going to do some guest speakers and there's going to be some coordinating, like a concurrent child group to help with, um, childcare, so the parents can make it out and get support from each other, as well as the professionals that will attend each meeting.*

*P4- Um, I really do think that it does need to go back out to the community and that families do need to be supported by their natural supports and by those that they are most familiar with, so I'm not absolutely sure that that needs to be from me. But I do think that having the group, having parent-teacher meetings, and that kind of ability to follow through and to make sure that families feel like they've got what they need.*

**Outcomes: what happens after the diagnosis?** Participants described the outcomes of a FASD diagnosis. This theme contains nine codes: sadness, positive experience, accepting the diagnosis, feeling relief, diagnosis increases understanding, diagnosis without intervention helps, no impact for some families, diagnosis benefits families, and access to services. Some of the codes relate to emotional reactions to the diagnosis and diagnostic process, reactions of clinic staff, clients, and families. While other codes relate to the functional outcomes of learning a diagnosis.

There was sadness felt by staff members to know that a child has been permanently affected by alcohol.

*P1- and I think it's, uh you know, it's sad, sometimes when you're telling them that something has happened that we can't go back and fix*

*P4-But, you know, I also find myself feeling awful when I say: "it's a good day, we got a diagnosis" like, that means that this little guy has been permanently affected by alcohol. So, that's, feels weird coming out of my mouth*

Participants commented that, generally, the experience was a positive one.

*P3-Um, yeah, I think uh, generally it's been positive.*

While this positivity may seem simple on the surface, it may be more remarkable when you consider the complexity and intensity of the comprehensive diagnosis over just a short period of time.

Accepting a diagnosis of any kind could be deemed emotionally difficult, but participants comment on the unique piece of an *FASD* diagnosis, coming to grips with prenatal alcohol exposure and, in some cases, coming to grips with adoption.

*P3-So that can be very difficult I think for kids; figuring out how their parents could have done that to them and then explaining that it wasn't a purposeful thing, right? And, and negotiating that with them can be difficult.*

Participants discussed the relief felt by clients and caregivers to have a *FASD* diagnosis, because it provides a reason and explanation for what was once seemingly senseless and shaming behaviour.

*C-Um?... uh... I guess in a way, more relief than anything. Because it put a name to some of the behaviours that he^ I think he just, at that point he had just started displaying more of the behaviours were^ He was kinda slow in some things, but I guess I never really attributed to anything.*

*C-so, when we were going through the process and it was kindof a relief to know that, you know, this is what it is and it's not um^ like, he can't help doing the things that he was doing anyways++.*

Learning of a diagnosis can be such a relief to families. It also explains how the diagnosis alone can be therapeutic, because caregivers now understand how their child works and, in so doing, have some ideas of how to help their child.

*P1-I mean, I think there are others for whom it really does help them understand why they are having so many difficulty. And I think particularly for *FASD*, that they are not stupid, they're not, uh,^ you know, often these are kids who are seen*

*as disrespectful, defiant, oppositional. And to^ for them to hear that somebody understand that, you know, the problem is that, you know really, they can't do something, it's not that they're being defiant, um, can be very helpful. And that even happens in the office as you kinda move past their anger at everybody as they move towards trying to figure out what they can and can't do.*

*P2-Um, you know, being externalizing, it affects their self-esteem, it affects their, um, you know, how others see them, and their relationships. So, to have a, a, reason for that, um, I think is is always, you know, a positive thing. And that they're not to blame and it's not them.*

*P3-And I think there's a lot of blame, they feel blamed a lot. For how their kids behave. And yet, they're trying their best and they don't understand why their kid is doing this. But they know it's not their kids' fault, because their kid isn't doing things purposefully. So, it's just an all around confusing, frustrating, feeling judged kind of situation. So, I think a lot of them are very eager for a diagnosis so they can say: look, here is what I'm dealing with. And please help and understand me, rather than judge me.*

Because the simple act of providing a diagnosis demystifies problem behavior and points to some strategies for families, a diagnosis can help, even in the absence of any formal intervention.

*P1-Um, and uh, so I think that that can be very helpful and there's certainly literature to support the fact that just knowing that that's the problem can be helpful in and of itself. so that's why it's ok to have the diagnostic clinic without the treatment component.*

*P4-and like I said, even if there's no other help in the world, but if I know how to treat my child in a way that makes more sense, that's more than half the battle.*

One participant noted that for some families, learning a child's diagnosis does not change much of their strategizing, because they would likely adapt to their child's needs out of their own intuition.

*P1- So I think just in general with diagnoses, you know, some families are like "yup, you know, thank-you very much, Billy is Billy and, uh, you know, I guess thanks for your advice and we'll do that" and they kinda go and you get the feeling that, you know they were happy they were there and they got a diagnosis, but if you told them there was no diagnosis, they would just take Billy away and carry on with Billy and do the right things just based sortof on their common sense.*

While there was a comment that diagnosis doesn't change what caregivers do with their children in *some* families, participants indicated that for the most part, learning a diagnosis can change a lot for children with FASD and their families.

*P2- Um, ~yeah, I think it's very impactful for parents, because most of the parents understand the life long impact that, uh, a diagnosis of FASD or somewhere along that spectrum means for them as parents and caregivers of a child or youth. Um, absolutely, this is really only the beginning when they get confirmation of, you know, life long support for these children and youth.*

Participants cited many examples of how a diagnosis can help by opening doors to various services.

*C-Um, I guess both of us at the same time, because I was able to access more, um, respite through [children's agency], so that's like a couple days a month he gets to go there and he enjoys going there. And he usually goes there during the week when there's less children there and that seems to work really well for him. So that's a good thing. And, for me, it's a rest++*

*C-everything that happens will help you in the end, like to access better services for your child.*

*P3- So, there's that, um, so they can qualify for disability, so some of the, older, like 18, 19 year old kids that I've assessed can get on ODSP sometimes, if they're really compromised if they've had an FASD assessment.*

**What does the future hold? Next steps and needs.** This theme contains participants' remarks on aspects of the clinic that require some change or improvement, system-wide needs for FASD service improvement, as well as clinic-specific next steps. This theme contains eight codes: uncertain future, needs for coordination improvement, need for caregiver comfort measures, need more research about FASD, FASD service needs, need for parenting supports, FASD in adulthood, and educating others about FASD. These data indicate that, while there have been great strides in the area of FASD diagnosis and treatment, there is still a long way to go.

Several participants mentioned that the future of the clinic is currently unknown. They expressed concerns over un-served children. They also commented on resources that have gone into building the clinic, not that these resources would be *wasted* if the clinic were to be discontinued, but rather that it would be a shame if it didn't continue to exist.

*P1- I think the, um, the other thing that makes this situation precarious is that it is funded for [number] months and I'm worried what's going to happen at the end of [number] months. So it's a lot of work and infrastructure if that's the end of it.*

*P4-and I'm scared. Because I'm really scared that we won't, um, what if we don't get funding for this? What if this pilot project fails? it's not failed. But I mean, what if we don't^ what if we don't get sustainable funding? and have we opened up, ~-you know, have we put that proverbial carrot in front of a number of people's noses and then unable to follow through?*

*Needs for coordination improvement.* While the remarks regarding the clinic's coordination and coordinator were overwhelmingly positive, there were some comments regarding the need for improvements in some aspects of the coordination.

*P2-Mhm. Um, I think there could be better coordination between the professionals who are the assessors.*

In an interview several months later, the researcher would learn that the clinic was developing a new documentation process to ensure better coordination among assessors. Participants also indicated that at the beginning stages, families didn't always know what was coming up next, in terms of diagnostic trajectories.

*P1- I think at this point we don't quite have it set up so that the families all know exactly what's going to happen over a period of time and that has to do because^ all the different clinicians. But, so there's a bit to work out there.*

However, as evidenced by comments made in interviews later in the clinic's existence, these issues are being addressed with increased coordination.

The caregiving participant mentioned that some comfort measures while attending appointments would be helpful. While this was, as evidenced by laughter, spoken somewhat in jest, it is important for the professional community to be aware of the measures that could be taken reasonably to ensure the comfort of clients and their families.

*C-I only wish I had a nice couch to sit on while I was waiting. And maybe a cup of coffee and a donut, that's about it+++*

Participants commented on the need for further research about FASD and FASD interventions, research that would be more applicable to families' needs, versus narrowly focused on one isolated skill.

*P1-So I think that sortof, broader, earlier intervention^ that works. To show that it works would help. And we have, in [city], lots of programs that potentially could, we just need to evaluate whether they work for kids with FASD or not and, and/or perhaps which groups of FASD kids, 'cause they're not all the same.*

Participants also report that it would be helpful to have more research about the long-term outcomes of FASD diagnosis.

*P2- Quality of life would be a very interesting thing to do prior to a diagnosis, and then, you know, a few years later, when it's all settled in, or even six months, to see, you know, is their quality of life any better in terms of how they see themselves? How they see their family? How they see their, um, parenting? Um, their relationships with, you know, within the family, marriage, and things like that?*

Participants commented on the need for more FASD services in the local community. Participants note that the local community (for the clinic) is not well endowed with FASD-specific services and supports.

*P1-Um, and I think it[the clinic]'s really a needed service and if you compare us to the provinces out west we're way way behind.*

*P2- Um and, uh, the other thing would be, and this isn't a problem with the clinic, per se, there's still not a lot available out there in the community to assist families. Um and so, you know, you can give the diagnosis and, um, give general ideas of support within the school or managing the youth at home, but um, you know, some actual financial support for some of these families and, uh, other supports in terms of education and things like that, um, isn't available.*

Participants also noted that while FASD-specific supports are lacking, that other community services may be helpful, even if they are not geared exclusively to FASD.

*P4-well, I believe that even though we are not where we need to be in terms of direct FASD support, as I mentioned earlier, I believe we're better equipped than we think, I believe that we can build it relatively easily if we dedicated some time and effort and training and support for that, for that.*

Participants made specific mention of the need for parenting supports, as the typically-used strategies to support parenting are not always appropriate for children with FASD, which can leave children, parents, and service providers frustrated.

*P4- and there's still, like FASD and parenting a child with FASD in most scenarios it cuts against the grain of every typical parenting st^ you know when you aim towards cause and effect, and learn from your mistakes, and consequences and rewards, and shaping behaviours based on your parenting style, that doesn't happen.*

*P4-And there are so many things that are out of your control and out of that child's control and so you have to do things in a way that, that's different.~but, you know ++ every instinctual parenting++ strategy++ is is something you kind of have to do sometimes differently. Not every one, that's kind of not fair to say, but you know.*

While the inquiry of the present study focused on the diagnosis of FASD in children and youth, some professional participants made note of some special considerations of FASD in adulthood, recognizing that many service involved adults may have an FASD that has gone unrecognized.

*P4-And to realize that our adult mental health population is^ has a high percentage of people who are not diagnosed and those people who just make you angry and never who up to appointments are not lazy.*

Perhaps part of supporting young people with FASD is also to ensure a smooth and supported transition into adulthood.

Participants commented on the need for and/or their struggles with educating other people about FASD. These utterances concerned education of society at large, in terms of prevention of FASD, educating the frontline workers' health, social, and educational services about FASD, as well as educating specific families who are affected by FASD.

*C-I guess my problem now is just trying to educate the rest of my family I try to describe as best I can, to tell them about his, you know about, he's^ he's not doing this on purpose.*

*P1-Um, the uh, one thing the clinic could do more of is go out and educate people, so educate other clinicians, families, that's very^ I think that might help with some of the referral patterns and so on.*

*P4-. I can't even get over how many people who I would assume would know better do not understand the risks involved with drinking alcohol and what, what it looks like. They don't have a clue. So that, that, that frustrates me. But yet, you have to be careful to say things in a way that makes people wanna still listen+++*

### **Summary of the Results.**

The current study investigated the lived experiences of five stakeholders in a community-based fetal alcohol spectrum disorders assessment clinic. Six themes emerged from this process including: clinic organization: systemic strengths and challenges; attitudes and approach: laying the foundation; beyond yes or no: assessment and diagnosis; the moment of Truth: delivering the diagnosis; outcomes: what happens after the diagnosis?; what does the future hold? next steps and needs.

These themes reflect a sequential story-telling of participant experience, from clinic inception through to thoughts on the future of the clinic and FASD services. What



were participants' experiences? Although the process had its challenges and complexities, generally, the participants reported the experience as a positive one, with many important outcomes for the betterment of children's lives. The participants shared their thoughts on how to optimize the clinic and shared their hopes for the future.

## **Chapter 5: Discussion**

The purpose of this study was to gather information about the subjective experience of caregivers and professionals during the FASD differential diagnostic process. To answer the research question “what were the experiences of caregivers and professionals during the FASD differential diagnosis process?”, the researcher conducted qualitative, phenomenological interviews with five stakeholders in a community-based FASD diagnostic clinic.

### **Answering the Research Question**

All interview data was transcribed verbatim and segmented into meaning units. These meaning units were coded and the codes were, subsequently, sorted into themes. This process resulted in six themes: clinic organization: systemic strengths and weaknesses; attitudes and approach: laying the foundation; beyond yes or no: assessment and diagnosis; the moment of Truth: delivering the diagnosis; outcomes: what happens after the diagnosis?; what does the future hold? next steps and needs. The themes told the story of participant experience, from the formulation of the clinic, right through to wondering about the future. The themes painted a picture of a complex and, at times, challenging diagnostic experience, but one that was rewarding and opened doors to strategies and services for families raising children with an FASD.

The study results thoroughly describe the experiences of caregivers and professionals during the FASD diagnostic process. Participants told of their experiences from beginning to end, from clinic inception to thoughts on the clinic’s future. Participants related their experiences of the clinic’s structure, involving many different

agencies coming together to create an interdisciplinary team of highly dedicated and highly skilled professionals, pulled together by excellent coordination efforts. The participants, including the caregiving participant, spoke fondly of their strong sense of team-belonging. The participants also discussed how the complexities of the virtual clinic, with so many participating agencies makes for a complicated system to navigate and understand in terms of moving through the organizational channels, disputes over professional turf, staffing issues, and inequalities in the distribution of labor. It seems that the clinic has been able to overcome many of the obstacles created by the organizational complexity.

The participants commented on their approach to the situation, how they interacted with each other and their attitudes about FASD and FASD diagnosis. There is a logical flow from hearing how the participants approached the situation to seeing how successfully the process went; participants were invested in the process of diagnosis and treated their fellow stakeholders with respect; one can easily understand how these positive attitudes set the participants up for success.

Participants told their stories of what they experienced during the assessment process. They talked about how, perhaps unlike other diagnoses, the FASD differential diagnosis is very complicated, involves many facets and, thus, many assessment appointments with different professionals. Participants commented on their role in the assessment process; for the caregiver participant, this centered on getting her child to appointment and answering questions about his development. For professional participants, this included noting the types of assessments used, diagnostic guidelines, and individual considerations during assessments. Participants commented on factors that

can interfere with a family attending appointments, specifically around transportation difficulties, financial difficulties, and mental health providing barriers to remembering appointments. The professional participants spoke about ‘clinic day,’ when every professional who collected a part of the assessment gathers together to synthesize a diagnosis and prepare for feedback.

Participants talked about their experiences during diagnostic feedback.

Professional participants discussed their experiences with ethical dilemmas around diagnostic feedback, in instances where caregivers did not want their child to know their diagnosis or know they were adopted. Participants talked about the things that made the feedback sessions easier for families to manage, such as sitting round-table style, involving cultural supports, and mindfulness of mental health concerns. Professionals in the sample indicated that there needs to be some improvement in the turnaround time of report writing, so that all components can be compiled in a timely manner to disseminate to families. The participants discussed follow-up; while there is no formal follow-up procedure, participants discussed re-visiting diagnoses when young children are more mature, liaising with children’s schools, and starting up a parenting support group.

Study informants talked about the outcomes of diagnosis. While a few families may not experience much change, as they are intuitively using appropriate strategies, many other families benefit greatly from learning their child’s diagnosis. Just knowing the diagnosis helps families understand their child better; this alone benefits children without any formal intervention. One of the most frequently cited benefits to diagnosis in the current study was the idea that diagnosis increases access to much needed services.

Participants shared their ideas about the future of the clinic and FASD services in general. Participants were afraid that the clinic may not secure sustainable funding and therefore cease to exist. Participants commented on some areas in which the clinic could use some improvement, such as increased coordination between professionals to reduce assessment duplication, and to have families more aware of each step of the process. The caregiver suggested that future caregivers could use some additional comfort measures while attending appointments with her child; this may well be a system-wide need. Participants shared their hopes for increased FASD-related services in the community, though some participants felt that appropriate services may already exist and that we simply need the evidence to show us which services could be efficacious. Participants noted some special needs of individuals with an FASD through adulthood. Participants all noted the importance of educating relevant care and service providers, as well as society at large, about FASD and FASD prevention.

### **Reflecting Themes Back to the Literature**

There is very little research about the subjective experience of the FASD diagnostic process. This literature indicates that there is a problematic amount of caregiver-professional conflict, reported by both caregivers and professionals (e.g. Dewane, 2010; Hess, 1996). Professionals have expressed frustrations with lack of FASD-related services, as well as many caregiver-related barriers to diagnosis (Chera, 2010; Dewane, 2010). These barriers included: missed appointments, refusal to recognize the effects of alcohol on children, and difficulty managing caregivers' emotional reactions. Other studies of professionals' beliefs indicate that they felt unprepared to make an FASD diagnosis, as they didn't feel adequately trained in the area, not having

enough time to assess, and not believing that the diagnosis would make any difference (Wedding et al., 2012).

The previous literature on caregivers and the subjective aspects of FASD diagnosis indicate that, like professionals, caregivers also feel frustrated by systemic gaps in FASD services (Chera, 2010; Hess, 1996). Other studies indicate that some caregivers find the diagnostic process to be a stressful and emotional time (Anderson, 2010). Previous studies indicate that caregivers felt negative attitudes towards health professionals, felt stigmatized, but felt the diagnosis was necessary to access services (e.g. Hess, 1996). The previous literature indicates that caregivers of children with FASD experience significant distress and associated psychological morbidity and that this is likely a function of distress over behaviour problems, not distress over the diagnosis itself (Payley, 2005).

The results of the current study suggest the participants, like those in previous studies, are frustrated when they encounter systemic gaps in FASD intervention and care services; and, one could extrapolate by the fact that they felt the need to create a diagnostic clinic, that they may have been frustrated by the gaps in diagnostic services as well. However, the participants in the present study did not indicate any problems related to caregiver-professional conflict. The professionals seem to have found an appropriate and respectful approach to caregivers and clients and the caregivers seem to be responding openly and doing their best to attend appointments and support their children.

**Systemic gaps.** The results of the present study are congruent with previous literature, that participants are frustrated with the lack of FASD-related resources

available. Obviously, with the advent of the diagnostic clinic, frustrations with the lack of diagnostic services would not be expected in this sample. However, the small number of assessments (one per month) may mean that other families in the community may still lack access to a timely diagnosis.

Participants also noted that there are some indications of changing winds, in terms of increased availability of services, some participants compared professional and public interest in FASD to that of autism, which has been increasingly important to the public and professional community in recent years. Perhaps we will see a surge of interest in and advocacy for FASD-related services in the local community?

Participants also noted that existing services may be useful, so although it appears that the service available for FASD, specifically, are very limited, it is encouraging to remember that other services which are not advertised as “FASD services” may still be useful to individuals and families. At any rate, a clear way to increase services for individuals affected by an FASD, whether the service is specifically geared towards FASD or is a more generally applicable service, is to educate others about FASD and the special needs of individuals with FASD and advocate for awareness and financial supports.

**Caregiver-professional conflict.** Previously reported literature has indicated a significant problem in this area, with caregivers and professionals indicating they have trouble communicating with the other group (e.g. Dewane, 2010). One significant difference between the results of this study and previous literature about the subjective

experience of FASD diagnosis is the relative lack of reported caregiver-professional conflict in this study.

This phenomenon could be attributable to a number of different factors. It could be that this clinic is better positioned to make the diagnosis and have it be a good experience for both professionals and caregivers for a multitude of reasons. Because this is a specialized clinic for FASD diagnosis, it has an adequate number of specifically FASD diagnostic trained professionals to complete the diagnosis. This may be beneficial to professionals and families as it may be easier to achieve a diagnosis in this context, versus other communities where general practitioners, who may or may not have any specialized training in the area of FASD, are expected to make the diagnosis.

Likewise, the clinic also involves a number of health and social service professionals, as mentioned by some participants, the diagnosis can technically be made by a physician or psychologist alone, but the ease of this diagnosis and the confidence with which it is provided is greatly enhanced with participation of other professionals, such as occupational therapists and speech and language pathologists. This may make the process less stressful for professionals, and in turn, create a less stressful environment and communication style for families.

One unique aspect of the clinic is that, with the exception of the coordinator, all professionals voluntarily sought to be involved with and provide in-kind services for the FASD assessment clinic. Perhaps the type of professional who seeks out this type of work may have less stigmatic attitudes and more helpful approaches to FASD than the general population of professionals. Again, this may create a less stressful and more



welcoming environment for families, easing tensions and facilitating communication between caregivers and professionals.

Another explanation for the relative lack of caregiver-professional conflict in this study may stem from the selection practices of the clinic. Currently, only once child is seen per month and the clinic only selects children for whom alcohol use can be documented. This could mean that the type of caregivers (biological parents open to telling an accurate alcohol use history and non-biological parents who know the history and are willing to share it) may be systematically different than the general population of caregivers of children who may be candidates for an FASD diagnostic assessment. Thus, if this clinic is seeing more open and upfront caregivers by way of selection, it may reduce the tendency towards caregiver-professional conflict.

Because all children assessed by the clinic are referred by a participating agency, it may be that the children seen are already associated with at least one pre-existing health and/or social service agency. Thus, these children may be more likely to be service-involved when they get to the clinic. This means that families, even in the absence of a FASD diagnosis, may already have some strategies and/or services for their children. This may, in turn, reduce child and family stress, making them easier to interact with.

**Caregiver beliefs.** The current study replicated some of the previous literature regarding caregiver beliefs. The caregiver participant's remarks, as well as some of the comments professional participants made about caregivers indicate that caregivers feel FASD-related stigma (Hess, 1996). This stigma was discussed in relation to the taboo

nature of prenatal alcohol use and also in terms of the misunderstanding of a child's behaviours.

Congruent with previous literature (Chera, 2010; Hess, 1996), participants saw diagnosis as a pathway to increased service access. Participants noted increased social supports through FASD groups, educational supports, community based services (both FASD-specific and non-FASD-specific), and financial supports.

In terms of distress felt at the time of diagnosis, Paley (2005) posited that caregiver distress was not attributable to the diagnosis itself, but rather the distress felt by the demanding nature of their children's problematic behaviours. The results of this study lend support for this idea. Within the current study, there was no mention of significant distress felt due to the diagnosis itself, but rather, what was discussed was the feeling of relief after receiving a diagnosis. Participants extolled the benefits of caregivers simply knowing why their child behaves this way, that the diagnosis explains why and it does not mean that their child is a bad child or that they are a poor caregiver.

**Professional beliefs.** The results of the current study demonstrate differences in attitudes from those of the professionals surveyed by Wedding (2007). The psychologists surveyed in Wedding's study expressed feeling ill prepared to diagnose FASD, as they felt they lacked training, lacked the time required to make the diagnosis, and didn't feel that the diagnosis would make a difference. The professionals in the current study seemed to feel adequately trained to make a diagnosis; but this is not terribly surprising, considering that they come from a specialized clinic that trains specifically for FASD diagnostic activities.

Participants in the Wedding (2007) study also felt they did not have the time to make the diagnosis. Participants in the current study expressed that their time was taxed and their workloads at their primary jobs may not be reduced enough to compensate for time spent on FASD work, in some cases.

Participants in the Wedding (2007) study also expressed that they were hesitant to make FASD diagnoses because they didn't feel that the diagnosis would make a difference. The results of the current study indicate that the participants felt quite the opposite. Overall, participants cited many ways in which a diagnosis can change the course of a child's life, from family strategies, to financial assistance, to community based programming. There is a logical link between believing a diagnosis can help and motivation to complete the assessments, educating oneself on the diagnosis, and, thus feeling confident to make the diagnosis. Perhaps one of the facilitating factors in the clinic's success is that the staff believe a diagnosis will help children live better lives.

Participants in the current study identified similar systemic woes as the participants surveyed in Dewane (2010)'s study of physicians in Alaska. Both samples identified and expressed frustrations with systemic barriers to FASD diagnosis and service provision. However, as one participant aptly noted, these systemic problems are not clinic-specific, nor even FASD-specific, but are common across mental health and developmental services in general.

Participants in the Dewane (2010) study also reported having problems with the caregivers of their pediatric FASD population. A common complaint was frequently missed appointments; participants in the current study offered some insights into

underlying causes of missed appointments. Participants cited having frequent and geographically scattered appointments, poor access to transportation, and parental mental health problems (more specifically, involving memory impairment) as reasons why caregiver may fail to attend appointments scheduled for their children. While participants in the current study discussed some of the reasons why appointments could be missed, they did not indicate that missed appointments had been a significant problem. This is, perhaps, because the clinic has put in place many measures to ward against missed appointments. Most importantly, the clinic uses a coordinator to liaise with families and clinicians, who makes reminder phone calls to ensure that clients are aware of upcoming appointments and know where to go. Also, on a practical level, on occasion transportation supports were provided.

Dewane (2010) also reports that professionals commonly cite a parent's reluctance to disclose prenatal alcohol use as a barrier; this was echoed in the current study, as participants noted that there were some parents who were reluctant to disclose. With a similar ultimate effect, what seemed to be a more common occurrence for the participants in the current study, who see more non-biological caregivers, was unclear prenatal alcohol use history and the need to frequently rely on third-party sources of information.

Participants in the Dewane (2010) study reported that they experienced difficulty managing the emotions of caregivers following diagnostic feedback. While the participants in the current study certainly did not downplay the existence of caregiver emotion following diagnostic feedback, they did not indicate a similar struggle to manage that emotionality. This could be attributable some of the underlying attitudes towards

and approach to caregivers. Professional participants in this study commented on the importance of rapport, true empathy and non-judgment, which certainly puts them in a place to understand what families are going through upon diagnostic feedback. Several participants also mentioned how they strive to select the most appropriate person to communicate a diagnosis to a family; this can be a balancing act between which staff member has the most appropriate specialty for the diagnosis and which person has the most well developed rapport with the client. So, with the appropriate approach, it seems that the struggles to manage caregivers' emotional reactions can be improved. However, one can also easily understand that these are precautions.

### **Implications for Professional Practice: Clinic-Specific**

The current study is well suited to make clinic-specific recommendations, as the results are by far most applicable to the scenario in which they were collected.

**Sustainability.** Several professional participants in the current study mentioned concerns around the topic of sustainability. Some participants discussed concerns around finding sustainable funding. Considering the resources that have been invested in building and operating the clinic, it would be unfortunate if the clinic were to close. Not to mention, the countless children who may not otherwise obtain a much needed diagnosis without the clinic in place.

Other professional participants suggested that the organizational framework may not lend itself to sustainable operations. This is particularly so in terms of the in-kind contributions of professionals' time. More effort could be made to ensure that all partnering agencies contribute equally towards the bank of professionals to contribute to

assessment work. Similarly, extra care should be exercised to ensure that no one diagnostic professional is overworked through his or her contributions to the clinic and/or insufficient reduction of the normal caseload to compensate for in-kind contributions to the clinic. It is clear that the clinic staff members are dedicated to the cause and are willing to do this in the short term, but it is unrealistic that this will be sustainable indefinitely. Perhaps a more clearly delineated breakdown of how and when contributions will be made could assist with the sustainability of personnel resources.

Many participants noted that a significant area of concern is psychology. The results indicate that the psychologists involved in the clinic are dedicated and valuable staff members. However, the psychological assessment is the most time-consuming part of the assessment, making the demands on this specialty quite extensive. One suggestion to facilitate sustainability of the clinic might be to acquire funding for a dedicated psychometrist for the clinic, who could work in conjunction with the clinic's psychologists. Similarly, participants noted that the involvement of occupational therapists and speech and language pathologists have helped lessen the assessment hours required of the psychologists; so, to maintain the role of these two specialties will also help build sustainability for the clinic.

**Bolstering strengths.** From the information gathered in the current study, it seems that the clinic is functioning well, considering the complexity of the organizational framework and the fact that it is in its infancy. Many participants commented that there have been 'bumps in the road' or that they have felt like they have been on a personal or organizational learning curve. However, it is important to note and recognize and bolster

the aspects of the clinic that professional and caregiving participants report as having worked well.

The participants indicated that the relationships and rapport piece worked well. Professionals and caregivers collaborated well and respected each other. The participants noted that the team approach was invaluable, noting that although technically you do not *need* the team to make a diagnosis, but the team allows a higher depth of assessment and higher confidence in the diagnosis. Participants felt that the feedback process was a strong one, one that was respectful and pragmatically significant, in that it delivered the diagnosis in an understandable manner and give families next steps and strategies to help their children. The caregiving participant also noted that the way the feedback meeting was conducted made her feel like a part of the team.

Although there were a handful of meaning units suggesting the need for some improvements in coordination, the feedback on coordination was overwhelmingly positive. The professional participants considered the coordination invaluable and necessary to pull together so many different agencies and individuals. The caregiving participant found the practical aspects of the coordination helpful, such as arranging for taxicabs, setting up appointments, helping families know where to do, and making reminder phone calls.

**Next steps and improvements.** Participants also expressed some concerns in specific areas that they felt could use improvement. Professional participants felt that reports should be written in a more timely manner; however, they also recognized that this problem may be unavoidable, considering how busy the clinicians are in their work

at the clinic *and* their usual, full-time work. Although it may be a stretch for some, clinic staff should strive to complete reports as soon as possible, as these are forwarded to the families, along with preliminary recommendations, which should not be delayed, if at all possible.

Participants expressed the need to better understand the referral process; bearing in mind that these are individuals who are already involved in the clinic, one can imagine how unclear these pathways could be to an outsider hoping to learn more about the clinic or to a frontline worker who suspects they have a child in need of a referral. This type of complexity is common across health, mental health, social, and developmental services and the advice to make channels more clear could easily be universal, however this issue may be a pervasive and unchangeable problem across these services due to the system's sheer size and number of service nodes.

### **Implications for Professional Practice: General**

Results from the current study also suggest some aims for the general professional community for the betterment of FASD diagnostic and support services. This 'professional community' could be thought of as including any professional who has a significant role in a child's life; this could mean physicians, teachers, daycare workers, speech and language pathologists, nurses, social workers, mental health professionals, and so forth.

**Education about FASD.** Participants expressed the need for ongoing education for frontline workers and general practitioners about FASD. One could understand the need for increased FASD-related education as twofold. The first facet being that a better



understanding of FASD would aid frontline workers and general practitioners in recognizing potential FASD-related problems. A better recognition of FASD related problems may lead to faster and more appropriate referrals. The second facet is that a better understanding of FASD could help frontline workers and general practitioners manage behaviours better and help families build appropriate strategies for their children, while they wait for specialized FASD services or when such services are not accessible.

**Approach.** Participants in the current study seemed to make strides with their clients and families by adopting open attitudes towards children with FASD, and caregivers. Perhaps frontline workers may find their work easier and families more open to service if they attempted to adopt similar attitudes towards their clients who have, or are suspected to have, an FASD.

The study results suggest that an open and accepting attitude towards individuals with an FASD and their families in order to maintain a therapeutic bond and a good working relationship. However, one participant warned that not only is it important to remember that we, as professionals, should accept individuals and operate from a place of non-judgment, we must also make strides towards the eradication of FASD. Meaning, while we must be open to individuals who are alcohol involved and alcohol affected, we must do our part to enforce that there is no safe time to use alcohol and no safe amount of alcohol to use during a pregnancy. One can see how this could become a delicate and difficult balancing act.

**Research.** Many of the professional participants noted the need for more research in FASD, particularly in the area of treatment. One participant noted that the current

literature on FASD intervention is far too specific, such as how to teach math, but parents and practitioners would benefit from some research into broader areas of behaviour and developmental services. Some participants suggested that some existing services would likely be beneficial to children with FASD, but further investigation is needed to demonstrate efficacy of such services and determine what sub-population of children with FASD the services are indicated for; as noted in the introduction, syndromal variation in the fetal alcohol spectrum is vast. One participant suggested that with advocacy and interest, the interest in FASD will increase, the funding will grow and, thus, the research knowledge body will become larger and richer.

**Service.** Many participants noted the need for increased FASD-relevant services needed. Again, participants noted that many existing services may be effective for children with FASD, so the professional community may be better positioned than previously assumed to provide care for individuals in this population. Other participants noted that it can be helpful if agencies are willing to loosen certain criteria to access necessary services in the case of individuals with an FASD. For example, an individual with an FASD may be severely affected, but still score in the average IQ range, if an agency is willing to relax IQ criteria to allow access to services, an individual could access much needed services.

The results of the current study also suggest the powerfulness of group supports for caregivers of children with FASD. While the clinic group program was just getting started at the time of interview, participants noted that they believed the caregivers benefitted from the supports they received from the group.

**Screening & documentation of prenatal alcohol use.** The current study indicates that the lack of reliable prenatal alcohol use history can be extremely problematic and can, in many cases, make an FASD diagnosis impossible to render. Even further, at current, the lack of an alcohol use history can, at current, make a child ineligible for an assessment at this clinic. This issue indicates a need for better screening for and documentation of prenatal alcohol use in the health and social service community. This proactive step, if feasible, can help assist diagnostic professionals render an accurate diagnosis in the future.

**Prevention.** The professional community, in general, should also be mindful of the need for prevention. This prevention could be in the form of education about FASD and prenatal alcohol use, improved screening of at-risk mothers, and improvements to alcohol abuse services. In order to increase the likelihood that a substance-involved expectant mother might seek support services, it may be important for professionals to maintain an open dialogue and an attitude of client acceptance. For further information on Canadian FASD prevention strategies, see Poole (2008).

### **Implications for Caregivers**

The results of the current study suggest certain measures that caregivers of children with FASD could take to ensure a positive experience during the FASD-differential diagnostic process. While the participants in the study were directly asked about their experiences during diagnosis, participants did comment on life beyond diagnosis. Also, one could extrapolate that the advice given by participants about the diagnostic process could also be helpful beyond that specific time frame.

The results suggest that caregiver should do their best to maintain openness with professionals. This refers to both receptiveness to professional's diagnosis and recommendations, as well as openness to share and disclose. Caregivers should do their best to share accurate reports of development, behaviour, and alcohol use history. Although caregivers must ultimately be open through their own volition, the researcher suggests that the onus to lay the foundation for openness and encourage this behaviour from caregivers is, ultimately, on the professionals.

Some participants noted that some caregivers struggle with emotionality during the process of diagnosis and diagnostic feedback, due to their perceptions of the process and/or perceptions of the system based on their own poor experiences. The researcher suggests that it could be crucially important for caregivers to seek support and do their own 'work' surrounding attitudes, emotions, and ghosts in order to keep themselves safe and well and be the best caregivers they can be. Again, although these are activities that must be taken up by the caregivers themselves, the researcher feels that the responsibility to educate caregivers about the importance of self-care and the availability of supports within the community ultimately falls on professionals as well.

Some participants spoke to the need for advocacy in order to improve FASD-related supports, public awareness, financing, and research. Caregivers who are open and able may consider involving themselves in advocacy work. This work could be an excellent opportunity to partner with and collaborate with the professional community.

### **Implications for Counsellors**

Although the participants in the current study did not report having any insurmountable caregiver-professional conflicts, one could imagine that these could arise in the future and could also arise in other clinical contexts. There could be a significant role for counsellors in mediating between diagnostic professionals and caregivers, if conflict does arise. Such a role could be that of an objective, third-party individual who could support clients, caregivers, and professionals and encourage more effective communication among these important stakeholders. A counsellor in this role may learn from the current study's results about helpful approaches and attitudes towards caregivers of children being assessed for an FASD, as the professionals from this team has adopted an approach that, from the current evidence, has been effective in setting a positive tone for the diagnostic process.

Counsellors who may be used to mediate professional-caregiver conflicts should also be aware that, as professionals themselves, they may be closely aligned with the professionals who are in conflict with a caregiver. A mediating counsellor should take extra precautions to emphasize their non-partisan and supportive position.

Counsellors may also have a role in helping families through the emotional toll of diagnostic feedback. As mentioned by some participants, it can be a very hard diagnosis to hear and clients and families could benefit from mental health supports. Likewise, counsellors may have a role in long-term follow-up and the prevention of secondary disabilities (Boland et al., & Karp, 1998; Streissguth et al., 2004).

Counsellors may have a role in providing supports to diagnostic and service-providing professionals. Although this experience is not likely unique to professionals

working in the FASD area, many professionals in the study commented on the emotional impact of working with this population. Although the professional participants in the current study did not indicate exceptionally significant emotional distress, one could extrapolate that professionals who are less well positioned to do their FASD diagnostic work may experience more stress and distress in a similar role. Counsellors who will support distressed professionals should educate themselves on the experiences of professionals working with individuals with FASD to better understand their experiences, as well as how to treat the specific presenting concern.

There is also a role for counsellors, as scientist-practitioners, to avail themselves of and become involved with research concerning FASD. As participants in the present study have noted, the therapeutic relationship is paramount in FASD diagnosis and treatment; and, thus, it is only logical that professionals who are extensively trained in therapeutic relationships might be involved in this type of diagnosis and/or treatment.

The FASD diagnosis, like most standardized diagnoses in the medical, mental health, and developmental disability realms, is deficits-based. While we must consider an individual's deficits and deficiencies to make a diagnosis, we must also realize that the interventions and strategies used to support an individual may (and should) involve a strengths-based perspective. A role for professionals from the counselling discipline may be to identify individual and family strengths and build strategies around these strengths. This could be done either autonomously or in consultation with the larger professional support network.

### **Strengths of Current Study**

The qualitative methodology was an excellent fit for this research question, considering the exploratory nature of the question and the number of available (and eventual) participants. The qualitative interview data provided a rich, in depth, analysis of participant experience that would not be possible in quantitative means.

### **Limitations of Current Study**

**Limited caregiver participation.** Only one caregiver of a child who was seen at the clinic participated in this study. The experiences shared by this caregiver *may* have been similar to the experiences of other caregivers, but they may have been dramatically different. This caregiver made mention that her reaction to the experience might have been different because the child in her care was not her biological child (she was a kinship caregiver). Considering the significant literature on stigma in FASD, one could imagine that the reduction of stigma for non-biological caregivers might make for a significantly different experience. Thus, the results should be taken with this in mind. However, in terms of practical applicability to the clinic, these results may be practically relevant, as (reported by the professional participants) the majority of the families seen at the clinic are led by non-biological caregivers. So, although limited, the commentary given by this caregiver is relevant and useful as feedback to the clinic and professional community on caregiver experience.

**Limited professional participation.** While four professionals from the clinic participated in this study, this does not represent the full breadth of health and social service professionals that are involved in the clinic. The professional participants were comprised of representatives of the three specialties: medicine, psychology, and social

work. However, other specialties, namely speech and language pathology and occupational therapy, have significant roles in the clinic, but were unrepresented in this research sample. One might wonder how the results would differ had individuals from other specialties participated in this research?

**Homogeneous gender sample.** Every participant in this study identified themselves as a female. This is not uncommon among the literature of child caregivers, where it is common for the respondents to be female, despite caregivers of either gender being invited to participate. Also, this is not surprising considering the staff makeup of the clinic, as the majority of staff members involved are female. While this situation is, perhaps inevitable, one might wonder how this gendered sample may live, recollect, and retell their experiences compared to their male counterparts?

### **Interview Driven Results?**

One may gather that the codes and themes could be attributed, in part, to the questions in the interview guides (see Appendix H and I). However, it is important to note that the interview guide begins with a very open-ended question about participant experience throughout the diagnostic process, many of the utterances that could be interpreted as interview-driven by subsequent (and more specifically focused) prompts, were offered by the participants freely, without being specifically asked about that topic. For instance, participants offered information about certain aspects of the clinic that could use improvement *before* overtly being asked what areas of the clinic could use some improvement. Similarly, many participants incorporated ideas that were topically linked with a specific prompt within the context of another prompt altogether. Therefore,



we can assume that the results were not exclusively driven by the format of the interview guide, as participants had comments about these various topics without being directly asked questions about that topic.

### **Transferability.**

The clinic is uniquely positioned, compared with many other fetal alcohol disorders assessment clinics. The work is a voluntary, part-time professional activity for all diagnostic professionals. This may alter how professionals experience the process of their work at the clinic, relative to other diagnostic professionals who may do this type of work full-time and/or as paid work. These differences may also impact how caregivers and clients experience the diagnostic process.

Another potentially unique factor is that the clinic is situated in a service-rich and professionally-rich area, meaning that there are more resources for the clinic and clinic staff in terms of training and consultation. These resources may make this experience much different for diagnostic professionals at the clinic, compared with other professionals that are more isolated from other health and social service professionals and/or services. Similarly, families that are based in a service-rich area may be qualitatively different than families located in more remote areas; these pre-assessment differences could influence their subjective experience of diagnosis.

The clinic staff reported significant prior experience working with individuals with FASD and also received specialized training in FASD and FASD assessment. This expertise in the area of FASD could mean that the study results are less applicable to professionals who do not have much experience with or training in the area. The

researcher does not note the uniqueness of this clinic to suggest that the experiences of the participants in the current study are not at all applicable to other settings, but rather, that anyone considering transferring the results of the current study should carefully consider the impact of different clinical settings.

## **Conclusion**

The subjective experience of the FASD differential process is inherently complex, due to the multi-faceted nature of alcohol related disorders and, thus, it necessitates a multifaceted assessment, involving many different professionals. The assessments are comprehensive and time consuming. The experience can be both emotionally rewarding and emotionally difficult. Supports for professionals, such as coordination, professional development, and professional consultation are facilitative of the process.

Support measures for families, such as respectful communication and rapport building can help facilitate their comfort during the diagnostic process. Similarly, supports for families following diagnosis can also be helpful in terms of parenting support, interventions, and services. Just knowing a child's diagnosis goes a long way in supporting a family, simply because it offers an explanation for unusual and trying behaviours. Professional-caregiver conflict that is reported in past literature was not indicated in the present study, this could be due to the more positive attitude and more positive beliefs regarding outcomes held by clinic staff.

The clinic has many inherent strengths that should be further supported, such as the team approach, the attention paid to relationships with families, and the coordination piece. Some areas were addressed that could use some improvement. Some of these areas

were starting to be addressed by the clinic, while others are systemic problems that permeate all health and social service systems. Ultimately, the clinic could benefit from increased sustainability, mainly through long-term funding and additional clinic-dedicated staff to assist in the lengthy assessments.

This clinic offers a unique and invaluable service to a community that previously lacked many viable routes to FASD diagnosis. The work done by this team, undoubtedly, changes lives.

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## Appendix A: Recruitment Flyer, Caregivers

### Research Participants Needed



#### **Who can participate?**

Any adult who cares for a child recently seen at the [*Clinic Name*]

#### **Why is this research being conducted?**

To better understand the experiences of families during the diagnostic process, so better services and supports can be designed for families.

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

Complete some short questionnaires and an interview about your experiences working with the clinic (e.g. What happened? What helped? What could be done better?). The study takes 1 to 1.5 hours to complete.

#### **Do I have to participate?**

No, you do not have to participate. Your decision to participate or not to participate has no impact on your child's current or future care at this or any other clinic. The clinic is not told whether or not you decide to participate

#### **Will I be compensated?**

An honorarium will be provided.

#### **To learn more, please contact:**

Erica Lundberg

519-###-####

[email address](#)

## Appendix B: Recruitment Flyer, Professionals

### Research Participants Needed



#### Who can participate?

Any professional who has recently participated in a diagnosis with the *[Clinic Name]*

#### Why is this research being conducted?

To better understand the experiences of professionals during the diagnostic process, so better services and supports can be designed.

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

Complete some short questionnaires and an interview about your experiences working with the clinic (e.g. What happened? What helped? What could be done better?). The study takes 30 minutes-to 1 hour to complete.

#### Do I have to participate?

No, you do not have to participate. Your decision to participate or not to participate has no impact on your involvement with the clinic.

#### To learn more, please contact:

Erica Lundberg

519-###-####

[Email address](#)

**Appendix C: Study Receipt**



*Obtaining a Diagnosis:*

*Experiences of Caregivers and Professionals*

*Erica Lundberg, BA, Western University*

*Dr. Jason Brown, Western University*

RECIEPT

I acknowledge the receipt of \$20.00 cash as compensation for the expenses I incurred to participate in the study “Obtaining a Diagnosis: Experiences of Caregivers and Professionals.”

Name (please print): \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Researcher: \_\_\_\_\_

Signature of Researcher: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix D: Letter of Information and Consent Form, Caregivers



*Obtaining a Diagnosis:*

*Experiences of Caregivers and Professionals*

### LETTER OF INFORMATION

### CAREGIVERS

#### **Introduction**

My name is Erica Lundberg and I am Masters of Education (counselling psychology) candidate at the Faculty of Education at Western University, supervised by Dr. Jason Brown. I am conducting research about the experiences of caregivers and professionals during the diagnosis process and would like to invite you to participate in this study.

#### **Purpose of the study**

The study aims to describe the experiences of caregivers and professions during the diagnosis process for children who are being considered for a diagnosis of a fetal alcohol spectrum disorder. This study aims to identify factors that help and hinder the diagnosis process. This study will involve 1-2 caregivers from up to 10 families who have completed the diagnosis process. It is up to you and your family which 1 or 2 primary caregiver(s) might participate. This study will also involve 15 health and social service professionals.

#### **If you agree to participate**

If you agree to participate in this study you will be asked to complete questionnaires and a personal interview. The interview will be audio-recorded. This will take place at a date and time that is convenient for you and will be held at Western University or a location of the London Public Library. The process is expected to take 30-60 minutes to complete. During the study, you may choose not to answer any questions for any reason. Please note this study has no direct connection to the diagnostic clinic and that your choice to participate and any responses you might provide will not

have any impact on the diagnosis or care of your child. You will be compensated \$20.00 for travel and childcare expenses you incur by attending the research session.

### **Confidentiality**

The information collected will be used for research purposes only, and neither your name nor information which could identify you will be used in any publication or presentation of the study results. All information collected for the study will be kept confidential. All data will be stored in locked cabinets and password protected computers, accessed only by research personnel. Research reports will discuss the results of the group overall, not any one person. Direct interview quotes may be used as examples, but will not include any identifying details.

### **Risks & Benefits**

You may find some of the research questions upsetting. If discomfort arises, please inform the researcher. If uncomfortable, you may choose to take a break, skip a question, or stop the study completely. There are no expected direct benefits to you by participating in this study. However, it is hoped that the information collected in this study will assist future generations of children by improving diagnostic services.

### **Voluntary Participation**

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time. If you decline the study, or any component of the study, there will be **no** negative effect on you, your child, or any care or services you or your child may receive now or in the future.

### **Questions**

If you have any questions about the conduct of this study or your rights as a research participant you may contact the Office of Research Ethics, Western University at 519-###-#### or [email address](#). If you have any questions about this study, please contact Erica Lundberg at [email address](#) or 519-###-#### or Dr. Jason Brown at [email address](#) or 519-###-### ext #####. This letter is yours to keep for future reference.

*Obtaining a Diagnosis:  
Experiences of Caregivers and Professionals*

*Erica Lundberg, BA, Western University*

*Dr. Jason Brown, Western University*

CONSENT FORM

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Name (please print): \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Name of Person Obtaining Informed  
Consent: \_\_\_\_\_

Signature of Person Obtaining Informed  
Consent: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix E: Letter of Information and Consent Form, Caregivers



Western  
Education

*Obtaining a Diagnosis:*

*Experiences of Caregivers and Professionals*

### LETTER OF INFORMATION

### PROFESSIONALS

#### **Introduction**

My name is Erica Lundberg and I am Masters of Education (counselling psychology) candidate at the Faculty of Education at Western University, supervised by Dr. Jason Brown. I am conducting research about the experiences of caregivers and professionals during the process of diagnosis and would like to invite you to participate in this study.

#### **Purpose of the study**

The study aims to describe the experiences of caregivers and professions during the diagnosis process for children who are being considered for a diagnosis of a fetal alcohol spectrum disorder. This study aims to identify factors that facilitate and impede the diagnosis process. This study will involve 1-2 caregivers from up to 10 families and up to 15 health care and social service professionals.

#### **If you agree to participate**

If you agree to participate in this study you will be asked to complete questionnaires and a personal interview. This interview will be audio-recorded. This may take place at Western University or at your office, whichever you deem more convenient. The process is expected to take 30-45 minutes to complete. During the study, you may choose not to answer any questions you are uncomfortable with. You will not receive compensation for participating in this study.

#### **Confidentiality**



The information collected will be used for research purposes only, and neither your name nor information which could identify you will be used in any publication or presentation of the study results. All information collected for the study will be kept confidential. All data will be stored in locked cabinets and password protected computers, accessed only by research personnel. Research reports will discuss the results of the group overall, not any one person. Direct interview quotes may be used as examples, but will not include any identifying details.

### **Risks & Benefits**

You may find some of the research questions upsetting. If discomfort arises, please inform the researcher. If uncomfortable, you may choose to take a break, skip a question, or stop the study completely. There are no expected direct benefits to you by participating in this study. However, it is hoped that the information collected in this study will assist future generations of children by improving diagnostic services.

### **Voluntary Participation**

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time. If you decline the study, or any component of the study, there will be **no** negative effect on you or your professional life.

### **Questions**

If you have any questions about the conduct of this study or your rights as a research participant you may contact the Office of Research Ethics, Western University at 519-###-### or [email address](#). If you have any questions about this study, please contact Erica Lundberg at [email address](#) or 519-###-#### or Dr. Jason Brown at [email address](#) or 519-###-#### ext #####. This letter is yours to keep for future reference.

*Obtaining a Diagnosis:  
Experiences of Caregivers and Professionals*

*Erica Lundberg, BA, Western University*

*Dr. Jason Brown, Western University*

CONSENT FORM

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Name (please print): \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Name of Person Obtaining Informed

Consent: \_\_\_\_\_

Signature of Person Obtaining Informed

Consent: \_\_\_\_\_

Date: \_\_\_\_\_

**Appendix F: Demographic Information Record Form, Caregivers**

## Demographic Information –Caregiver

Age: \_\_\_\_\_

Gender:

 Male Female Other

Age of Child being seen at Clinic: \_\_\_\_\_

Gender of Child being seen at Clinic:

 Male Female Other

Relationship to Child being seen at Clinic:

 Biological Parent Biological Relative Foster Parent

\_\_\_Adoptive Parent

\_\_\_Other, please specify\_\_\_\_\_

Please estimate the number of hours you spend in direct contact with your child each week: \_\_\_\_\_

Weeks (approximate) since communication of diagnosis: \_\_\_\_\_

Please describe your involvement with your child’s diagnosis (e.g. took child to appointments, completed questionnaires., etc.)\_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Please select the professionals that your child saw during the diagnostic process:

\_\_\_Family Physicians    \_\_\_Pediatricians    \_\_\_Neurologists

\_\_\_Geneticists    \_\_\_Nurses    \_\_\_Social Workers

\_\_\_Psychologists    \_\_\_Teachers    \_\_\_Child & Youth Workers

\_\_\_Lawyers    \_\_\_Counsellors    \_\_\_Occupational Therapists

\_\_\_ Other, please specify

\_\_\_\_\_

Please select the professionals that you see for your child's ongoing care:

- Family Physicians     Pediatricians     Neurologists  
 Geneticists     Nurses     Social Workers  
 Psychologists     Teachers     Child & Youth Workers  
 Lawyers     Counsellors     Occupational Therapists  
 Other, please specify
- 

Please select any resources/supports you have caring for this child:

- Spouse/Partner     Physical Therapy     Out of home childcare  
 School Supports     Medications     Naturopathic Supplements  
 In-home childcare     Behaviour therapy  
 Occupational Therapy     Other, please specify:
-

**Appendix G: Demographic Information Record Form, Professionals**

Demographic Information–Professionals

Age \_\_\_\_\_

Gender:

\_\_Male

\_\_Female

\_\_Other

Profession/Specialty: \_\_\_\_\_

Number of Years in Profession: \_\_\_\_\_

Approximate Number of Children seen through [*the clinic*] to date): \_\_\_\_\_

Approximate Number of Children with FASD served throughout career: \_\_\_\_\_

What types of Caregivers do you typically interact or collaborate with in providing a diagnosis for children with suspected FASD?

Biological Mothers Biological Fathers Biological, Female Relatives Biological, Male Relatives Female Foster Parents Male Foster Parents Adoptive Mothers Adoptive Fathers Other, please specify:

---

What types of Caregivers do you typically interact or collaborate with in providing care for children with FASD (or suspected FASD)?

 Biological Mothers Biological Fathers Biological, Female Relatives Biological, Male Relatives Female Foster Parents Male Foster Parents Adoptive Mothers Adoptive Fathers Other, please specify:

---

What types of professionals do you typically interact or collaborate with in providing a diagnosis for children with suspected FASD?

 Family Physicians Pediatricians Neurologists Geneticists Nurses Social Workers Psychologists Teachers Child & Youth Workers

Lawyers       Counsellors       Occupational Therapists

Other, please specify

---

What types of professionals do you typically interact or collaborate with in providing care for children with FASD (or suspected FASD)?

Family Physicians     Pediatricians       Neurologists

Geneticists       Nurses       Social Workers

Psychologists       Teachers       Child & Youth Workers

Lawyers       Counsellors       Occupational Therapists

Other, please specify

---



## Appendix H: Interview Guide, Caregivers

Grand Tour Questions:

Could you please tell me about your experiences going through the diagnosis process?

Prompts:

In your opinion, what things helped the diagnosis along?

In your opinion, what things interfered with the diagnosis?

What activities were involved with diagnosis for your family?

What feelings or emotions did you have through the diagnosis process?

Can you tell me about what it was like to interact with professionals during diagnosis?

In your opinion, what things made it easier to work with the clinic professionals?

In your opinion, what things made it harder to work with the clinic professionals?

In your opinion, what aspects of the clinic worked well?

In your opinion, what aspects of the clinic need improvement?

Has the diagnosis provided changed your life or your child's life?

If so, in what way?

-health?

-family life?

-school life?

What advice do you have for caregivers who will go through this process in the future?

## Appendix I: Interview Guide, Professionals

Grand Tour Questions:

Could you please tell me about your experiences going through the diagnosis process?

Prompts:

In your opinion, what factors facilitated the diagnosis process?

In your opinion, what things disrupted the diagnosis process?

What diagnostic activities were you involved with?

What feelings or emotions did you have through the diagnosis process?

Can you tell me about what it was like to interact with caregivers during the diagnosis process?

In your opinion, what things made it easier to work with the caregivers?

In your opinion, what things made it harder to work with caregivers?

In your opinion, what aspects of the clinic worked well?

In your opinion, what aspects of the clinic need improvement?

In your experience, does receiving a diagnosis change childrens' lives?

If so, in what way?

-health?

-family life?

-school life?

What advice do you have for professionals who will go through this process in the future?



## Appendix J: Meaning Units by Theme and Code

### Clinic Organization: Systemic Strengths and Challenges

#### Planning clinic

*P1- I was, um, involved very early on with some, a group that sortof looking at whether the clinic was a good idea or not. Then I was not involved with the actual planning of how the clinic would run.*

*P3- Like before the diagnostic clinic even started, like 2 or 3 years before that, um, during the process of, like, capacity building, and trying to get people on board, and trying to^ trying to convince people that there was a systems gap, and^ um, so, uh, I've been in it, like, since the very, very beginning. So~ um, there's been a lot of bumps in the road*

*P3-I was involved for the 2 or 3 years to set it up, then as soon as the first client was to be seen I went on [type of leave] leave. I was gone for a year. Um, so some of those things are difficult for me to say because when I came back in, they'd already seen a bunch of clients and probably had worked out #some of the kinks.#*

#### Organizational structure

*P1- And I think the other piece is just our system. Even as we have it set up for our clinic, makes it quite difficult. So, it multiple agencies, you come through and^ it's actually working not too badly, I don't think.*

*P1- Right, and I mean the very first patient that I saw, um, those nuts and bolts were uh, really not there at all. You know? Including, including them arriving at our front door here and nobody knowing who they were and what they were supposed to be here for, and so on. Even though we have our [unclear] staff, but because they were not part of our general system, it uh, made it very difficult. So I think that that is a barrier and it still is to some degree.*

*P1-so I think that is a^ so it's a strength that there are multiple agencies involved, because there is a lot of buy-in, but it's also a weakness in the sense that if [agency], for example, and I don't think it's a good idea, but wanted to cut something because they needed to streamline, the FASD clinic would be easy, because it's like an add-on It's not part of, you know, our residential or core business*

*P2~...Uh, certainly um, the commitment of all the stakeholders to be involved and participate. Um, the clinic is running on a [granting agency] grant right now, so all the work we do as professionals is in kind. Um, and uh, so, I think that it's amazing that, I forget now where we're at, I think it's [number] stakeholders can come together in a community as large as [city] and provide this type of service that has never been*

*available here, you know, according to how, um, it probably should be diagnosed. Um, and, I think, initially, with any new endeavor there's growing pains.*

*P2-right, Um, so a little bit of clearer picture in this particular type of diagnosis, who's going to do what. And that's part of learning how to work #together# as, um, as professionals and also we're all from different organizations, we're not in the same building. we don't meet regularly, just about, you know, a particular clinic. We do meet regularly, but every few months, so um, that's part and parcel of just the way its set up.*

*P3- and I think the outcome has been pretty good, considering the number of people you had to have come together to make the clinic work.*

### **Team approach**

*P1- So, absolutely having a multidisciplinary team and a set clinic, um, is very important and we^ it gives you a lot of confidence in the diagnosis, whether it's there or not.*

*P1- Whereas, without the team, we can make the diagnosis, but it's just not done in the, the way that is, that it's done across the country for example. So, without the team, our kids that are diagnosed FASD are not the same that are done in BC or Alberta or elsewhere around the world. So I think because there's no one marker, there's no xray or blood test, we really need to be doing things in a similar way. And it's only with that team that we can do that.*

*P1-I think the best part about the clinic is, uh, that opportunity to sit down with the team and discuss the findings. And that's the experience of people across the country as well. Um, that is is that discussion that is the most helpful and that it's the group's opinion in the end that sortof makes a diagnosis happen or not. And that doesn't happen very much anywhere else*

*P2- Um, and then I did some supervision with the coordinator*

*P2-uh, then uh, you know, it's really been a team approach that we've had and it's been very helpful. So, having the pediatric part of it, in terms of medicine, the psychology, the speech and language, um and OT.*

*P3-Um, I think good teamwork between professionals, I think mutual respect for each other's disciplines and um, being willing to listen and hear what the other people are saying. It's quite a collaborative process when we come together on clinic day. Um, you know, everyone says their part and them, um, and then we sortof come together to figure out, like we rate, you know the 4-point diagnostic code is?*

*P3- we do the recommendations together as well, so we sit around and talk about what recommendations would be good. So, I think, um, that has been helpful, we have a pretty good group.*

*P3-yeah. I think is^ there will always be some difficulties around turf and stuff, right? So, finding that is a bit challenging. But, I find people are pretty, pretty good.*

*P3-And I find people pretty generous of their time and pretty^ like, I'm sending around a chart right now to, um, so we don't duplicate. So, I'm writing down all the measures are going to use and I want the OT's and SLP's to fill out the chart as well, and um, I have no doubt that they'll do that. And that's a bit extra. I mean, it'll be good upfront and it'll help us in the long run, but they have to sit down and think about it and, and they're^ the fact that they're willing to do that is good. Also, people are willing to sit of committees, so like the process committee, um the research committee. So, you have some of the diagnostic professionals who are willing to sit on those committees. Um, which is, again, even more over and above*

### **Caregivers feeling like part of the team**

*C-I guess it made me feel more a part of the process, rather than, um, I'm way over here [gestures off to the side], sometimes when you are involved with professionals it feels like they are way over here [gestures] and they are going to decide everything over here and they kindof just let you in in as an afterthought, kindof thing. And I never felt that at all during this process.*

*C-Yup. Yes, I felt a part of it at all times.*

### **Coordination**

*I-Ok. Uh, in your opinion, what things helped the diagnostic process along?*

*C-Um, the support of the co-ordinator^*

*C- giving me the dates and times and if there was any kind of support available.*

*.C- I think the one guy phoned me ahead of time and [unclear] told me over the phone and I'll repeat it and we got to the appointment.*

*P1-certainly, the service coordination is essential, like pulling everything together to find, to be one person to talk to the family. And also to gather up all the information. I think that's^ that's very important.*

*P1-Uh, having it set up ahead of time by the service coordinator, this sortof paved the way, um makes it very easy having, uh, structure framework, so they can come in the door being greeted at switchboard++ and know everybody and have that infrastructure to support them. So that they know what they're doing.*

*P2-The coordinator is also invaluable, who sets everything up, makes contacts with the families initially. Um, and does all the background information and gets that to all the professionals.*

*P2-Mhm and [coordinator] does a great job of setting that up at the beginning, explaining the process and what to expect. And you know, that type of thing, so they're well informed of what to expect over the next while+ when they engage in the clinic.*

*P2- Um, but we uh, I think, you know, it runs very smoothly and everyone contributes and coordinates and, um, uh, in the end, um, you know, the report's put together. And the you^ the family receives that and sometimes school or whomever its appropriate to, um, and that kind of coordination and getting that information out there goes very well, too.*

*P2- I would say that, uh, definitely you need to have a, uh, coordinator. Um, you need a central person who is going to assist the professionals all together and, yeah, as effective as possible.*

*P4- Well, from my perspective, it involves a lot of planning and a lot of organizing and a lot of making sure that I'm^ I've dotted all my i's and crossed all my t's and gathered all the information.*

*P4-and make sure that I get it to everybody and everybody has what they need in order to make this as efficient as possible. ++*

*P4-there's so much involved just from, you know, meeting the families and keeping my head straight around who's all involved with what family and what child I'm actually talking about when I get a random phone call, my chart's not sitting in front of me. so, because I don't really have a lot of direct contact with the families, um, I you know, I collect all the information and I try^ we've incorporated, um, an intake meeting now, so that I make sure I meet everybody before.*

*P4- [before doing in-person intake] It was phone calls and if we could meet with them we did. But we didn't have to always, because a lot of the information was supposed to be neatly packaged coming from the referral source. And then I was just supposed to coordinate the scheduling, like the team membership and then the scheduling of the clinic. And then corresponding with the families. but sometimes it was just through mail or phone calls. whereas that just felt so impersonal to me, that an intake was required.*

*P4- but even that, you're intaking in august and then maybe you won't see the family again until july, or june or September even. so, so there's still a disconnect and, uh, but you know the families are well aware of my contact information. If they need anything in the interim. But when I get those random calls three months in ++ it's kindof like, help me remember who, who everybody is. But, uh, I think I do ok, I think we do pretty good and families are really gracious and respectful of the fact that, you know, it's been months since we talked and that's ok.*

*P4-so I think first and foremost, that's^ that that's the one thing. But to facilitate the whole process it's it's the coordination of, it's the team^ team membership. It's the linking^ whether it's virtually, so all the team members know who everybody is, what's going on. They receive all the information. So they know how to move forward. Um, the go-to person if there's a question. So, that facilitation, the the coordinator needs to do that*

*P4-. Um, so, that [the coordinator]'s the go-to person for everybody. So if there's a piece of paper missing or if there's a consent missing, or if there's a question or if somebody*

*needs to gather more information. They need one person to go to and not assume that it goes to anyone else, right? So that conduit of information I think is essential.*

*P4-I'm there to coordinate and to make coordinate and mitigate any possible scheduling conflicts, right?*

### **Professional development**

*P1-Um, I was involved with the, kindof, opening, I guess education uh, and understanding of how we were all going to run the clinic. So, there was a guess an education session down at the [a partnering agency] and I gave a presentation there about the diagnosis and so on, as well as attending the rest of the day.*

*P1- Then other things I've done related to the clinic are attend conferences, uh and so on, just to learn more about FASD and diagnosis, diagnostic issues.*

*P1- I think, um, you know, educate yourself around what we know about, uh, FASD and what we don't know. And there is a wealth of, you know, facilities across Canada that provide training and, um, and I think if we were to do it again, there is like a training facility in Alberta that we, um, would have been be^ rather than do just the online manualized training; if, you know, funding would have allowed it would be better to go out and and get the, what is well developed, onsite training, in Alberta. See kids, see how they do things.*

*P2-Uh, the importance of ongoing training, both within the training in the community for those who will bring forward the referrals*

*P2-and, um, for the diagnosticians, um, there's a couple of excellent conferences each year. World conferences where, um, you can certainly learn a lot about the various measures and what's, you know, in the last year, what's been tested and seems more valid in terms of, uh, the FASD population or, um, you know, various things like that.*

*P2-So, um, I think that's a really important piece [attending conferences], because it's a very evolving, um, area right now. So, um, being very aware of those types of things is, is important to provide the best practice possible.*

*P3-And then I think ongoing professional development, um, is really important. So there's not a lot of money. I think all the diagnostic professionals, all of them, would benefit from going to the conference. I can't see that happening, but honestly, it's an amazing conference. Your knowledge just goes from 0 or 90 the whole time you're there. it's really, really a valuable experience. But there's, there's not a lot of money. But, I think anyone who wants to be a diagnostic professional, should have that opportunity, even though it's not available so I think those are some of the things that would work better.*



*P3-we do have a great resource, [name], for psychology who is in [neighboring city], so she is coming in September and she is willing to consult whenever we want. Um, we haven't used her that much, because, you know, money too right? you can't ask her to do that for free, although, she probably would? I mean, how much are you going to ask of people, right? So, she has come down a couple of times for free. to help the psychologists. Like, driven all the way here, talked to us for a couple of hours and gone back for nothing. I mean, she's being paid for her big talk in September, but really we should be paying a consultation fee whenever she does that++just from the community, outside of the [clinic's city] area.*

*P4-Hm. Well, I think what advice I'd have is just to make sure that...hm+ I think that we just really need to be open to training*

### **Distribution of Labor**

*P1- but I think there's a kindof push from the different agencies to not let one, have once person have it become a bigger part of their job.*

*P3-yeah, so I think...so, part of the difficulty, I think, of the actual clinic is getting the number of diagnostic professionals that you need to get the diagnosis done. And not over-weighting any one particular agency or one particular professional with the work.*

*P3- And I think part of this stems back from^ so, it's a coalition of agencies, we had to get everybody on board and everyone was supposed to provide in kind services #and# that's, just like anything, some people give more, some people give nothing.*

*P3-And so, trying to find the right balance between not over-burdening the people that are giving more. And trying to create some, um, incentive or that kind of thing, for to the people who are not giving at all, to give some is difficult and think we are just sortof in the beginning of, um, figuring that out.*

*P3-So, although everyone was on^ so in those three years, everyone got to be on board, everyone wants to be a part of it, but then when the rubber hits the road, people fall away a little bit. Like, they'd like to be a part of it, but I'm not sure they are, um, willing to put as much money or professional expertise into it as other agencies.*

*P3-. Um, I think, um, lessening the burden on the few and sharing the burden with the more would be really important for sustainability. I mean it's ok now, but in the long run, it's not gonna, that's not gonna be sustainable.*

*P4-and so that, so that it wasn't me going: "well, I can't use [name] on this one, I have to use [name] on this one, because I've already used her on this one and she's really busy, she doesn't want to do back-to-back, but she's^ but this kid is the right age, so how am I goin g to^. So, then I've got to move this kid to April because^" you know what I mean? it's it's a juggling. And then, whose got maybe private benefits that they could help out with? Whose got different access? You know, whose got previous reports and who hasn't*

*P4- I just wish we could have clinicians who that dedicated to June, dedicated to you know whatever and we just put them in. and if they had an easy clinic 'cause a lot of the reports were done, terrific, then we just trust that that'll happen again, but right now, it's a matter of me. Ok, this one's been overworked, I need to make this an easy clinic for her. So, this is goin^ you know what I mean? So it's just a lot of, a lot of juggling right now.*

*P4-exactly. So to me, that^ and it's not like I'm asking, we're not asking for a ton of extra money, because again these kids are being seen and they will be seen through OT at the school, potentially, or [community agency] or whatever. But not in a way that's necessarily congruent with what's needed for the diagnosis. so, so we're^ we need to build capacity in that area.*

### **Staffing Issues**

*P3-the big gap is psychology, of course, because it's the main part of the assessment. it's the most time consuming and you can't do a diagnosis without it. So, you have to have it. Um, SLP and OT, um, you could, I mean they are essential as well, but there are clinics that run with just a physician and a psychologist. Um, but the more OT and SLP you have, the less a psychologist has to do So, it's re^ it is important to have them, but psychology is essential.*

*P4-and I think that, you know, our clinicians are some of the best.*

*P1-so I understand the need to involve as many different people as possible to make this sustainable, but I think it would be helpful if there were a core group of people who, who continue to do the assessments, rather than continually bringing on new people because there is, there is a bit of a learning curve as to what's helpful and what's not and it's not, you know, it's not um, well, I don't know who to use as an example, but we're not all interchangeable.*

*P1- So just the experience of doing the assessments, helps your next assessments and so on. And if we were to constantly change physician, it wouldn't be a very good assessment, as compared to having one or two continue on and see a larger number. And the same for speech and OT and, uh, psychology. So where we have had a number of the psychologists or speech and language therapists there for a number of times, that has really helped the assessments, I think. And helped the team work together. Unfortunately, the system likes to take people away and give you different people and that's a problem, I think.*

*P1-but I'm not, I mean, I don't get to choose the people. If asked, I might give advice, say well, this person, I think, prefers younger kids or something like that, but that's the only sortof input [unclear]*

*P1-right and I'm not saying just if five people are needed for the, you know, team, just five, but, you know, maybe ten, rather than you know twenty, just dropping in to do a speech and language assessment in one meeting, because there are some subtleties to it. So there are quite a few people who have done more than one*

*P3-So, getting enough psychologists has been difficult. and we learned^ and I didn't know this, actually, but psychology is hard to come by all around, like Dr. [name of physician] was saying they're having trouble finding psychology for other things as well, I didn't realize that it was so difficult to find psychology, just generally. But, um, yeah, so you have the issue of there's just not enough of them.*

*P3-The ones [psychologists] that are around, a lot of them don't really want to touch it. 'cause it's very, it's very complicated. It's a big learning curve. Um, And, you know, then people don't, people don't want to have to pay for it either. And, so, it's difficult.*

*P4-- what factors help facilitate the diagnostic process? Well, we need to have clinicians, we need to have clinicians who have the appropriate time available in order to incorporate all the measures and to be flexible^ to meet the needs of the children who are coming in.*

*P4-, that's a barrier, to make sure that we have enough clinicians*

*P4-and we don't have an OT, yeah, we lost, we lost our OT which we really, you know. And, but OT is not a billable, like, it's you know, it's not a free, OHIP billed service. So, um, we have to find funding for that and I can't expect anybody^ and most OT's are contracted out, it's not even like I could get one that's got a salary position +++ somewhere. But you know what I mean?++ that would^ everybody pays for OT, whether it's the school board, or, you know?*

*P3- Because, although people are giving in kind, from my agency, for example. um, we're like half ministry and half fee for service and so, I need to bring in money to my agency. And FASD doesn't bring in any money. So, the do^ the idea is that your agency is supposed to give you in kind and they do to some extent, but in a lot of cases, your in-kind is you providing your personal in in kind time. So, all the psychologists are feeling that their caseloads have not been reduced enough to compensate for the FASD assessments, which means that they're doing it on their own time, so they're sacrificing their families essentially, time with their families.*

*P3- Ok, so a lot of people who are taking their own family life time to complete assessments. Because they're work load has not been reduced.*

### **Beyond typical work activities**

*P1-some of the, um, professionals, so psychology, these assessments are just above and beyond what they normally do, so it's like an extra, which isn't really sustainable in the long*

*P1-so, for me, if I see a new patient, it doesn't actually matter whether they're in here for that^ this clinic or some other clinic, it's^ I just have my time and I see people. For the others, they may you know, in some situations, may have to do some assessments which actually bring in money for their, uh, agency. That agency depends on them for their money, so they have to do whatever their quota is. And the FASD is above and beyond that, which seems like not a very good situation.*

*P1-I guess, with the exception of myself, who might have made the diagnosis in the office using just what I can gather from other people. Um But, for the others, there was no clinic before so they weren't doing it. So, every^ for every agency, it's like an add-on, so, it becomes a bit lower priority than if it's your main business.*

*P3-So, I think that's difficult. I think that the physicians are not in the same situation because they can bill; or they're on salary and they're seeing those kids anyways and it's only a 20 minute assessment, or a half hour or whatever, so it's much less time consuming. I think the SLP's and OT's are finding the same thing.*

*P4- I would do this full time if I could. you know? But I can't and that's one of the problems++ nobody^ everybody's doing them on the side of their desk and above and beyond.*

### **Capacity building**

*P1-Well, I think the biggest factor is capacity, so the lots of kids out there who could have a diagnosis, may who need a diagnosis, who are struggling and, you know, the clinic is seeing one patient per month. And, uh, that is just really a small number in comparison to, uh, all that are out there.*

*P3-Uh, well, I would say it[external consultation]'s essential to build capacity.*

*P4-the capacity building right now and the sustainability focus is really time consuming*

### **Referral procedure**

*P1- Uh, but that took quite awhile to kindof smooth out how a child gets from, you know, person A that says maybe they have FASD, let's send them for an assessment to actually getting to the clinic.*

*P2-Also I have been on the team that vets the referrals. So, deciding who is an appropriate candidate, Who isn't, and putting them on the list and prioritizing.*

*P1- I don't know that people sit here at [agency] know how to make a referral and I don't think we know how to prioritize those. So, in other words, if we get 10 referrals from [agency], and 10 from [other agency] and none from somewhere else, what^ do we just see those 20 or do we seek them out from other places? That actually hasn't been ~ clarified, so, and maybe make it more equitable,*

*P1- maybe we just see more people here at [agency] who would have the diagnosis and other places, they might not, so I'm not sure that it has to be equal numbers from each place, but anyways, those are sortof, again, details that haven't been sorted out, and so the path is not easy.*

*P1-You know, parents can't just Google it and call the number and have an appointment in a couple months*

*P1- they have to be associated with one of the 13 agencies. Although, we've tried to be flexible. So I think the flexibility helps, but on the other hand it's because there's so many agencies, and there's reasons for that, um, it just makes the path not clear. But I have to say that applies to all of mental health and developmental services*

### **Attitudes and Approach: Laying the Foundation**

#### **Enjoyment and Passion**

*P1-...oh, the whole gamut, uh, I can't say that, uh, there's any one [emotion]. I mean, the kids are, uh, you know, fun. This is my work that I do, so I enjoy it, but um you know, you laugh, they're happy and interacting. You always try to look for strengths in kids and and certainly, you know not to overgeneralize, but many of the kids are very social, very uh chatty and interactive. So that part, you know, is very pleasant*

*P4-hm. Well, I think that the, I think that the clinicians are just amazing and I think all of us are incr<sup>^</sup> I think that all of us want to do the best that we can do, so I think it just happens. Like, I think our clinic is successful because we've got people who are really committed to it. Everybody at the table says I wish I could do this full time*

*P4- but everybody who's I<sup>^</sup> who I've had the pleasure of working with is there because they really, really, want to do it. And they find the work both fascinating, you know emotionally gratifying, challenging, all of the above, but they, they know that there's a need and that we're doing good things.*

*I-So, if someone else was in your shoes, what advice might you have for them about, about this?*

*P1-Um, make sure it's an interest of yours to start with++*

*P3-yeah. Yeah, I think, you know FASD at this stage is run on passion. Like, the diagnostic of FASD and the capacity is run on passion. As opposed to money+++ So, you know, it's how long that passion will last before we start to get a bit burnt out.*

*P4- I'm pleased to be a part of this whole process to help facilitate better understanding and a, and a different approach to parenting and supporting our little people and out adolescents*

*P4-the passion, the desire to learn. The desire to see things differently. And the openness.*

#### **Rapport**

*C-She was really helpful. And...all the doctors were really nice. And down to earth people, I guess. Easy to talk to.*

*C-Everybody was pretty, like, open*

*C- Like, even the final meeting, like we met at the CPRI and everything like was in a circle. And, to me, that was really good because everybody, I could look at each person as they are giving their diagnosis, so that was really good.*

*P3-So, whoever knows the kid best, whether it's the physician or the psychologist, will generally do the diagnosis with the kid. Um, and then, for the parents, it's just depends on, sometimes for ARND the psychologist will do it 'cause it's mainly a^ the psychology that's doing the assessment. For FAS, um, sometimes a physician. So, generally, so last time the physician did the diagnosis with the parents and I did the kid, later another time. Uh yeah, so, and that seemed to work pretty well*

*P3-So that can be helpful. Um, we're ^ so part of the process is we're instituting some new things. So, [coordinator] is going to be meeting more with the families at the beginning, she's gonna be doing a bit of an intake. P3- so she meets them right from the beginning, so she's there at the beginning to talk to them throughout, and talk then at the end again, instead of just being this voice on the phone. until the end. And then she can set them up for some things that are really important.*

*P3-Um, I don't know. I've not really had that much trouble working with caregivers.*

*P3-I work with caregivers all the time, it's my main job. So, you know, I think sometimes people just need a little bit o' time to warm up to you. So if you're just patient, I think I^ I've never really had...*

*P3-And anyone can be, sortof, you know, uh^ with time and understanding, I've never really not been able to^ and rapport^ bring someone around to understanding what needs to be understood.*

*P4-It's getting to know the families*

*P4-Mhm. And, um, the group that we're doing, that we're incorporating will give families and opportunity to be connected, even prior to the assessment, too. so, that will, kindof help with the continuity and help with the relationship building and, um, just that resource, you know that constant, I'm hopeful that that maintains. But it might grow too big too, you know?*

*P4-. But I'd like to have more direct service time++. I'm not sure how much more time is actually required.*

*P4- So, um, but yeah, I mean, some, some people, and it depends on, it depends on the day too, it depends on relationships, you know? If you don't have a relationship with somebody, why am I gonna want to tell you my story? So that gets a little bit tricky*

*P4-abosultely, yeah. And I think it's, like, you know somebody was saying to me, for example, again going back to the capacity building, there was somebody who implied that the coordinator really could just be administrative staff or just be somebody who pulls the team together and duhdaduh duhdaduh da. There's a r^ there's a role for administration. I would love to have some admin support, because they're way better at a*

*lot of this stuff than I am. But I think without a social work background or a therapeutic, um, involvement with the family, even if it is really short term, I can't see it, I can't see it being successful at all.*

*P4- I think you need to have somebody who's there to really, you know, empower, but also hold their hand a little bit, if needed. And you need to be able to take off that professional hat and that administration piece is not of interest to families, you know? They don't^ they'll help you and they'll fill out all kinds of paperwork and they'll do what they need to do, but that's not what this is about.*

*P4- If they have a question, they have a piece of paperwork that needs to be signed, or filled out or photocopied or something, or just to facilitate further understanding, it's still me that they call. And I would like to think that part of that is based on my personality and my contribution, but I also believe, and I know that it is, but I also believe that I'm also that first point of contact and I'm that go-to person. And so this role has to be^ somebody has to fill it that takes that really really seriously and really has that, um, desire to be helpful and supportive*

*P4-So, what makes it run well? Is, you know, our connection with families and I think the clinicians are amazing with families and how they are so, the way they deliver information is just so kind and so eloquent, but yet very pragmatic and and professional.*

*C-like they all sat down and talked to me, and this is what we're gonna do. I think the psychologist had some things for me to fill out and then she told me what she was gonna do when she took him in and interviewed him. I didn't have no^ I wasn't apprehensive about anything, like him going to a room with a strange woman, you know or anything like that.*

## **Empathy**

*P2-Uh, so for me, that's uh, uh that's very^ I feel very empathic for them*

*P3-Um, I think being as non-judgmental as possible and really listening is really the key. And trying to understand where they're coming from, and trying to really understand what it is like for them with their kid. Because a lot of kids behave really well in an assessment, it's one-on-one, you're working with like blocks and, like, manipulatives, and they have your undivided attention and they have your undivided attention and you're not really putting any demands on them, like you're role playing and having fun, so um, so your experience with them is much different than the day to day with the parents.*

*P3-So, I think really listening to the parents and trying to understand where they're coming from and giving them that chance has been a really, really helpful^ and I think that works for the workers too, especially CAS workers and stuff that are really having a lot of trouble with the kid. If you give them a chance to talk about and explain their frustrations, and what's been really difficult, I think that is helpful to get engagement from them, in terms of facilitating their support around getting through the diagnostic process, which is pretty onerous.*

*P4-And I think my experience with the diagnostic process so far is that I really, truly believe it shouldn't be this hard for families. I think that we should have a place, like, if my child was diabetic or struggling. um with a physical illness, I wouldn't stop until he or she was diagnosed and treated properly. and then I was given the resources that I needed in order to make sure that my child was as healthy as I could^ as she could, as he could be. So I'm not clear yet why we're not there and why we have to work so hard*

### **Dedicated Caregivers**

*C-Um...I think I just adapted to how he was. 'Cause, like, he's the only child in the house. So, like for instance, um, he used to throw his plate when he'd be done eating and it would break, so I just switched everything to plastic so nothing would break. I read about that later on, after the fact, that you can't do anything to change a child with FAS. You have to change yourself. And, I just automatically started doing that, without even thinking about it.*

*P1-Well they've been fantastic. And, um, I think that's one thing that stands out is the just work and dedication and so on of, uh, parents and, I mean guess I didn't mention this at the beginning, but there's a lot of grandparents, great-grandparents who are doing a lot of the childcare and you have to really admire them for taking that on, often with their own^ they have their own illnesses and, uh, energy levels and so on.*

*P1-Uh, so with caregivers, I mean they're very dedicated people. And it's a substantial time commitment for the parents, if they work: time off, um, you know, that's a^ it's an onerous^*

*P2- The caregivers have been amazing. I think that when you get to the point where you can provide confirmation that there has been drinking during pregnancy, um, you're fairly motivated to figure your yo^ your child out.*

*P2-And so, for many of them [caregivers], they have been very motivated, like attending the appointments, even though it's been a struggle to get off work or get here or whatnot. They've been very, um, they've been excellent at returning questionnaires and completing those. Um, attending, you know the feedback sessions, asking great questions.*

*P3- So, for the non-parental caregivers, like the non-^ um, with teens that I work with, some of them are helpful some of them are not. Some of them just want the kid off their plate. and are, just, you know, looking for a placement or trying to get the case done. and others are really invested in the kids and will drive them to appointments, call them in the morning to make sure they're awake for getting on the bus to come to my appointment and that kind of thing, or if they're not awake, they'll drive and go get them, wake them up, and get them to the appointment. So there's a huge gamut in terms of the commitment that the workers, um, workers have for their kids, I think. It's amazing when they do that. Very very very helpful, yeah.*

*P4-Um, so, I see resilience. I see amazing families. And I see people who face day to day challenges that would make most of us...very tired++ very tired.+*



*P4- and how they keep going and feel like it's their, their role and it is what it is and how they're still so positive and nobody really gets too bent out of shape about, you know about what it is they^ . I'm speaking specifically around the kinship care.*

*P4- And the, the foster families and the adoptive families and the people who don't have to be in that role. #they choose to be in that role#. And they aren't^ even some people have chosen to be in that role but were unaware. And so thought they were bringing home a healthy baby. and then their world has turned upside down. Um~ but they still are so full of love and commitment and wanting to fix things and wanting to do things the best way they can do. So, I find, uh, it's humbling and inspiring all at once, if that makes any sense. +*

### **Caregiver attitude**

*P1- the rest kindof depends a little bit on the caregivers that come, what they're um, attitude is. So sometimes they're here and they don't want to be here and somebody told them they had to come, so they are pretty angry, so you can kindof feel that. Um, So, they may direct the anger toward um, me. Not overtly, but you can just kindof feel that.*

*P4-yeah, they're grateful, grateful for the opportunity to be^ have their child diagnosed.*

*P4-well, I think that, I guess going back to one of the barriers, too, I think is that, you know, some, some parents are leery of the system. Some people don't really want to have much to do with the system. They haven't had really good experiences.*

### **Stigma**

*C-I think so. I don't think I worried about it that much [that a diagnosis would lessen herself/her child], maybe because he's not my birth-child or anything like that.*

*P3-So I think that helps. Birth parents~ um, maybe a little less eager. We don't get^ we haven't had a lot of birth parents, I think*

*P3- and it's very, um, they're very reluctant to admit it because, of course, they didn't know at the time, but now it's all over billboards, it's^ it's you know, washrooms in bars and it's very, the public health has been pretty, um, open about it, so I think they know there's something wrong, but they're not as willing to admit it, but if they did it could really help.*

*P4- And in this situation, it was biological, so there was a, an element of "I feel pretty awful I did this to my child"*

*P4- that was just, uh, and again I just don't think things should be so hard for families and because it's got the term "alcohol" in it, I don't think kids and families are treated as fairly as they would be if it was "autism" or "down syndrome" or "diabetes"*

*I-so, that that word really changes things*

*P4- I feel it does, even though I think it needs to be, like I wouldn't propose changing it. 'cause if we ever wanna eradicated this, we can't dance around it.*

## Beyond Yes or No: Assessment and Diagnosis

### Comprehensive assessment

*P1-When there isn't a specified clinic, then we have to use assessments done by people who may or may not know about FASD, they may or may not know what tests we need to do to really clarify it. So, commonly used tests like IQ aren't particularly helpful, but might be helpful in giving you clues to what other tests might need to be done or to clarify.*

*P1- And then often, it's putting together something that's minor on one tests, but it's minor on everybody's assessment then it's a true bill and it's real, so paying attention to these details and so on, is not common or really needed in other kinds of assessments that we do, say we're looking for intellectual disability, it really does depend on the general tests that we do. We're not looking for so much for the subtleties, and the time. So, if I ask for some testing from psychology, for example, that could take a year.*

*P2-yeah, primarily I'll do the, uh, psychological pieces, including cognitive, adaptive, uh, executive functioning and then, uh, within executive, there'll be other measures in terms of attention and different things like that.*

*P2-And, uh, also, background history and that kind of thing. We try to get as much of that up front through other, well we have a, a extensive questionnaire that our coordinator will do, so we get that background information, but then we also get a fair bit of collateral information, which is really helpful.*

*P2-Uh, it's fairly standard, I mean they're all standardized measures, for sure. And, um, we try to follow best practices, in terms of what's, um, what we know right now is, sort of the best measures for, um, the various ages or populations of youth that we're testing for this reason.*

*P2- Um, I would say that, um, similar training on the^ and agreement on how to diagnose is very important. There are different ideas out there on how to diagnose, different^ Having come from the same angle, with the same lens is very important. Or you could have a lot of conflict. Um, knowing in advance who's going to do what role in terms of the, some of the overlap in the areas that are required diagnosis, um, would be really important.*

*P3-Um, well, so for FASD you know there's like several domains of function that you have to evaluate. So, psychology assesses ma^ most of them, not motor and sensory, that would be OT*

*P3- because we have SLP, which we're really lucky with, we [psychology] just don't do any language whatsoever, so that takes away a huge chunk. I'm left with people who are, you know, who have gone to school for years to study that, so it's perfect.*

*P3-Um, so involved with evaluating the extent to which the remaining brain domains are affected and the severity of the effect.*

*P3-And, um, in some cases, rendering the diagnosis. Depending on if the physician is there or not and if the physician feels comfortable or not. Or, depending on the diagnosis, so um, or depending on the person.*

*P4-right. so we need that. So it's really helpful for me if I've got parents or previous caregivers or system support that has that documentation in place. Um, you know, previous report cards and, uh, a general history. Even birth records and growth charts, things like that. Those are all really, really important.*

*P4-So, any previous involvements that would help us further understand each domain. So, if there was [language program] involved, if there was an initial OT assessment, if there was, um, yeah, medical concerns documented. Previous^ yeah, and any psych reports, obviously, behavioral concerns. Plan of cares, mhm. Pretty much anything. And some of our^ like speech and language, they like to look at report cards, like every single one of them through the entire spec^ like the span of the life, like the child's. So, so that's really important. I've said developmental history, so that incorporates the social, family^*

### **Canadian DX system**

*P1-And, and really without the team, it's very difficult to make a diagnosis, a true, well thought out diagnosis, that follows true Canadian diagnostic guidelines, you really need the team.*

*P1-The Canadian guidelines are very useful, so I'd say, you know, make sure you read those and I'd say follow the Canadian guidelines, which are um very clear, very helpful, uh, in comparison to the Washington manual, the four-digit code. The Canadian guidelines takes that in, and just puts in in a slightly different format. That's what people across Canada are using.*

*P1-Um, so there was a little bit of confusion at the beginning, around that but I think, [unclear], we're just using the Canadian guidelines since this is Canada and we have these guidelines. So I think those would be important to have read and sortof internalized.*

*P3- ^ we use the Canadian guidelines, but embedded in that is a 4-point code. So we come together to, um, put ratings on things and come up with the diagnosis that most fits*

### **Assessment appointments**

*C-Mostly, just getting him to the appointments*

*P1-And then I have seen kids, um, I see them in my office initially for, uh, the same kind of thing I would do for any neurodevelopmental consultation but with a view towards determining whether or not there was an FASD diagnosis or not.*

*C-At least an hour for everyone. Some, some were an hour and a half or two hours.*

*C- Answer questions about his development.*

*P4-It's It's uh getting, getting to the appointments, but also filling out various tests, measures and scores, right? You get asked a lot of questions. you have to re-tell your history, you know, a number of times, even though we're really cognizant of that, but there's still some duplication.*

*P1- Um, this way it's all done in a month. So that's very efficient for the families, they kinda remember what we're doing and we all remember what it is that we're doing and we get a snapshot of the child at the same time as opposed to me seeing them now and then, you know, next spring they get an assessment And then, we try to get everybody back together. It's just very difficult to coordinate and I think it's very difficult to families to kindof follow along what the process is.*

*P2-and there are a lot of appointments. Like, to see the psychologist alone, there's three or four, right? So, 'cause it's a lot of testing. Um, then they still have to see speech and language at least once. Um, OT at least once and the pediatrician once or twice.*

*P2-yeah, I'd say about six [visits] would be the average. It usually is like a month, or you know, sometimes we have a bit more leeway, like six weeks. It really depends, um, on the professional's schedule, the, you know parent or caregiver's availability with the youth and things like that.*

*P3- So, I work mainly with teens. I think they're scared, first of all, because they don't want to be^ feel stupid. Is that they're worried they're going to come out on the other end, being labelled "stupid", of course not that you were feeling that way or whatever, that's the exact word that they use. So, ~ um, there's a lot^ there's some anxiety around that. So sometimes getting them in, even in the first place, is difficult 'cause they're trying to avoid it a little bit.*

*I-are^ in your opinion, are families usually able to handle this [attending appointments]? P2-they have been. Yeah, they all have, that I've worked with. Um, um, but I'm sure, as a parent myself, that's very challenging to fit all that in in a short amount of time. And, uh, be committed to it. And we can't change our clinic dates, so we have to have it done by the clinic date and um, so, yeah.*

### **Attending Appointments**

*P3-the assessments take a long time and the kids we're seeing are very challenging, so it's not like you can see them for one day, test them for six hours. I mean, these kids have significant attention difficulties.*

*P3-And for some of the kids, like I work with teens who are in the justice system, I mean they're homeless, so they come in they haven't eaten, they haven't slept all night, they've been on the street. Like, I am I really going to do an IQ test on a kid that's, who's coming in like that?*

*P3-So, you have to spend some time making sure they're well rested, you have to get them a meal to make sure they're fed. Um, and that's the nature of my work, generally, because I'm a [sub-specialty within psychology] psychologist. But it does mean that you have to see them more often and, you know, sometimes when they come in they're not in a position to give their best. and so it's not fair to test them under those circumstances, so it does make it a little more complicated.*

*P4-'cause sometimes they [the children] 're testable and sometimes they're not.*

*P2-Um, ~uh, uh parents who have a struggle, uh, getting here or getting to the various appointments. Either in terms of, um, transportation, mobility themselves, or uh funds #to# get here*

*P4-well, simple things like transportation. Simple things, like, um, yeah, if families can't get to all the appointments, it doesn't usually happen*

*P4-Um...uh, I, you know, mom and dad's mental health, as well. Whether they're able to, kindof remember. There's a lot of things, there's a lot of appointments over a very short period of time. I'd have a very hard time keeping it together for my family, so it's a lot. It's a lot of, um, lot of work for families to do in a quick turn around time.~*

*P4-um, so I just think that there's a lot of things for families to remember. They have to go to four different places. Right? To get^ they have to^ they have to come here. Sometimes I'll go to their homes if needed, we definitely try to do that. The clinicians do go to the school, if that's possible. You know? But they also have to go to [agency] if that's where the psychologist is [agency] where our OT was, we don't have him anymore*

*P4-[agency] and you have to pay for parking there and it's very busy and, you know, there's a lot of people, a lot of congestion. So I think that, that might be seen as a barrier, but there^ it's, once you're in the building, it's so very warm and welcoming*

*P4-so, any any other barriers? I can't^ money for gas, and you know, that kind of thing, to get people. For sure I've come across that.*

*C-The only reason I needed a cab was that I wasn't sure where I was going. So, and, that would have added time, because, you know, you don't know where to get off the bus and , you know, stuff like that.*

*C-I think I was able to get a cab to some of the appointments and different things like that.*

*C-.....well, being able to take a cab to one appointment was helpful.*

*P2-Um, you know, on a few occasions, and it's uh, you know, we've been creative in assisting families [with transportation]. But it's not something that's part of the budget.*

*P3-Uh, well so the clinic coordinator [name] um, does a lot of calling to help facilitate things, uh, for some of my kids, the teens that are in the justice system, you can engage*

*some community services. Like, [community agency] to dri^ to help drive them and that kind of thing, so um that's helpful, um, sometimes getting [coordinator] organizing to get them money through their agency for, um, cabs or busses. We've paid for a cab before when a family just couldn't get here.*

### **Prenatal alcohol use history**

*C-Some things were difficult because I didn't know...um...um...well the prenatal kind of stuff I didn't know about all that. Because the mother doesn't really, didn't stay in touch during the pregnancy*

*P1-I think um...~one of the hard parts of this particular diagnosis is that you really need a parent, the mother, to be able to give a history. And typically, we have not had that person, sometimes we have and that's very helpful, and they have been very honest, but often we don't.*

*P1- sometimes you just can't get that history of alcohol exposure.*

*P1-you can make a diagnosis only in a very small subset of kids with FASD, if there is no confirmed alcohol.*

*P1- Uh, you know I think there's a lot of, there's lot of things caught up with admitting that there was alcohol exposure prior to birth. So, I think people don't come forward because they don't think about it, they don't know that alcohol would affect the child, they don't^ they know it, but they don't want to address it, they just^ whether they're just suppressing the idea or they're actively avoiding it, uh.*

*I-Ok. Uh, in your experience and opinion, what factors disrupt the diagnostic process?*

*P2-Um, well, definitely if the assessment begins, um, and there isn't confirmation first, of use.*

*I-so, when there's no confirmation of alcohol use in pregnancy, what has typically happened in that kind of scenario?*

*P2-well, we don't get a diagnosis and that's, you know, it's a lot of work that another youth could have benefitted from, when, you know, we'd start and assessment without that confirmation of^. And that only happened once; it was the very first case. And it was a good learning curve for the clinic. And we thought we had it, but didn't actually, weren't able to physically verify it.*

*P4- And they don't really wanna readily admit that they've consumed alcohol or drugs, and most often in combination.*

*P4- And then they also don't wanna tell on other people who've done that [consumed alcohol during pregnancy] either, because they feel, uh, I mean I have one circumstance where a family member was the one who indicated "yes, I've seen her drunk many times and throughout the pregnancy" whatever whatever, and then she went "am I the only person that gave you that information? Because now I'm really feeling like maybe I didn't see it as much as thought and maybe" you know? "Maybe it's not this fetal*

*alcohol spectrum, maybe if I just kept my mouth shut some of these other things just would have gone away?" you know?*

*P4-So she was just kind of owning this whole diagnosis. The behaviour of~ the biological mom. So she was totally owning it and it was, you know, it was difficult to reframe that for her and make her understand or help her understand that, you know, what's done is done and there's no blame associated and there's no, there's no, there's no positive to be gained from that. It's about moving forward and supporting this little guy the way he needs to be supported. And you can't do that if you, you know, avoid the obvious and dance around it.*

*C-and I, uh, approached the mom directly too, and asked, you know, for confirmation directly. She confirmed that she, you know, had drank until she was 3 or 4 months pregnant*

*I-Ok great. Um, in your experience, uh, what factors facilitate the diagnostic process? in the clinic.*

*P2-well, definitely confirmation of uh, uh, use of alcohol during pregnancy*

*P4-previous reports, previous involvement. And um sometimes that clear history. Obviously, we need, um, documentation confirming prenatal exposure.*

*C-Uh, because were involved with the CAS [Children's Aid Society] and it [prenatal alcohol use] was a matter of court records.*

*P1-so we're kindof relying on grandparents, adoptive parents and so on, to tell what they think happened and have to go get information from the CAS and so on. So that bit can be difficult, but it's not their fault, they're doing the best they can.*

### **Clinic day**

*P1- Um, I think the comprehensive assessments that people have done and the opportunity to sit down and discuss it has been very helpful in both understanding the child and how their problems are manifest and also making the diagnosis or not.*

*P1-And then I participate in the uh, feedback and conference session where all the team members get together, we discuss the various findings, we determine whether there is an FASD diagnosis or not*

*P1-Uh, I'm also involved with some before-and-after discussion back and forth primarily with our service coordinator [name] as to what's needed and what we can use. And, sometimes, but less commonly, with the other professionals that are doing assessments. Generally, we discuss that on the day, of clinic^ what we call the "clinic day" the sortof conference/discussion time and feedback.*

*P1- So this way it's all coordinated, there's an opportunity to sit down and discuss it, with a particular view to making the diagnosis.*

*P3-Um, well I think clinic day works really well. Having that all done on one day is good. I think, um, that all the professionals work together, like are pretty open to working together, is good. I think, um, hmm, I from a nuts and bolts, like the basics, work fine. I think. I don't think we've had any slips, really, yeah I think it's^ it's pretty well, yeah.*

### **The Moment of Truth: Delivering the Diagnosis**

#### **Feedback**

*P1-And then [after clinicians arrive at a diagnosis] we provide some feedback to the family.*

*P1-Uh, so that^ we we provide reports. So all the clinicians that see the child provide reports and then there is a summary diagnostic letter that says if they have FASD or not. And all of that goes as a package to the family. And, um, in addition, some information about FASD or whatever else they might have. Uh, and then there are recommendations for treatment for whatever we identify as the problem.*

*P2-We also had to, as a team, we had to strategize: ok well who is the best person to help the family do this? Because they did ask for some help around that. So, um, you know, deciding well who has had the longest relationship with the family? And who, you know, has a positive relationship with the family? And things like that.*

*P2- usually we like to give feedback on the day of the clinic feedback day to both the youth and the ch^ but that didn't happen [in a specific circumstance discussed], we had to strategize around that. So it took a bit more, yeah.*

*P3- I think from the professionals' standpoint, um, I, for me, it's always^ feedback is always a challenge to figure out the most humane way to deliver really bad news.*

*P3-So, um, I'm used to delivering bad news, so um I'm not really anxious about it. So, um I do parenting capacity, so I'm telling parents all the time that I don't think they can manage, manage it and I'm going to recommend that they don't have their kids and that kind of stuff. I'm accustomed to and I'm accustomed to, yeah, people being really upset. And family dynamics and, so it doesn't make me anxious.*

*P3-What I think I spend a lot of time thinking about is how I'm going to say it to this person in a way that keeps them intact.*

*P3-Um, you know, keeps all their family relationships intact as much as possible and, um, allows them to come to terms with the diagnosis without a lot of anger and frustration and just more acceptance. so I think that is, is the challenge and I spend a lot of time thinking about that.*

*P4-We try not to^ I present the families with a layman's terms of reference, so that they and I can understand some of the lingo+++ that's used++ I'm not sure that, you know,*



*when you go to a [professional's] assessment, I'm not sure that [professionals] are always aware that sometimes the terminology is difficult for families. So I just normalize it across the board and throw myself into the group as well, because^ it's been quite a learning curve for me too, despite of the fact that I'm in this field.*

### **Ethical issues**

*P2-well, in terms of the clients, because these are children and youth, um, sometimes the youth are informed about why they're coming and sometimes they're not. So, um, that's always a challenge in giving, uh, having youth particularly if they are older, give informed consent, if they are younger, assent.*

*P2-But, it's uh, yeah that's challenging, because for the most part, I like, even if they're children and youth, to understand what they're there. so, uh, if we had a youth who, uh, was not aware that he was adopted. #so#, we not only couldn't venture there, but obviously then not speak of, you know, the basic reasons why he was seeing all of us. That was very challenging, I think, for that parent, for the youth. Um, for us. Um, and uh in terms of giving the feedback and diagnosis at the end, um and the ethical obligations that go along with all of that.*

*P2-Um...caregivers~...that's a good question...Mm, I think the only real challenge I had was the case where, um, the youth didn't know why they were here or even that they were adopted.*

*P2-well, we certainly had to be very careful about what we said to the youth and, um, various things like that.*

*P2-So, um, we really felt, ethically, the youth needed to understand the diagnosis and the impact at, you know, his or her level. So, um following up to see that that was beginning to happen and things like that.*

*P3- Like, um, you know the fact that the^ you know a child, especially the kids that I work with, have a right to know their diagnosis. And parents are very, sometimes reluctant to have that passed onto their kid. But, you know, ethically we had a big ethics thing about this at [partnering agency] it's really important, and even for my college, like^ the client has a right to feedback, right? So, um, and if the kids have capacity, they should get it. So, you know, just warming parents up to the fact that, that is an expectation. How it gets done is, you know, we'll coordinate with them, but it's not whether or not it gets done, it's how it gets done instead. And so, talking to them about that early is good*

### **Reports**

*P3-Uh, I think probably people getting the reports out is difficult. It doesn't affect the diagnosis getting made, but it does affect, a little bit, what people can do with that diagnosis. So, I know there's still some outstanding reports that people are having a hard time getting done. That speaks to the^ you know, how busy people and how over and above what they'd normally be doing outside of their mandates. so, um, I think that does have an impact, actually and probably does affect families.*

*P3-So there's^ they get the diagnostic letter as well as some recommendations to jumpstart them, to get them started. Um, and then they're supposed to get a report from each professional, together, like it's all together, like in one package. And then, um the clinic coordinator has a bunch of resources for them in a binder, it's pretty awesome actually. and then she hands the whole thing to them.*

*P3- But she [clinic coordinator] can't really do that [compile reports] until all the professionals have their pieces of the report into # her# so she can compile it. So, I think that's been a bit of a difficulty, I'm not sure what we're going to do about that. But, that is a challenge and that's a predictable challenge, like, you knew right from the beginning that that was going to be probably a problem.*

*P3- now it's figuring out how to motivate people to get it done and how to modify your report so they're not as time-consuming and lengthy, and so I'm working on that right now and I'm going to send out, sortof, a draft to the other psychologists to see what they think about making it quite a bit shorter and maybe that'll help.*

*P3- But, um, it also depends a bit on who's going to be compiling the information. So, in order to lessen the load on psychology, it might make more sense for the physician to pull everything together? Um, and then so, we just give our parts and they take care of it. I'm sortof going down that way, 'cause if you deliver the diagnosis, you need to be pulling everything together from all the professionals and doing the background, and so, I think that's^ it sorts depends a bit on time.*

*I-Are there any aspects of the clinic that you feel could use some improvement?*

*P3-Um, yeah, so getting reports+++ in a timely fashion*

### **Individual Considerations**

*P4-yeah, well, sometimes it's cultural, a number of our families have been Aboriginal. So, we recognize that the way we see groups and the way that they like to be in a group environment is sometimes different. So we're cognizant of that. But it's different for every one of them, too. So, it's just from our perspective, we ask and try to make sure that they are able to voice whatever needs they have*

*P4-yes, and we do offer, um, for [agency] clients, for example, we have an Aboriginal liaison, we have partnership with [aboriginal health agency], so if our families are connected to [aboriginal health agency] then they are more than welcome to participate, they come to clinic day with them. if needed, so we definitely consider that*

*P4-. But one family, for example, got a little bit claustrophobic in closed rooms so we were aware of that as well. Um, seating arrangements; she didn't want to have her back to the door.*

*P4- we had one, you know, one [caregiver] who had significant anxiety and mental health issues, so the whole day was, was very difficult for her. Um, and so, we took breaks when needed. You know, we just try to make it as^ a very uncomfortable situation as comfortable as possible.*

## Followup

*P1--now, the idea was that that would go back to the referring agency, so let's say [agency] refers, then we would refer back to [referring agency] and they would take care of that. To be honest, I am not sure whether that, in fact, has happened.*

*P1-But we don't have a formal followup, the only ones that we do are those where they're young children and we may have deferred a diagnosis Um, then we kinda have them on the list to see them again. assuming that the clinic continues.*

*P1- We have had followup conferences with places like schools, so a psychologist and I will go out to the school and give them the information. Uh, there was one child where there were a few diagnoses at^ at^ kindof on the table, so I had to conference with some other clinicians and the parents to discuss what, in the end, we determined was the diagnosis. So, I worked with the agency that would be taking care of the diagnosis the child had. Um, uh, so there's a limited amount of followup*

*P2- Um, I know that we provided a fair bit of, um, information and suggestions on books and things like that. Both for adoption, explaining adoption, and you know FASD. This you^ this family required more followup because um...this youth was 11 maybe? 12?*

*P3-. Um, she [coordinator]'s also going to be doing some groups. Um, starting some groups, um starting some groups, which will be really good, she's got a couple of students that are gonna help her, um, set up some groups. She's going to do some guest speakers and there's going to be some coordinating, like a concurrent child group to help with, um, childcare, so the parents can make it out and get support from each other, as well as the professionals that will attend each meeting.*

*P4-The other day, for example, in our group we had parents. And I, one of them sent me this email. And parents, we did a, a relaxation exercise and a meditation focus at the end of it, not meditation, mindfulness at the end of it, and everybody, you know all the kids and all the parents and the clinicians and the facilitators all worked and did it together. And this one mom sat in the corner and she just sobbed, just was so, just overwhelmed with the special kids and the fact that we're all there together and we've got these bonds that are pretty, pretty strong, in spite of just meeting people, you know? um, and that sense. so that was, that was kindof overwhelming to me.*

*P1- Um, you know, I think it can work the other way too, sometimes, so we have to be careful and have some means of followup for some of those in which um, they go through a grieving process and that, um, you know often the parents are^ so, that can affect the child, but maybe not in the way we want them to, so you've gotta have some support there to help them through that.*

*P4- Um, I really do think that it does need to go back out to the community and that families do need to be supported by their natural supports and by those that they are most familiar with, so I'm not absolutely sure that that needs to be from me. But I do think that having the group, having parent-teacher meetings, and that kind of ability to follow through and to make sure that families feel like they've got what they need.*

*P4- To help share that information with others, who could then further support, um, I think that's critical. So I think we need^ so, I'm, you know, um, it would be nice to be able to have more time to be able to do that followup, but I am ~ I think that it is a priority, that I'm still doing that.*

*P4-So, just being able to make sure that families are, you know, really well supported.*

*P4-and you do need that followup, you can't just drop them. Because I'm still getting calls from September clinics a year ago, from October.*

*P4- I think we need to be better able to ask the questions and screen both children and parents to make sure that we're adequately supporting kids, even if they don't have a diagnosis. You know? So I think if we got better at it at the little people end, then we would be better positioned to diagnose people later. That it would be more effective, more user friendly, more supportive, more empowering process for all the family members. And it would also be cost effective.*

### **Outcomes: What Happens After the Diagnosis**

#### **Sadness**

*P1- and I think it's, uh you know, it's sad, sometimes when you're telling them that something has happened that we can't go back and fix*

*P4-I find it bittersweet*

*P4-But, you know, I also find myself feeling awful when I say: "it's a good day, we got a diagnosis" like, that means that this little guy has been permanently affected by alcohol. So, that's, feels weird coming out of my mouth*

*P4-Www, well, um, well I I kinda spoke to it a little bit in that it's bittersweet.*

*P4-I think, um, obviously sometimes when you see a little person really struggle, it, uh, can't help but hit ya.*

#### **Positive experience**

*I-could you tell be generally what your experiences were like at the clinic?*

*C-Pretty good.*

*C-Um... Good, like everybody was really helpful*

*P3-Um, yeah, I think uh, generally it's been positive.*

*P2- Um, so, uh, yeah, it's been very positive in that sense.*

#### **Accepting the Diagnosis**

*P3-Um, I think, coming to the end, for the kids, coming to terms of the cause of the diagnosis can be really difficult. Um, especially when^ so, I've had circumstances where, um, the kids know nothing about their birth parent or a story, a very lovely story was told to them about their birth parent who might have died. So, I have one kid whose family told them that the birth mother had died from cancer, but actually she died from alcohol poisoning. He totally idealizes the mother, so, do you disrupt that, you know, attachment. I mean, they have a r^ they have to know, obviously. So, how do you, sortof negotiate around that?*

*P3-So that can be very difficult I think for kids; figuring out how their parents could have done that to them and then explaining that it wasn't a purposeful thing, right? And, and negotiating that with them can be difficult.*

### **Feeling relief**

*C-Um?... uh... I guess in a way, more relief than anything. Because it put a name to some of the behaviours that he^ I think he just, at that point he had just started displaying more of of the behaviours were^ He was kinda slow in some things, but I guess I never really attributed to anything.*

*C-so, when we were going through the process and it was kindof a relief to know that, you know, this is what it is and it's not um^ like, he can't help doing the things that he was doing anyways++.*

*P1- Uh, so, uh, the whole gamut, I think ~it's somewhat surprising, I mean some people are quite relieved to get a diagnosis, other people are quite upset about it, so I think it depends a little bit on how, how the caregivers and the kids themselves take it.*

*P1- And most of the time people are, you know, kinda, relieved, or you're telling them what they knew and then they can go forward.*

### **Diagnosis increases understanding**

*P1-I mean, I think there are others for whom it really does help them understand why they are having so many difficulty. And I think particularly for FASD, that they are not stupid, they're not, uh,^ you know, often these are kids who are seen as disrespectful, defiant, oppositional. And to^ for them to hear that somebody understand that, you know, the problem is that, you know really, they can't do something, it's not that they're being defiant, um, can be very helpful. And that even happens in the office as you kinda move past their anger at everybody as they move towards trying to figure out what they can and can't do.*

*P2-And so, um, trying to uh facilitate and help that caregiver work through all of those issues with their child so that, uh, they could move forward and so that he could have a better understanding of himself.*

*P2-yeah, I mean, I think definitely, because it gives answers for a lot of really, um, difficult behaviour. And, um, you know, these kids know that they repeat things they're*

*not supposed to be doing, um, and not learning, you know, from their mistakes. These kids, you know, over a period of time and repetition of being a difficult kid, not paying attention, not being able to do schoolwork as well.*

*P2-Um, you know, being externalizing, it affects their self-esteem, it affects their, um, you know, how others see them, and their relationships. So, to have a, a, reason for that, um, I think is always, you know, a positive thing. And that they're not to blame and it's not them.*

*P2-That you know, this is an issue that you have, this is what, what^ why we know you have it and now let's work on it. it's not any fault of yours. Or you as a human being, or whatever. you're not a "bad kid."*

*P2-and for families too, I think, it's very puzzling and, uh, I know a couple of the families that I spoke with, the parents, the moms, feel that they haven't done a very good job parenting and what have they done wrong? And, uh, things like that. So this helps them, it gives them some answers, too. And frees up any kind of blame for themselves or their child. so I think that is a huge benefit that is so hard to measure.*

*P3- Yeah, the parents that I have dealt with have been very eager for a diagnosis because they need to understand their kinds and^ and I think they need the system to understand their kids.*

*P3-And I think there's a lot of blame, they feel blamed a lot. For how their kids behave. And yet, they're trying their best and they don't understand why their kid is doing this. But they know it's not their kids' fault, because their kid isn't doing things purposefully. So, it's just an all around confusing, frustrating, feeling judged kind of situation. So, I think a lot of them are very eager for a diagnosis so they can say: look, here is what I'm dealing with. And please help and understand me, rather than judge me.*

*P3-And I think just for the parents' understanding. It's not that they are parenting wrong or that they're terrible parents. Or, you know, especially for adoptive parents who adopt a kid who think it's going to be so easy and wonderful and they've got all the resources they could possibly need and then, nothing's working.*

*P3- I think, um, that to get the diagnosis can be helpful for them to put things into perspective and to understand that they^ they're parenting is going to be taxed and that it's not necessarily poor parenting. that's, that's the issue. So I think that psychologically it can have an impact*

*P4-I find it very helpful and I'm honoured and pleased to be in this role, to be able to shed some light and to help families understand everything a little bit differently and a little bit better.*

*P4-Um, but I think that more than half of the battle is watching adolescents, if they're adolescents and they can really understand what's going on to some degree, um, to watch that that weight go off their shoulders, when they realize I'm not^ I'm not crazy. and I'm not, um, it's not my fault and I'm not a bad person. That this is, you know, this is the way*

*I'm wired, this is me, this is my brain damage that makes it a little bit difficult, but these are my strengths. And this is what I really need to focus on. And this is not my fault.*

*P4-And also, that weight going off the parent's shoulders. In most cases and I think in all cases, because they realize, oh my gosh, I'm not a bad parent. Like, it's not my fault, I'm not a crazy person I'm not, you know, this child does not respond the way my other child did or does not, you know respond the way the rest of the world [tape blip] parents think he should.*

*P4-It's because^ and then when I talk to them [caregivers] about, you know, commonalities across the spectrum, and they go: "Oh~~ that's him, that's him! Oh" you know? And then, or mine does this, but yours does that and, you know, like they can^ it's just that awareness*

*P4- It's something as simple as the dismaturity and the commonality along that, I mean when I say things like: "would you allow your 6 year old to ride his bike and go uptown and not expect that he might loose his money?" so, you can't expect your 12 year old, necessarily, to do that either, so it's up to us to protect them differently, right? and still being cognizant that they are 12. So it's tricky, but it's, it's that awareness. An Awareness of their vulnerabilities and the expectations. And what the behaviour looks like and what it might mean.*

*C-Uh, family life?...maybe somewhat, like maybe I have more patience now. I think I always had a lot of patience and I kindof I guess cut him a lot of slack already, but it really helps to know that he's not being just^ he's not, like he does do things like hit people, and stuff like that at different times. But it's not like he's doing that like 24-7. And, I'm not trying to^ I'm not sure how to describe what I mean.*

### **Diagnosis without intervention helps**

*C-So, I guess it just helps to know*

*P1-Um, and uh, so I think that that can be very helpful and there's certainly literature to support the fact that just knowing that that's the problem can be helpful in and of itself. so that's why it's ok to have the diagnostic clinic without the treatment component.*

*P4- And giving parents that better understanding is more than half the battle. So you don't need the treatment, you do, but the treatment providers are their families, essentially.*

*P4-and like I said, even if there's no other help in the world, but if I know how to treat my child in a way that makes more sense, that's more than half the battle.*

### **No impact for some families**

*P1- So I think just in general with diagnoses, you know, some families are like "yup, you know, thank-you very much, Billy is Billy and, uh, you know, I guess thanks for your advice and we'll do that" and they kinda go and you get the feeling that, you know they*

*were happy they were there and they got a diagnosis, but if you told them there was no diagnosis, they would just take Billy away and carry on with Billy and do the right things just based sort of on their common sense.*

### **Diagnosis benefits families**

*P1- But in general, I'd say it was a positive thing*

*P4-But I know that , given the circumstances, the diagnosis will be helpful.*

*P2- Um, ~yeah, I think it's very impactful for parents, because most of the parents understand the life long impact that, uh, a diagnosis of FASD or somewhere along that spectrum means for them as parents and caregivers of a child or youth. Um, absolutely, this is really only the beginning when they get confirmation of, you know, life long support for these children and youth.*

*P4-that's what I believe. So, yes. Does diagnosis make a difference? Absolutely. I do believe, oh, whole heartedly.*

*I-Ok. Sounds great. Um, may I ask now, what advice do you have for caregivers and families who are going to go through this diagnosis process in the future?*

*C-Um, I guess not to worry about, try not to be so apprehensive, like it's not going to be the end of the world or whatever. Um, like the diagnosis will only help, it won't um, it doesn't diminish your child in any way, or yourself.*

### **Access to services**

*C-Um, I guess both of us at the same time, because I was able to access more, um, respite through [children's agency], so that's like a couple days a month he gets to go there and he enjoys going there. And he usually goes there during the week when there's less children there and that seems to work really well for him. So that's a good thing. And, for me, it's a rest++*

*C-Um, he's got a better sense of patterns [with speech and language therapy] and, I think, she worked on rhymes. And at different points, like sometimes we'll be doing something and he's like "oh! That's a pattern, like this and this and this" right? Or sometimes like I hadn't really noticed it either. I think it's helpful to him, 'cause then he knows like, you do this, then you do this, then you know. It helps him with his getting certain things done.*

*C-yeah, and then the diagnosis also helped me to access more respite services to community living [city]. There's two different places. There's one up, up around [road ] and [road] someplace. I can't remember [unclear] the house. Like I had a time, which I felt was really good. And it was a house where I guess they don't take no more than eight children at a time and more or less the same age group. And the ratio of people, like*



staff, to kid is like three to eight. Which I think is pretty good. So that makes me feel good about, like, him going there. That he'll be safe when he goes there.

C-And then I toured [another agency] and they gave me the ratios there as well and they don't take in like 50 kids and expect two adults to deal with them. It's like ^ it's about the same as the other place, the ratio. So I feel comfortable, like, sending my child there.

C- [three months from time of interview], I expect to be getting more respite. Which will be good, yeah.

C-well, because they have the, the speech and language therapy started. and I think he got a lot more help in the resource.

C-everything that happens will help you in the end, like to access better services for your child.

C-so, I don't know, so I went to a meeting at his new school and I know the one mother she didn't seem like she wanted her child to go there and she was apprehensive. And^ but myself, I really enjoyed the visit because everything happened, like this one child did something that I know my that child does sometimes and the teacher handled it beautifully. There was a couple little incidents and I watched how they handled things and how they interacted with the kids and it was just great++. So now I don't have any worries about him going to school there. So that really helped me going on that visit.

P1- And then, I think, it also allows them access to some, not all, services and financial support. So, in that sense it can be life changing.

P3-it's it's^ that's a bit difficult for me to answer, so I'll only speak to some of the kids that, I think, for some of the kids in the justice system, absolutely. 'cause it opens opportunities for services that they wouldn't normally have, so for example, they can be diverted. Instead of be on probation. Which can help them not be in and out of the justice system. Like, they don't get trapped in the revolving door of the justice system. If they're diverted, so, if they, if they do certain things for a year, their charges are stayed. Which means they don't get a record. an^ so, there are opportunities for that, so that can really change a kid's life, instead of going to jail or whatever, probation.

P3- So, there's that, um, so they can qualify for disability, so some of the, older, like 18, 19 year old kids that I've assessed can get on ODSP [government disability financial assistance] sometimes, if they're really compromised if they've had an FASD assessment.

P3-Um, there, there are some rumblings and in certain counties, community living. will work with FASD people, even though they don't have the IQ deficit that is needed, generally, for community living.

P3-Sometimes an FASD, they're looking more at working more with that group. There's certain programs that are starting, so like [agency] has a special FASD program, so that they have a worker that sees like 4 or 5 kids and really is their external

*brain and will see them every day, if needed. or for a few hours everyday, if needed, so that's pretty good.*

*P3-Sometimes parents will apply for disability funding, which will enable them to get more professionals into their home, so that's good.*

*P3-and, like, monetarily it can have an impact. And then, in terms of services, it can have an impact.*

### **What does the Future Hold? Next Steps and Needs**

#### **Uncertain future of clinic**

*P1- I think the, um, the other thing that makes this situation precarious is that it is funded for [number] months and I'm worried what's going to happen at the end of [number] months. So it's a lot of work and infrastructure if that's the end of it.*

*P4- there's just too many unknowns.*

*P4-and I'm scared. Because I'm really scared that we won't, um, what if we don't get funding for this? What if this pilot project fails? it's not failed. But I mean, what if we don't^ what if we don't get sustainable funding? And have we opened up, ~~-you know, have we put that proverbial carrot in front of a number of people's noses and then unable to follow through?*

*P4-we're just, we're just putting the finishing touches on a website. And how to we make that go live if we don't know it's going to be here beyond that.*

*P4-But, at the same time, how do we not move forward? And get everybody on board and get everybody to know how important this is? And how hard we're working so that if, if we don't get sustainable funding, then maybe we'll have that voice to help us. So, it's kindof like, there's no other choice but to keep moving forward.*

*P4-I'm really really really confident [about clinic future]. But scared every now and then. Like, I can't imaging it not^ I can't imagine us not being successful in one way or another.*

*P4-We're building^ I just got a call from [neighboring city] who want to work with us. Last week, I got a call from [another city] that wants to work with us, as we build more of a regional approach. Yeah, so from [city in the west] right through to [city to the north] now, so proposals are being written now. So there's a lot of work on that end of it that I'm really committed to*

*P4-well, it just. What aspects of the clinic could use some improvement?...um, we just need, we need dedicated funding for dedicated service provision*

#### **Needs for Coordination improvement**

*P2-Mhm. Um, I think there could be better coordination between the professionals who are the assessors.*

*P2-Um, in terms of, I mean, there's overlap between what the pediatrician does, what the psychologist does, speech and language, and OT. So, um, coordinating who's going to give the Connors, for example. Right? 'cause the pediatrician did once, I did one, you know? Like^ you don't want to be giving the same measure too.*

*P1- I think at this point we don't quite have it set up so that the families all know exactly what's going to happen over a period of time and that has to do because^ all the different clinicians. But, so there's a bit to work out there.*

*P1-They [families] don't, they don't know what's coming up, they, they, I know that there's a conference coming up that the family here doesn't know that somehow, so I'm not quite sure why. So, on the one hand, you^ they all make it through and they get to all the appointments, so that's a very very helpful, on the other hand I have the odd moment, where I have a date and they don't and I don't know why they don't.*

### **Need comfort measures for caregivers**

*C-I only wish I had a nice couch to sit on while I was waiting. And maybe a cup of coffee and a donut, that's about it++++*

### **Need more research about FASD**

*P1- I guess, my goal would be to tie it to some kind of research based treatment. because there's very little in the literature about treat^ effective treatment. And what there is is~uh very narrow. So, it's about how to teach math, you know. But the parents want to know how to get them to go to sleep at night, or stop running around the house, or stealing things.*

*P1-So I think that sortof, broader, earlier intervention^ that works. To show that it works would help. And we have, in [city], lots of programs that potentially could, we just need to evaluate whether they work for kids with FASD or not and, and/or perhaps which groups of FASD kids, 'cause they're not all the same.*

*P2- Quality of life would be a very interesting thing to do prior to a diagnosis, and then, you know, a few years later, when it's all settled in, or even six months, to see, you know, is their quality of life any better in terms of how they see themselves? How they see their family? How they see their, um, parenting? Um, their relationships with, you know, within the family, marriage, and things like that?*

### **FASD service needs**

*P1-Um, and I think it[the clinic]'s really a needed service and if you compare us to the provinces out west we're way way behind.*

*P2- Um and, uh, the other thing would be, and this isn't a problem with the clinic, per se, there's still not a lot available out there in the community to assist families. Um and so, you know, you can give the diagnosis and, um, give general ideas of support within the school or managing the youth at home, but um, you know, some actual financial support for some of these families and, uh, other supports in terms of education and things like that, um, isn't available.*

*P2-And you kindof feel: "mm, I've given you this diagnosis and there's not that much added support out there for you." Unfortunately, but that often comes after. You know, you need to be able to show that there's a population of families that need something before ministry or government is going to fund anything. So, hopefully the clinic itself, the diagnostic clinic will help it, uh, help facilitate that*

*P3- the services are few and far between, so it's the lucky ones that can get into that. But I think it's changing. FASD's becoming^ people are more aware of it. There's more, sortof, money going into; people are starting to understand it better. And so I think the services will increase, sortof like autism, right? where it started off slow, people started advocating, advocating and now it's, like, so well funded.*

*P4-and~ again, I think that community agencies and support staff are better positioned than they even are aware to provide better services that are FASD specific. I think everybody feels that we have no options for kids with FASD, but I believe we do. Because^. I believe there is a lack of confidence in our own abilities um and a lack of, it seems to be in this point in time, nobody's job to work with FASD.*

*P4-well, I believe that even though we are not where we need to be in terms of direct FASD support, as I mentioned earlier, I believe we're better equipped than we think, I believe that we can build it relatively easily if we dedicated some time and effort and training and support for that, for that.*

*P4-t's because it's not solely mental health and it's not solely medical and it is, you know, there's learning disabilities; it's a developmental disability. But, sometimes their IQ is so high that they don't necessarily meet that criteria. so, it seems like it's nobody's job, but essentially it's all of our job. Like, they're all of our kids. And we see them regardless, because they make themselves seen.*

*P4-+So, so to just keep pushing it off for families and say we can't provide them the support. Yes you can, you can help.*

*P4-There's a ton of strategies online, there's a ton of really, really, really good resources that you could take the time to read and understand and learn what we as social workers or health care providers always look at best practices, whenever we've got a new^ and we can read and share it and continue to practice it and get better at it.*

*P4-And there are people out there who are familiar with FASD and as I said to you I've probably worked with a 100 kids [with FASD, as discussed prior to interview], have I done everything right with all those 100 kids? Have I had misunderstandings? And unrealistic expectations? Absolutely! But, we're getting better at that now. And if we're*

*better able to see them through the prenatal exposure to alcohol lens, so to speak, then I think that administration can incorporate FASD into some of these things. Because it's part of our, I think it's part of our mandate ++ to help kids, regardless.*

*P4-Are we where we should be in terms of school support and meeting the needs in a way that that makes the most sense? No. Do we have a lot of work to do to facilitate that understanding and commitment from schools and other ag^ you know, yes. But, we won't get there without diagnosis either*

### **Need for Parenting Supports**

*P4- and there's still, like FASD and parenting a child with FASD in most scenarios it cuts against the grain of every typical parenting st^ you know when you aim towards cause and effect, and learn from your mistakes, and consequences and rewards, and shaping behaviours based on your parenting style, that doesn't happen.*

*P4-And there are so many things that are out of your control and out of that child's control and so you have to do things in a way that, that's different.~but, you know ++ every instinctual parenting++ strategy++ is is something you kind of have to do sometimes differently. Not every one, that's kind of not fair to say, but you know.*

*P4- Of what we typically^ and to focus on independence, for example. Of course we want all of our children to learn to be independent, but sometimes kids can't be and we need to focus more on interdependence. and um, semi-supportive environments, rather than complete independence and setting our kids up to fail. The expectations have to be different and that reduces the likelihood of compounded issues and secondary disabilities.*

### **FASD in adulthood**

*P4-And to realize that our adult mental health population is^ has a high percentage of people who are not diagnosed and those people who just make you angry and never who up to appointments are not lazy.*

*P4-Those people who just, you kinda go, really? You know, they just don't fit and don't make sense. And just keep making silly mistakes and not, they're not malicious in most cases, but just "you stole money from where?"+++ why??++ you know? Yeah, yeah and you kinda have to stop and wonder.*

*P3-But I have interviewed in my parenting capacity role, a lot of grandparents whose kids I think may have FASD, whose kids I'm assessing++ yeah, and so you know, the parents are really not doing well, and I don't think I'm going to be able to recommend the kids to go home or whatever. But, I wonder if the parent has an FASD, so I'm talking to the grandparent and I ask them*

### **Educating others about FASD**

*C-I guess my problem now is just trying to educate the rest of my family I try to describe as best I can, to tell them about his, you know about, he's^ he's not doing this on purpose.*

*C-And...I guess, like, certain of his cousins he doesn't get along with too well. Mostly the older ones, but the younger ones he gets along with well. Because they're probably at the same mental age. And the older ones get impatient because he's not where they're at. ++ kindof thing.*

*P1-Um, the uh, one thing the clinic could do more of is go out and educate people, so educate other clinicians, families, that's very^ I think that might help with some of the referral patterns and so on.*

*P4-Maybe, maybe opportunities to go into the school and do a little bit more training at each school, so that people know. Like, we don't have that kind of time right now.*

*P4- I can't even get over how many people who I would assume would know better do not understand the risks involved with drinking alcohol and what, what it looks like. They don't have a clue. So that, that, that frustrates me. But yet, you have to be careful to say things in a way that makes people wanna still listen+++*

*P4-Yeah. And I've had so many times a mom come to me and say " could you please speak to the father? 'cause he doesn't understand and he thinks that I'm coddling him, he thinks I'm protecting him , he thinks that I'm not kicking him not kicking him in the butt enough" that you know^yes, mhm and step-parents, versus, whatever and there's all kinds of different^*

*P4- So, I^ that's kind, you know, of the whole proposal and our our thrust towards the regional perspective is big focus on training at the gate-keeping level. So that's daycares, schools, and medical providers, because they're the ones that see the behaviours. So if we had that, those individuals kindof flagged a little bit, at least we could, we could move our services, you know, through that lens, even without a diagnosis. And then move forward that way.*

*P4- But keep plugging away and keep doing the advocacy work, because we're not going to move forward without it*

*\*text in [square brackets] indicates a text replacement made for confidentiality, clarification of acronyms, clarification of an unclear pronoun, or provision of context gleaned from a previous meaning unit.*

*\*\*transcription characters: "+" indicates laughter, "^" indicates self-interruption, "... " indicates a long pause, "#" indicates overlapping speech, and "~" indicates a sigh.*

# ERICA R. LUNDBERG

## CURRICULUM VITAE

### Education

**Western University** September 2012-April, 2014  
Master of Arts (Counselling Psychology)

**Western University** September, 2004-April, 2009  
Bachelor of Arts (Honors Specialization in Psychology, Certificate in Writing)

### Academic Awards

**Ontario Graduate Scholarship** 2012-2013, 2013-2014  
Administered by the Ontario Ministry of Training, Colleges, and Universities

**Millennium Award of Excellence Scholarship** 2007  
Administered by the Millennium Foundation

**Western Scholarship of Excellence** 2005  
Administered by Western University

### Presentations (selected)

**Combining Supported Post-Secondary Education with Supported Employment for College Students who have Mental Illness: An Exploratory Study.** Rudnick, A., Wedlake, M., Lau, W., McEwan, R., Lundberg, E. Department of Psychiatry Research Day, Western University. June, 2010

**Attitudes towards the sexuality and relationships of persons with intellectual disabilities.** Lundberg, E. Ontario Psychology Undergraduate Thesis Conference, Hamilton, Ontario May, 2009

### Major Papers (selected)

**Therapeutic horseback riding for ACT clients with schizophrenia or schizoaffective disorder: a qualitative exploratory study.** Corring, D. J., Lundberg, E., Rudnick, A. (2013). *Community Mental Health Journal*, 49(1), 121-126.

**Neuroimaging Self- Esteem, an fMRI study of individual differences in women.** Frewen, P. A., Lundberg, E. Theberge, J., Brimson-Theberge, M. (2012, online ahead of print). *Social Cognitive and Affective Neuroscience*.

**Visual-Verbal Self/Other-Referential Processing Task: Direct versus Indirect Assessment, Valence, and Experiential Correlates.** Frewen, P. A., & Lundberg, E. (2012). *Personality and Individual Differences*, 52(2), 509-514.

**A conceptual analysis and selective review of the stress-vulnerability model of schizophrenia.** Rudnick, A. & Lundberg, E. (2012). *Current Psychiatry Reviews*, 8(4), 337-341

**Letting Go: Mindful Breath Attention, State versus Trait Mindfulness, and Depressive Cognition.** Frewen, P. A., Lundberg, E., Mackinley, J. D., & Wrath, A. (2011). *Mindfulness*, 2, 254-269.

**Attitudes towards the sexuality and relationships of persons with intellectual disabilities.**  
Undergraduate Thesis, Western University April, 2009

## **Clinical Experience (Selected)**

<b>Psychological Services Intern</b> Thames Valley District School Board	December, 2013-June 2014
<b>Research Assistant/Assessor</b> Drs. Paul Frewen & Ruth Lanius	September, 2009-present
<b>Research Assistant/Interviewer</b> Dr. Deb Corring	June, 2009-December, 2011
<b>Research Assistant/Assessor</b> Dr. Abraham Rudnick	September 2008-September, 2011
<b>Call Volunteer</b> London and District Distress Centre	September, 2007-August, 2009
<b>Family Support Worker</b> V.O.N Middlesex-Elgin	June 2003-August 2009