

Advocating against the Tide
Child welfare social workers responding to cases of
Fetal Alcohol Spectrum Disorder(s) in Ireland: A Grounded Theory study

William C. Curran

A Thesis
In
The Individualised Program

Presented in Partial fulfilment of the Requirements
for the degree of
Doctor of Philosophy (Individualised Programme in Social Science) at
Concordia University
Montreal, Quebec, Canada

March 2020

@William C. Curran, 2020

CONCORDIA UNIVERSITY
SCHOOL OF GRADUATE STUDIES

This is to certify that the thesis prepared

By: William Curran

Entitled: Child welfare social workers responding to cases of Fetal Alcohol
Spectrum Disorder(s) in Ireland: A Grounded theory study

and submitted in partial fulfillment of the requirements for the degree of

Doctor Of Philosophy (Individualized Program (INDI))

complies with the regulations of the University and meets the accepted standards with respect to
originality and quality.

Signed by the final examining committee:

_____ Chair
Dr. Charles Reiss

_____ External Examiner
Dr. Kristy Durkin

_____ External to Program
Dr. Catherine Richardson

_____ Examiner
Dr. Patti Ranahan

_____ Examiner
Dr. Varda Mann-Feder

_____ Thesis Supervisor
Dr. Elizabeth Fast

Approved by

_____ Dr. Rachel Berger, Graduate Program Director

March 20, 2020

_____ Dr. Effrosyni Diamantoudi, Dean
School of Graduate Studies

Abstract

Child welfare social workers responding to cases of Fetal Alcohol Spectrum Disorder(s) in Ireland: A Grounded Theory study

Liam Curran, Ph.D.
Concordia University, 2020

In the early 1970s, clinical evidence emerged documenting the first direct causal links between prenatal alcohol exposure and children's behaviors observed in child welfare services. Subsequently, the term Fetal Alcohol Spectrum Disorder(s) (FASDs) was introduced to encompass the range of possible diagnoses associated with prenatal alcohol exposure. Although forty years have passed, FASDs remains in the margins of public health priorities. It is considered a widespread problem and is increasingly recognized across countries as a fiscal and social burden on society. A plethora of research exists documenting the direct effect of prenatal alcohol exposure on physical, cognitive and behavioral outcomes. However, few studies focus on the critical interface of children entering public care with an FASD, and the statutory requirement of Child Welfare Social Workers (CWSWs) to plan safe care. Applying a Constructivist Grounded Theory methodology, this doctoral research sought to document the voices of CWSWs about the manner in which they respond with this vulnerable cohort of children using methodology based on constructivist grounded theory. Eleven CWSWs, five allied health professionals and three foster parents comprised the study sample (n=18) and participated in in-depth interviews. Findings indicate that social workers are struggling in their mandated statutory duty to offer plans of safe care for children with a FASD. Specific concepts in the data included struggling advocacy, professional positioning and lack of procedural guidance. CWSWs are in urgent need of a clear pathway and FASD informed knowledge to help guide their interventions and their capacity to advocate for this vulnerable population of children.

Keywords: CWSWs, constructivist grounded theory, statutory duty, FASDs, child welfare service.

Acknowledgements

I offer an immense gratitude to everyone who made this study possible, many of whom cannot be identified for reasons of confidentiality. These are the interviewees who gave generously of their time and honestly shared their experiences of FASDs in their practice and caring duties. This study could not have succeeded without such contributions. I am genuinely grateful to each one of the 18 for their support and their desire to improve the system of care for those living with this lifelong disability.

I am a farmer's son from rural Ireland and the dream of completing a Ph.D. one day was very much just a dream – but dreams do materialize, and here I sit writing this acknowledgement.

Many people have contributed to this work, some of whom I never even met. I first want to thank Concordia University for accepting this research proposal in 2015 and then granting me fellowship funding. People behind these early decisions whom I never met reviewed my proposal and placed faith in me to address a need in society. My grateful appreciation to the Individualised Programme (INDI) of Concordia University, which throughout the journey provided additional funding to attend conferences and funding to support the data collection phase in Ireland. Without such financial and professional support, the journey may have ended before the final stage.

My supervisor, Dr. Elisabeth Fast, stood by me, even in times when I did not want to stand by myself. Her calm, thoughtful and astute critique guided me through more than one meltdown. If I didn't always show it, I was, I am, and always will be truly grateful for her guidance on this journey – *Merci!*

The support of my supervising committee members was crucial to the success of this study. Dr. Patti Ranahan's guidance on methodology was invaluable in the early days of this

study. I'm grateful for the numerous guest lecturing opportunities in her youth mental health worker studies program. Thank you also to Dr. Varda Mann-Feder -- her expertise and knowledge of child and youth work needs were evident throughout. Her motivational tips were heart-warming and showed that she understood this research was needed for both maternal and child health. I would also like to acknowledge Dr. Roisin O'Connor of the Psychology Department of Concordia University and Dr. Tonino Esposito of Université de Montréal for their invaluable guidance in preparation for my comprehensive examination.

The Center for Research on Children and Families (CRCF), McGill University, invited me to become a member and offered me a workspace within a vibrant research family. The center helped promote my research to a broader audience. My colleagues at CRCF and In the Qualitative Data Analysis Group QDAG who supplied friendship, support and happiness that filled many lonely voids. Dr Mohammed Khan was an inspiration -- a friend and confidant who picked me up when I fell down. Dr. Gina Glidden who also supported me at times of great need.

The social workers in Ireland who responded to my call for research participants deserve special mention. Discussing FASDs in the Irish culture of alcohol dominance is not easy. Their courage was admirable in speaking about what some might suggest is unspeakable.

The management team at Tusla, the state child and family agency, displayed foresight and fortitude within the aforementioned culture to validate my research. The hard-working Irish foster parents have my admiration and thanks. Also, I'm very grateful to the allied health professionals within different disciplines who helped in bring me to saturation in the study.

My family in Ireland helped me make some invaluable contacts possible during data collection. To my mum -- who in her eighty-fifth year still gets the most of life -- I am most grateful.

Dedication

This work is dedicated to my wonderful life partner Saud. without whom this thesis would likely never have made it to final manuscript. You were kind, gentle and found the right words to keep me in focus. Having gone before me on the lonely academic journey of medicine and then Ph.D., he shared a wealth of academic insight at times of doubt. Without his love and constant support, I would not have survived the many trials and tribulations that erupted over the past four years. Furthermore, his superior academic knowledge and skills were an invaluable guiding force, shared as they were over the journey of this study.

Finally, I dedicate this work to children and young people living with Fetal Alcohol Spectrum Disorder. Eamonn is a fourteen-year-old whom I talked to at length alongside his foster parent. I came to sympathize with his plight -- and that of his caregivers. His constant struggles with school where a lack of knowledge on FASD fails to give allowances for his neurocognitive difficulties. Also, his sensory difficulties, both at home and at school, all make for challenging days for both him and his foster parents. The vicissitude and burdens inflicted on Eamonn and other children before they were born is immense and lifelong. This work was motivated by Eamonn, with a hope that you will be seen more clearly within our system of care and education

Table of Contents

List of Figures	x
List of Tables	xi
Glossary of Terms	xii
Chapter 1: Introduction.....	1
FASD – What is it?	1
Research Questions.....	7
The Irish Context.....	8
The Impact of FASDs on Child Welfare Services.....	11
Child Welfare Adopting A Subservient Role?.....	15
The Role of Social Work with FASDs.....	17
Conclusion	22
Purpose of the Study.....	23
Researcher Identity Memo.....	24
Chapter 2: Literature Review.....	31
Introduction.....	31
Prenatal Alcohol Exposure: The Historical Context	33
Alcohol in Pregnancy.....	38
Alcohol in the Irish Cultural Context.....	41
The Current Picture of FASDs	44
FASDs and Child Development.....	48
Current Developments in Child Welfare Services.....	52
Exemplary Models.....	58
The Diagnostic Quandary - Ethical Challenges.....	60
Prevalence of FASDs in Child Welfare.....	67
Quantifying Prevalence	72
Chapter 3: Methodology.....	76
Introduction.....	76
Theoretical Foundations.....	78
Ontology	79
Epistemology	79
Symbolic Interactionism Theory	80
Grounded Theory	81

The rationale for the application of Constructivist Grounded Theory method	86
Research Question	88
Research Procedure	88
Ethical Approval(s).....	88
Ethical Approval Process	89
Informed Consent.....	89
Distress Protocol.....	91
Participant Recruitment.....	91
Specific Recruitment	92
Summary of Criteria for Social Workers:.....	93
Summary of Criteria for Foster Parents:	94
Summary of Criteria for Allied Health Professionals:	94
Data Collection - Interviews.	94
Data Collection Methods	95
Constant Comparative.....	97
Simultaneous Collection and Analysis of Data	98
Memoing.....	98
Memoing Within the Process.....	100
Transcription.....	101
Computer-Assisted Data Analysis (CADA).....	101
• Interactive Visualizations and Analytics	103
• Open Import/Export Migration	103
• Secure and Integrated	103
• 24/7/365 web-based access to tutorials, user guide, and other digital supports.....	103
Data Analysis.....	103
Initial Coding.....	104
Figure 3. <i>Example of Initial Coding</i>	107
Theoretical sampling	107
Document Analysis	108
Saturation	109
Trustworthiness.....	110
Chapter 4: Findings	112
Introduction.....	112

Professional Positioning	116
Intellectual Haze	126
Broaching Difficult Conversations	138
Disabling the Enabler	148
Introduction	162
Operating Within Culture of Denial	169
Knowledge Translation	171
Implications for Child Welfare Practice	178
5-Step neurodevelopmental screening	194
Intervention	200
Policy Implications	202
<i>Conclusion</i>	<i>214</i>
<i>References</i>	<i>217</i>
<i>APPENDICIES</i>	<i>261</i>
Appendix A: Recruitment Flyer	261
Appendix B: Ethics approval Phase 1 (site)	262
Appendix C; Ethics Approval Phase 2 (site)	263
Appendix D; Ethics approval Phase 1 (University)	264
Appendix E: Ethics approval Phase 2 (University)	265
Appendix F: Site Access Approval	266
Appendix K: Transcription Agreement	270
Appendix J: Interview Guide	272
Appendix H: List of resources give to participants	275
Appendix G: Access Approval to foster parents (Phase 2)	276
Appendix M: A sample of personal reflection	277
Appendix N: A Sample of Memoing – “Not Once”	278
Appendix O: Screen Shot dedoose software	280

List of Figures

- Figure 1.** The many crossroads when adopting a grounded theory methodology P. 76
- Figure 2.** An overview of the sequential steps taken during the application
of constructivist grounded theory and analysis of data P.80
- Figure 3.** Sub-Categories and Core Category as constructed within this study P.98
- Figure. 4** Factors creating the Tide -- Over Researched, Diagnostic Medical
Model, Social Media and Advocacy Dominance is squeezing the role of CWSWs. P.142
- Figure 5.** Recommended: 5-Step Neurodevelopment Screening process to aid pathway
development within child welfare services P. 171

List of Tables

Table 1. All substances impacting the unborn	P.34
Table 2. Codes to pseudonym name.	P.90
Table 3. Overview of divergent views in grounded theory	P.79

Glossary of Terms

AHP	Allied Health Professional
CWSW	Child Welfare Social Workers
CPD	Continuing Professional Development
FASDs	Fetal Alcohol Spectrum Disorder's (Plural)
An FASD	Singular – where an individual is living with a specific diagnosis or suspected of having an FASD within the Spectrum of FASDs
FCIRL	Foster Carer Ireland
SWIRL	Social Worker Ireland
HSE	Health Service Executive
ICD -9	International classification of Diseases <i>Ninth Revision</i>
ICD-10	International classification of Diseases Tenth revision

Look Like abbreviations but are not

CORU	The State body responsible for professional registrations of allied health professionals in Ireland
TUSLA	The State body responsible for children and families 0-18 in Ireland. The site of this inquiry

Note on Spelling

Fetal	International medical spelling (used in this study) corresponding with the majority of empirical literature.
Foetal	UK and Commonwealth nations spelling.

Chapter 1: Introduction

Statement of the Problem

In recent years society has seen a plethora of research studies documenting and articulating the impact of Fetal Alcohol Spectrum Disorder(s) (FASDs) on public child welfare services (Popova, Lange, Shield, Burd, and Rehm, 2019). FASD or FASDs terminology has developed significantly over the past five decades. Within this time frame of FASD research, the pivotal role of the child welfare social worker has received little attention. The following is a brief summary of the salient points in that history to present day understanding on FASDs.

FASD – What is it?

FASD is an overarching term that encompasses a range of possible diagnoses associated with an alcohol-exposed pregnancy (Bertrand et. al., 2004). These include fetal alcohol syndrome, partial fetal alcohol syndrome, alcohol-related birth disabilities, alcohol-related neurodevelopmental disorder, and neurobehavioral disorder associated with prenatal alcohol exposure (Turchi and Smith, 2018; Williams and Smith, 2015). Of the multiple interlocking labels for the full range of associated effects relating to an alcohol-exposed pregnancy, fetal alcohol syndrome is by far the most recognized, researched and clinically accepted term following its identification and publication in the *Lancet Journal* back in the early seventies (Jones and Smith, 1973). The clarity of diagnostic procedures related to fetal alcohol syndrome was subsequently incorporated by the World Health Organisation (WHO) in the International ICD-9 WHO (1978) and ICD-10 WHO (2007).

Children with fetal alcohol syndrome experience weak growth deficiencies, as they often fall below the 10th percentile for height and weight (Stratton, Howe and Battaglia, 1996). Fetal alcohol syndrome is characterized by microcephaly, facial dysmorphologies such as elongated

palpebral fissures, a smooth philtrum, and a thin upper vermillion (Jones and Smith, 1975; Jones, Smith, Streissguth and Myrianthopoulos, 1974; Jones, Smith, Ulleland and Streissguth, 1973). In 1996 the United States Institute of Medicine (IOM) defined the wider implications of prenatal alcohol exposure as:

1. **Fetal Alcohol Syndrome (FAS)** with confirmed maternal alcohol exposure (As discussed above)

2. **Partial Fetal Alcohol Syndrome (pFAS)** with confirmed maternal alcohol exposure.

This term describes children who have known prenatal alcohol exposure but does not meet the full diagnostic criteria for fetal alcohol syndrome.

3. **Alcohol-Related Neurodevelopment Disorder (ARND)**

This term describes children who have a hidden brain impairment due to alcohol exposure but will likely have no physical attributes. This condition is largely associated with intellectual disability, behavior and learning.

4. **Alcohol-Related Birth Defects (ARBD)**

Confirmed prenatal alcohol exposure with one or more congenital defects and malformation.

Collectively, all possible diagnoses stemming from prenatal alcohol exposure are known under the umbrella term of FASDs, denoting plural of the multiple diagnostic possibilities stemming from prenatal alcohol exposure. Fetal alcohol syndrome is believed to be a fraction of the total FASDs births, with Johnson stating that fetal alcohol syndrome accounts for “between 10% and 30% of all fetal alcohol cases” (Jonsson, 2019, p. 161). This indicates that the level of FASDs within society with no visible features is between 70% and 90% of the total birth rate of those experiencing prenatal alcohol exposure in any given society where alcohol is consumed.

Therefore, FASDs can be contextualized broadly as a range of congenital health conditions with lifelong consequences. Collectively, the range of effects of prenatal alcohol are shown to offer severe detrimental impacts on an individual's ability to navigate life's journey (Cook et. al., 2016). There are no recognized pharmacological treatments for FASDs but early identification of FASD can support a positive outcome for the child (Kable and Mukherjee, 2017; Mukherjee et. al., 2016).

The relationship between FASDs and child welfare and protection services is receiving growing international recognition across various platforms denoting the direct and compelling impact FASDs is having on state systems of child welfare services (Mukherjee, Cook, Norgate, and Price, 2018; Walker, 2014; Wilson, 2013). Walker (2014) makes clear that this burden on child welfare services requires “specialist child protection assessment and planning” (p.9). It was also noted by Turchi and Smith (2018) that:

“Referral to child protective services is required if the child has been diagnosed with an FASD in the period between birth and 3 years. The intent of this referral is to develop safe care and possible treatment plans for the infant and caregiver if needed, not to initiate punitive actions” (p. 5).

Such developments are placing a heavy burden on state systems of child welfare and protection services globally, a development going largely unseen at senior levels of child welfare management (Chasnoff, 2011). It's a burden, described here in the case of sixteen-year-old Tyla, in a recent coroner's report, that has major implications for all concerned with the welfare of children receiving services from public providers. In this report, Tyla, at the time of her death was subject to “18 investigations, 1 application, 1 temporary guardianship order, 7 custody agreements, and 3 support agreements with the guardian prior to her apprehension in 2015” (McLellan, 2018, p. 4). The report further acknowledges that Tyla was not diagnosed but was

suspected of having an FASD. Indeed, an FASD support worker was assigned to her case prior to her premature death. All interventions documented above are significant, costly and time consuming of the CWSW practice in seeking to establish safe care. The financial implications of such will directly fall on the CWS. However, in order to achieve a fluid system of psychosocial interventions all allied health personnel alongside CWSWs need to have education on understanding the psychosocial needs of those living with an FASD (Durkin, 2016; Badry & Choate 2015).

Although compelling evidence denotes the impact of FASDs on CWS structures, such evidence repeatedly fails to discuss the statutory mandated response of child welfare social workers (CWSWs) in responding to such referrals to child protective services. As noted by Durkin (2016) in her study “little is known about social workers working in the child welfare system, particularly those who may be employed as frontline child welfare work” (p.9).

The present study is situated within the Irish state child welfare services, services which are delivered by the Irish state agency Tusla. The site of inquiry is situated within a culture that is at a very embryonic stage of addressing FASDs. Currently, Tusla cares for just over 6,267 children within its fostering and residential care programs (Furey and Canavan, 2019, p.16). The Irish child protection and welfare system operates in a similar model to all western developed countries. Historically, the social needs of children and families were responded to by charity and church organisations. Until the 1990s, the Catholic Church rather than the state had been the main provider of social care. However, the 1990s, saw a declining role of the church while at the same time an increase of social needs within society. The state became increasingly involved in the provision of social care and is now the main employer of social professionals. Today the vast majority of social professions such as social workers, social care workers and youth workers are directly employed by the state (Christie, 2005). With the transference of social professions to

state employment, many of these employees also became instruments of state laws to protect and promote the welfare of those in need. The CWSWs operates under such laws and have an assigned mandate to ensure the safety and welfare of children to age 18.

Child and family social work operates from a premise of prevention and family preservation through early intervention and the provision of supports (Buckley, Carr, and Whelan, 2011). Tusla has over recent times sought to reduce its use of residential care services in favor of more family oriented fostering for the child in out-of-home care (Devaney and Gregor, 2017). CWSWs provide initial assessment and screening in an effort to prevent children from entering the care systems (Leslie et. al., 2005). Given the emerging evidence in the literature of the burden and prevalence of FASDs within child welfare services, sparse evidence exists documenting the experiences of CWSWs responding to FASDs in screening and initial assessment duties. This critical interface between a child with an FASD presenting to child welfare services and the statutory responsibilities of the CWSWs is poorly articulated within the site, a fact demonstrated in evaluations of training offered in the site by me.

CWSWs, when conducting screening and assessment of FASDs, will do so within a statutory and mandated duty to plan safe care for a child. Currently, only one jurisdiction includes FASDs in its child protection and welfare legislation. In its reauthorization of the Child Abuse Prevention and Treatment Act (CAPTA) legislation in 2010, United States federal law included a requirement to Plan Safe Care for a Child with an FASD (CAPTA Reauthorization Act of 2010; P.L. 111-320,106(b)(2)(B)(ii)). Although Ireland does not have any formal legislative requirements for children who were prenatally exposed and have an FASD, (Covney, 2018), the potential for such developments is likely across western child welfare and protection developments in the coming years. Such ‘likely’ developments will be driven by the rising social and monetary implications, factors that will be discussed in the literature of this study. Such

developments in child protection and welfare legislation further highlights the critical need for explicating CWSWs' process in responding to cases of FASD.

Within the collective body of Irish state employees, social work is the primary profession with the responsibility of keeping children safe and promoting their welfare. As evidence continues to document the prevalence of FASDs within child welfare structures, CWSWs are in a pivotal position for responding to cases of FASDs in child welfare services (Lange, Shield, Rehm, and Popova, (2013). Lange et. al., (2018) further noted that Ireland has the third highest birth rate of FASDs in the world. Although Tusla has not measured prevalence rates of FASDs, the site does have well-documented alcohol in pregnancy rates. One study placed the alcohol in pregnancy rate at 82% (O'Keeffe et. al., 2015). It is acknowledged that there are major difficult, methodological and ethical challenges in assessing the prevalence of alcohol use during pregnancy and the incidence of FASDs in any given cultural setting (Lange et. al., 2017). This study will seek to explore such difficulties and challenges of 'cultural settings' which may impact a CWSWs response to FASDs. These challenges resulting in many children living with prenatal alcohol exposure deficits having their needs unrecognised, with many being misdiagnosed in favor of more socially acceptable conditions.

Existing international prevalence of FASDs in child welfare services, Lange et. al, (2013), offering a 16.9% prevalence in Canadian Child Welfare Services, would suggest that CWSWs in the Canadian CWS are encountering cases of FASDs in their interventions. The following excerpt of data from the pilot which was collected in Quebec, Canada suggests the CWSWs are void of a pathway in dealing with cases of FASDs: *"I do have a variety of children for whom I do have concerns in this regard and I have asked the doctor at the clinic what her perceptions were of this and she said 'well ya know you just have to wait and see'" not very helpful at all"* (Phillipe). (02/27/2018).

It was such findings offered in my pilot study that helped to focus my research objectives as the evidence was pointing to CWSW not having any clear guidance in responding to FASDs on their caseload. As Phillippe states, he describes having concerns for children on his caseload, children not carrying any form of diagnosis. However, his concern is somewhat rebuffed leaving him feeling unhelped in his mandated role of ensuring a child's welfare. As previous literature indicates, a majority of children with or suspected of having an FASD will remain undiagnosed or misdiagnosed within child welfare services (Chasnoff, Wells, and King, 2015). This is further unhelpful to the CWSW and indicates the complexity of responding to FASDs within CWS, and such complexity may be a factor of CWS globally. Phillippe is rebuffed, as the medical profession is indicating an unwillingness to address the concern collaboratively while offering a denial of the needs of the child as expressed by Phillippe.

Within the study site, denial of FASDs are may be common place due to cultural denial and lack of services Covney, (2018) and also a cultural lack of awareness on the dangers of alcohol use in pregnancy (Barry et al, 2007). This presents the CWSWs with a difficult challenge in conducting an assessment for a child who may be carrying a disability due to prenatal alcohol exposure. It is a problematic and challenging, given the empirical evidence that traditional interventions and assessment do not work for this vulnerable cohort of children (Pelech, Badry, and Daoust, 2013). There is growing recognition and urgency on the need for more considerable attention to the prevalence rates of FASDs and their impact on child welfare services (Badry and Chote, 2015). The CWSW, as a gatekeeper of the child welfare services, is on the frontline of this growing recognition.

Research Questions

As the current body of research indicates a high prevalence rate of FASDs both diagnosed and undiagnosed within the Irish state child welfare structures, in this qualitative study

I aimed to explicate the process of how CWSWs respond and respond with this particular cohort of children. The main question for research was:

R1: *How do child welfare social workers respond with children who are living with an FASD or who are suspected of having an FASD?*

The Irish Context

At the time I was preparing to enter the field to collect my data, Tusla had 6,329 children in out-of-home care with over 93% in a preferred foster care placement. The number of children in out-of-home care placements fluctuates between 6,300 and 6,400 yearly (Tusla, 2017). The number of children living with an FASD is difficult to estimate since the conditions associated with FASD are not formally recognized in state disability services, policies or documentation. However, some international scholars have pointed to a seriously high rate in Irish society with a suggestion that the birth rate of FASDs in Ireland is 47.5 per 1000 births compared to a global average of 7.7 per 1000 births (Lange, Rehm, and Popova, 2018). Findings concerning the levels of alcohol use in pregnancy would suggest that FASDs are a major hidden public health issue in Ireland. Currently, this is largely an unseen burden on Ireland's child welfare service. A recent publication within Tusla suggested that children's needs associated with prenatal alcohol exposure are not being met as required by United Nations mandates (Coveney, 2018).

What is known and well documented is that parental alcohol use/misuse is a constant feature of Irish child welfare services. For example, Butler (2009) noted that children's needs are not picked up clearly or managed effectively due disjointed efforts and poor collaboration on the issue of parental alcohol use/misuse. Most child welfare focused literature concerning substance abuse and child welfare within Ireland has steered clear of the emotive topic of prenatal alcohol exposure and its impact on child welfare services. Documented levels of

alcohol use in pregnancy range from 65% to 80% and 82% by Barry et al, (2007,) O’Keeffe et al, (2015) and Mullally et. al. (2011), all signify that CWSWs are encountering children suffering parental alcohol exposure at substantial rates. It also signifies that the state system of child welfare is incorporating a major statutory obligation to respond to this vulnerable cohort under statutory instruments to keep children safe and promote their welfare.

The advice of the Chief Medical Officer of Ireland -- that pregnant women and women wishing to conceive should avoid consuming alcohol altogether (Department of Health and Children, 2007), -- seems to be having little impact on changing the cultural norms of alcohol use during pregnancy. Furthermore, it is essential to consider that evidence points to a need for a specific cultural sensitivity needs to be applied when addressing prenatal alcohol use within Ireland. It needs to be acknowledged within every culture seeking to prevent alcohol exposed pregnancies that “Women’s drinking patterns are influenced by the cultural norms and practices of the ethnic groups to which they belong, in addition to other environmental and biological factors” (Collins and McNair, 2002, p. 251). Kendall et. al. (2017) notes, “Implicit cultural understandings challenge those working to increase public awareness and support for programs to prevent and address fetal alcohol spectrum disorder (FASD)” (p. 105). Cultural insensitivity to both the prevention of alcohol-exposed pregnancies and the psychosocial interventions for children living with an FASD contains risks of imparting stigma in such responses.

The core of addressing both prevention and management of FASDs, shame, stigma and silence also needs attention. This will require the development and deployment of FASD-informed professionals through professional education to combat stigma, shame and silence within state service structures (Bell, et. al., 2015; Choate and Badry, 2018).

Scant attention is being paid to the concern of FASDs within Irish society; however, efforts are now being made to address broader systems issues concerning the burden of alcohol misuse on society. The Irish Minister for Health stated both problematic drug and alcohol levels within Irish society needed addressing. He noted that Ireland currently has an estimated 1.35 million harmful drinkers and stated the this “must be tackled” when launching the 2017–2025 strategy to combat substance use/abuse in Ireland (Department of Health, 2017). An analysis of this government publication on 'Reducing Harm,' unfortunately, yields no results on the prevention of FASDs within the paradigm of reducing harm from alcohol within Irish society. Conversely, literature and research are appearing within Irish society, calling for more significant efforts to educate and prevent FASDs (Catterick and Curran, 2014; Curran, 2007; Gill and Sharif, 2017). Such inaction on this vital public health need must be viewed within the context that "there is long-standing scientific agreement that alcohol is a teratogenic agent, passing quickly through the placenta, un-metabolized by the fetus” (Sher et. al., p. 2, 2019). The failure to acknowledge the long-standing scientific evidence is likely offering a long-term social, monetary burden on society, and directly impacting Irish maternal and child health in the 21st century.

More recently, the Government of Ireland introduced the Public Health (Alcohol) Act (2018) brought attention to the public health issue of alcohol consumption in pregnancy. Section 12(1) ii of the Act reads:

“[A] warning that is intended to inform the public of the danger of alcohol consumption when pregnant” (p. 14)

while section 12 (4) (b) the legislation requires commercial premises of alcohol sales to display notices as follows:

“The holder of a licence shall, in the prescribed manner, inside the premises to which the licence concerned relates, display a notice or notices in the prescribed form, which shall include in the prescribed form, in both the English and Irish Language”, a warning that is intended to inform the public of the danger of alcohol consumption when pregnant.” (p.14).

Both of these legislative requirements brought forward to promote public health activities of preventing alcohol-exposed pregnancies will be seen as welcomed measures by many advocates that have campaigned for such. However, as with any new legislative drive within any culture, the real measurement of success will be in the application and enforcement of both 12(1) and 12(4) within Irish society. Enforcement of both sections can and will have measurable public health benefits in addressing Ireland's high rates of alcohol consumption during pregnancy as discussed. Benefits of enforcement may be attributed to very similar legislative directives in the USA by the surgeon general in 1986

The Impact of FASDs on Child Welfare Services

The evidence offered here and indeed in the more extensive empirical literature would suggest that currently, the child welfare services globally are demonstrating a level of systemic failure in incorporating FASDs into mainstream service structures and acknowledging the intellectual disability needs of those living with or suspected of having an FASD (Badry and Choate, 2015). Greenspan, Brown and Edwards, (2016) discussed intellectual disability policy and services and described individuals with an FASD as “among those most victimized by the current practice” (p. 244). Evidence would suggest that the children and young adults listed in the following vignettes suffered the ultimate victimization due to their diagnosis, a diagnosis that seems to have offered little to the post-diagnostic life and needs of the children and young adult discussed. The vignettes come from international sites outside of the cultural site under inquiry.

Currently, researchers in North America produce the majority of FASD interventions, prevention evidence and literature. The introduction of these international vignettes below offer evidence, which can serve the development of knowledge mobilization and interventions within Tulsa, through a culturally sensitive approach, and work to prevent such fatalities associated with an FASD. The vignettes touch on both foster care and residential care, two service structures that serve all child welfare services globally.

Vignette 1 (Australia)

On March 13, 2013, a 15-year-old in care of the Department for Child Protection and Family Support (DCP) Western Australia ran away from his foster home placement. On the morning of March 14, he was found deceased in the swampland of the Australian outback. He had died from a suspected crocodile attack. HLS, the subsequent reference of his name, was diagnosed with a condition within FASDs soon after his birth and spent the majority of 15 years in foster care. The subsequent coroner's report documents a tragic trajectory of HLS within the care services, to his untimely and horrific death (Linton, 2018).

Vignette 2 (Canada)

During the evening of August 21, 2013, two foster-care children of separate foster placements attached to the Ministry of Social Services, Saskatchewan, Canada were playing together outside a local bingo hall while their foster parents were inside. Sam (6) and Derek (10) (not their real names) drifted to local woods to play, where, in an impulsive act, Derek attacked Sam with a piece of woodland debris resulting in Sam's death. Derek was living with a diagnosis of an FASD, a diagnosis he had received in March 2013. Pringle (2014) catalogued a systemic failure in responding to Derek's needs, documenting that the assigned a mental health professional was not aware of Derek's diagnosis. Badry and Choate (2015) documented a "systemic failure" in planning safe care for Derek in their analysis of this tragic case. The

primary failure was to acknowledge the needs of a child with an FASD and CWSWs lack of capacity in their case management of FASDs.

Vignette 3 (Canada)

Maxim Baril-Boulin died at the age of 26 from an overdose of fentanyl while in judicial custody in July 2018. Maxim was diagnosed with an FASD as a child. He was an adopted child, who from around the age of fifteen spent a majority of his time in the care of social services. His adoptive parents fought for him through his adolescence and young adulthood. In the month before his death, his mother Sylvia spent that month searching the judicial systems trying to find him. The news of his death was conveyed to his mother over the phone.

Vignette 4 (Canada)

Brooklyn spent the first year of life with her birth mother before entering child welfare services and being placed in foster care. At age of six years, Brooklyn had experienced 17 different foster placements with child welfare services. Brooklyn was diagnosed with an FASD around the four years of age (Cromarty, 2018). By the age of 6, Brooklyn was placed with her sibling sister in a foster placement which lasted 6-years. Following the breakdown of this long placement, Brooklyn had two further foster placements before entering residential care. Brooklyn had eight residential/group home placements to age 16. On the day of her death, Brooklyn reacted to residential staff when her Internet access was withdrawn by barricading herself in her bedroom by blocking her bedroom door with a mattress and setting fire to it. Her death was ruled accidental due to smoke inhalation. She was 16 years old. The report noted that “there seemed to be a lack of understanding about the most effective treatment options and support for young people living with fetal alcohol spectrum disorder” (p.51).

What the children and young adult listed in the vignettes were missing (but needed) in their life was a social model of understanding on their disability. Oliver (2013) described the

principle of the social model in this way: “We were not disabled by our impairments but by the disabling barriers we faced in society” (p. 1024). For children born with the neurodisability of an FASD, the barriers in society are immense, which will be discussed in this work leading to a discussion and findings calling for a refocusing of the FASD disability to be seen and acted upon within a social model of care.

The problem impacting child welfare services, is that there is limited published information on specific evidence-based interventions to guide CWSWs in identifying, screening and responding to FASD in practice settings. Given the critical role played by CWSWs in upholding the statutory duty to protect and promote a child’s best interest, their role is rarely articulated or even acknowledged within the broader dialogue concerning FASD. The four vignettes illustrate the urgent need for recognition and service response to FASD within child welfare services structures. The voice of social work is absent in the vignettes despite the pivotal role it plays in the lives of these children. The experiences of CWSWs are airbrushed out of subsequent inquiries on child fatalities with child welfare services and more significantly the debates that rage in social media following publication of such inquiry reports.

As Reder, Duncan and Gray (1993) describe, "the trouble is that, intense as these debates may be, they have taken place in very restricted circles and left the vast majority of social workers struggling on in a kind of intellectual fog" (p. 9). How these CWSWs who worked the case files of the children in the vignettes viewed their responses, process and practice concerning the tragedies that befell their caseload, is not discussed in any of the dialogue or debates emerging from these very public discussions on FASDs. Ironically, CWSWs see their as role that of a gatekeeper in preventing and slowing down admission of children in to state systems of care, yet poor evidence exists articulating this role of identifying and screening children with an FASD

on entry to child welfare services. Yet again, a paucity of literature or evidence documenting the specific task of CWSW is absent, rendering CWSW vulnerable within the FASD dialogue in society. Prior research demonstrates that a child fatality on a CWSW's caseload, will have a 'profound effect' personally and professionally (Reder, Duncan and Gray, 2003, p.9).

Child Welfare Adopting A Subservient Role?

The reasons behind the failure of child welfare services in properly managing cases of FASDs was potentially identified by an inquiry in Canada in 2015.

An Ontario appeals court judge, the Honourable Susan E. Lang, (2015) reviewed 16,000 child protection cases from 2005 to 2015 for what was described as "inadequate and unreliable" scientific procedures in identifying children at risk of alcohol and substance abuse in pregnancy. Over this period the Ontario child protection agency relied on the Motherisk Drug Testing Laboratory at the Hospital for Sick Children, Toronto, confirmed alcohol and substance abuse, for potential evidence in removing children from parental care.

The inquiry found that the service was "unreliable" and "inadequate" for use in child welfare and protection assessments (p. 4). A critical acknowledgement coming from this inquiry is that "flawed science played a role in tearing families apart" (MacLeod, 2018, p. 4).

Unfortunately, child welfare services and CWSWs assumed that everything was above board in this scientific lab, which screened for parental substance and alcohol misuse. The report finds a lack of transparency in the lab's clinical practices, a factor which left both CWS and CWSWs in a vulnerable position.

Child welfare services need to develop a social lens of good ethical governance and oversight when seeking to plan safe care for children impacted by prenatal alcohol exposure or other illicit drugs. In this case it may be argued that the commissioning of third parties in planning of safe care for these vulnerable children and families was conducted with poor ethical

and moral governance and oversight by the child welfare services. It is without question that FASDs pose many questions within the boundaries of ethical, legal, and social issues for child welfare service structure. For example, the need for senior policy and financial decision makers within child welfare service structures to be FASD informed is a critical need within current structures. How CWSWs deliver on the ethical, legal and social issues when responding to prenatal alcohol exposure concerns is crucial to understanding current child welfare policy and education developments.

Although, confusion reigns concerning FASDs within CWSWs and society at large, FASDs are seen as placing a "substantial economic burden on the child welfare system" (Popova, Lange, Burd, and Rehm, 2014, p. 84). What is also noted is that children who have been prenatally exposed to alcohol will exhibit special health care needs, which places extra demands on the health care system that far exceed those of non-alcohol-exposed children (Streissguth, 1997). The absorption of FASDs into the child welfare services presents major professional and ethical challenges for CWSWs in responding to and intervening in a statutory professional manner to ensure a child's welfare and ensure a safe plan of care. This essential component of a CWSWs statutory duty is described by Gibson, Samuels and Pryce (2018) as:

"Child welfare systems are people-changing in that they are legally and socially charged with creating changes in the lives of children and families through various interventions to improve family functioning and (or) ensure child safety and stability. At the same time, child welfare systems are legally accountable for processing these children and families as they move through the system" (p. 43).

O'Reilly and Dolan (2016) further describe the statutory requirement of CWSWs as: "Child protection and welfare social work practice is faced with many challenges in its statutory duty to protect children at risk of abuse and neglect" (p. 1192). Further, Burns, O'Mahony, Shore

and Parkes (2018) describe the role of Irish social workers when attending court: “Their job requires them to intrude into the strongly protected sphere of family life to protect the rights of vulnerable children. Every decision they make inherently involves an assessment of the rights at stake, the evidence available, and the likelihood of meeting statutory thresholds” (p.118). How this 'statutory duty' is defined and conceptualized when responding to cases of FASD is of critical importance giving the evidence offered within the vignettes of this study and the broader empirical evidence of FASD impacting child welfare services (Chasnoff, Telford, Wells and King, 2015; Drabble et. al., 2011; Fuchs et. al., 2010; Lange et. al.,2013). It is without question that CWSWs were case managers to the children discussed previously in vignettes 1, 2 and 4, all of whom were in either foster care or residential care of the state at the time of their death. Furthermore, CWSWs would have been involved with Maxim throughout his teenage years.

The Role of Social Work with FASDs

Social work as a profession operates across many strands of both social services and health services. Central to the profession is the objectives of facilitating collaboration between the different services within social services and within wider health settings to achieve social justice for clients.

As described by Fraser, et al (2018), social workers in integrated care provide clinical interventions for depression, anxiety, phobias, and other behavioral health problems, including substance-use disorders. In addition, social workers often serve as care managers for patients with comorbid behavioral health and chronic physical health problems (p. 200).

It is within this wider description of social work that the specialist role of CWSW operates. As a specialist role of social work, it is perhaps the most significantly impacted by FASDs. It's this specialist role of the social work profession, the focus of this inquiry that is

largely absent in current FASD discussions concerning the prevention and case management strategies.

The social work profession, and particularly CWSWs, in all developed cultures operate within a legislative power in delivery of services to vulnerable children and families in society. The social work role is also one that is heavily predicated on delivering on social justice for those in need within society. CSSWs are tasked to promote fundamental human rights and to make a crucial contribution to establishing social justice (Stuckler and Basu, 2013). Within the site of inquiry, the Code of Ethics of social work equally states that human rights and social justice are fundamental to the social work profession (Irish Association of Social Workers (IASW), 2006). Ethical issues are multifaceted when seeking to address both the prevention and management of FASDs within cultural settings. How CWSWs are managing such ethical challenges within their statutory duties on cases of FASDs is not currently addressed within the professional literature.

CWSWs within the broader dialogue concerning FASDs in society is largely absent within the substantial body of research and empirical literature documenting FASDs impact on child welfare services. The question is whether the CWSW is voluntarily removing themselves from this dialogue or whether the macro system of child welfare services is failing to support the CWSWs in their social justice efforts for this vulnerable cohort.

Numerous social work professors have enunciated the need for child welfare services and CWSWs to be more engaged in the prevention and management of FASDs within society. Badry and Choate (2015) in discussing the skills vacuum of social workers on FASDs state, "social work educators should intentionally build these skills. It is often not at the forefront of social work training as much effort is made in building knowledge of the theories and practice perspectives" (Badry and Choate, 2015, p. 27). In another view, Wilson

(2013) a social work student, notes “it is essential post-secondary education prepare students in human service programs for their coming encounter with FASD with the appropriate curriculum that is practical and culturally sensitive” (Wilson, 2013, p. 36).

Steiker (2009) noted, “social workers are in a unique position to educate other disciplines in medical and social agency settings so that misinformation or denial about FASD can be eradicated. In her 2016 doctoral study, Durkin (2016) noted that CWSWs "who are more aware of children/youth with fetal alcohol spectrum disorders (FASDs), their unique services needs and available strategies to help them can improve their outcomes” (p. 85). Collectively, this suggests there is a clear and pressing need for CWSWs to be FASD informed in their practice. What is also evident in the international dialogue concerning FASDs is an urgent need for child welfare services management personnel to engage proactively with the mounting concerns of both social and economic impacts the disability is placing on society.

Significant obstacles to discussing alcohol use with the client/patient are reported by health care professionals and providers. In a study conducted by George Mason University (2015), they identified such obstacles are as follows:

- Time constraints
- Client/patient denial of alcohol use
- Discomfort with the issue
- Unsure who is responsible for screening/discussing issue
- Need more training
- Lack of referral sources
- Lack of financial reimbursement
- Unsure about the research on FASDs

This study demonstrates the challenging role of CWSWs in intervening and responding to FASDs in child welfare services. The study found a dearth of knowledge was a critical factor in seeking to respond to prevent FASDs. Coupled with the dearth of knowledge, is the compounding experience of discomfort, perhaps due to the emotive and ethical challenges that prenatal alcohol exposure entails in most cultural settings. The dearth of professional knowledge will need to be addressed through a significant ideological shift within the setting of this inquiry. Professionals need to be prepared to discuss alcohol use with pregnant women and families in a culturally competent and trauma-informed manner to educate and provide help, guidance and support (Poole, 2008; Rasmussen et. al., 2012). CWSWs have a strategic role in seeking to maintain and create a stable home environment for the child living with an FASD, either within the birth family or in out-of-home placement (Pelech et. al., 2013). Chasnoff (2011) notes, “almost two-thirds of children identified as affected by prenatal alcohol or drug exposure are raised in out-of-home care” (p. xviii).

The need for responsive professionals and especially CWSWs is repeatedly discussed in the literature with caregivers wanting to provide such stable care and seeking support in the task (Chamberlain et. al., 2017; Mukherjee et. al., 2013). When a child is not afforded the stable environment, usually because foster parents and CWSWs are not educated on FASDs, the rates of placement disruption and breakdown are all too common. Within mainstream discussion on placement disruption and breakdown, FASDs are not considered as a potential causal factor for a child with disabilities in out of home care (Hill, 2012). Placement disruption and breakdown is a major time consuming and costly aspect of child welfare service provision and of the CWSW trying to juggle a heavy caseload.

CWSWs deliver services in a range of settings, reaching women at risk of alcohol-exposed pregnancies, as well as families, children, and adults affected by FASD (Pomeroy and

Parrish, 2011). Therefore, CWSWs operating on the front line of child welfare services, are strategically placed to identify, respond and manage the complex needs of children living with an FASD (Badry and Choate, 2015). Evidence strongly indicates that CWSWs need to be aware of the possibility that children for whom they are providing services may have FASDs. However, for social workers to be effective in responding to this possibility they need to understand the irreversible neurobehavioral, neurocognitive and neurodevelopmental profile of these children during intake duties, and to have the relevant knowledge and skills be effective in responding (Badry and Choate, 2015; Wilson, 2013) in order to offer a safe care plan for the child. Within such learning, it is also imperative to understand within this education paradigm, that no one intervention has been found to be sufficient to meet all the unique and complex needs of children living with, or suspected of having an FASD and their caregivers (Coggins, 2011).

The evidence contained within the vignettes and subsequent analysis in inquiry reports and literature publications, indicates that CWSWs currently do not have sufficient knowledge and skills necessary to identify, screen and manage FASDs in their practice (Badry and Choate, 2015; Pomeroy and Parrish, 2011). As noted by Mukherjee et. al. (2013), foster parents found it difficult to access support from social workers as they lack the knowledge and skills on FASD, resulting in them being unable to “make informed decisions about the children” (p. 50) .

CWSWs may also experience a lack of community therapeutic and diagnostic service structures to support them in responding to children presenting with FASD and their families during intervention and screening activities (Badry and Choate, 2015; Wilson, 2013). Interventions for working with children living with or suspected of having FASDs do exist (Bertrand and Consortium, 2009), but current ineffectiveness of knowledge translation suggests that such interventions are not being utilized effectively to meet the needs of this vulnerable population.

Conclusion

Within Ireland this vulnerable population is significantly shrouded away from mainstream welfare services and responses. Their needs for services and supports are rarely articulated in public welfare strategies. This is primarily due to the cultural norm, which carries a positive disposition towards alcohol that may ultimately shape the personal perspectives of professionals, such as CWSWs, in responding to FASD prevention and management goals with Irish culture. A comprehensive body of literature has been offered within Ireland over the past two decades depicting the worrying concern of parental alcohol exposure levels in Irish society. The work of Barry et. al. (2007) was a significant milestone within the culture under inquiry. Although a robust longitudinal study situated with Irish maternity services, its findings on the high levels of alcohol use in pregnancy at 65%, were largely ignored by public health agency responses. This was confirmed recently by the work of Coveney (2018) who offered: “The many calls for change, be it from children’s rights activists, researchers, and Members of Government or voluntary groups, have largely gone ignored, seemingly in favour of the benefits to the powerful Irish drinks industry and the already suffering exchequer” (Covney, 2018, p. 654). As Covney notes, ignoring the issue of parental alcohol exposure and FASDs is likely to place a heavy financial burden on the Irish taxpayers, as the state exchequer will have to fund the over 400 health conditions associated with prenatal alcohol exposure and FASDs (Popova, et. al., 2016). Health budgets are continually under pressure within the Irish health system. Prevention of FASDs will therefore likely reap benefits directly back to the exchequer.

However, the cultural predicament of positivity towards alcohol against a backdrop of internal and international calls to action on preventing FASDs will continue to be a significant challenge for the Irish CWSWs to impart prevention messages and plan safe care for a child living with an FASD, a key mandated action of their statutory role.

Considering that some of the highest rates of FASDs are found in children in care (Chasnoff, Telford, Wells and King, 2015; Fuchs, Burnside, Marchenski and Mudry, 2007; Lange et. al., 2017; Lange, Shield, Rehm and Popova, 2013), with many of these from environments of abuse and neglect (Mukherjee, Cook, Norgate and Price, 2018) there is an urgent need for more significant investment in child welfare service and the education of CWSWs concerning FASDs. Currently I am not aware of any empirical studies documenting the prevalence rate of FASDs in the Irish child welfare services. As a complex neurodisability presentation, the identification of children suffering from prenatal alcohol exposure (Rangmar, Lilja, Köhler, and Reuter, 2018) and the subsequent display of FASDs across many systems of care provision (Caley et. al., 2008; Durkin, (2016); Kable and Mukherjee, (2017) calls for a more substantive response to FASDs in child welfare settings. FASDs may be perceived as an insidious phenomenon currently impacting the role of the CWSW within Ireland and internationally.

Purpose of the Study

Although the eight children coming from the Washington child welfare services suffering from failure to thrive and were subsequently re-labeled with fetal alcohol syndrome, the responses of CWSWs within FASD dialogue has been poorly articulated in the 45 years since this occurrence in 1973. Several areas have emerged in the literature over the past half a century that point specifically to child welfare services but the specific responses of CWSWs require investigation. As the vignettes demonstrate the child welfare services globally is struggling to grasp the reality of FASDs.

Badry and Choate (2015) described this struggle as a “systemic failure that contributed to a child’s death” (p.12) How ‘systemic failure’ is impacting the profession of CWSWs in responding to FASDs is therefore a very pertinent question to be asked. It’s a question put to

Irish CWSWs but may have relevance to CWSWs globally. This study seeks to explain how CWSWs respond as they serve children with an FASD entering child welfare services and enact statutory requirements of safe care. It aims to offer a grounded theory to explain how CWSWs respond on this critical service point of child welfare services. It is hoped the theory offered can be used to better support CWSWs in their interventions on cases of FASDs.

As key informants, I recruited participants directly from frontline CWSWs within the Irish child welfare services. The data offered gives a direct vision to the challenges CWSWs experiences in their professional actions of planning safe care for children with an FASD. Though the collection of data and subsequent analysis of both initial and theoretical sampling, I offer a grounded theory identified through the analysis data over two stages. I derive this grounded theory with interpretations of both personal and subjective interpretations of the data. This is not a limitation as reality is viewed to be relative, multiple and constructed, which subsequently is applied to the research experiences (Clarke, Friese, and Washburn, 2017). Equally, as will be discussed later in methodology, prior knowledge is perceived as a valid entity in the constructivist approach.

Researcher Identity Memo

“The hearts of social scientists exercise a cogent influence on research questions, findings, concepts, generalizations, and theories.” – J.A. Bank

I sit to write this researcher identity memo on what is the twentieth International FASD Awareness Day, September 9th, 2019. You might ask why I need to reflect on my identity on such an auspicious day. Well, as I enter year four of my doctoral study, and having collected the data in my first phase of a constructivist grounded study, I am struggling with my identity. It's an identity of three parts. Firstly, I'm a social worker with over 30 years' experience from my first job in residential child care in Humberside, UK in the late 1980s. It wasn't until 1995 that I

became officially qualified with a bachelor's in social work. It would be some ten years later in 2005, that I entered Trinity College, Dublin, to undertake my M.Sc. in Social Work, and perhaps another irony in the identity journey – it was almost to the day, ten years further on, that I entered Concordia University to undertake this doctoral study. However, my identity as a social work practitioner is firmly rooted.

For some researchers, their reflections on how they came to be in their particular area of research may not have an accurate crystallizing moment. However, for me, this is very much the case in explaining where I am now. In 1999, I was a principal peripatetic social worker moving between two social work teams of the East Rising Social Service Department in the UK. It was in this role that I was given a complex case to manage. A mother of two young children was expecting her third child. The initial goal of the intervention was for the two birth children. The mother's chaotic drug and alcohol use signalled that these birth children were suffering from neglect and emotional harm.

It wasn't until some weeks after an initial intervention that concern was raised for the unborn child due to mother's substance use disorder. It was decided the case needed a pre-birth focus, not so much by me, but by others within the wider multidisciplinary team that was now operating around the case. So, some weeks later, a full pre-birth case conference took place, and it was during this that my 'crystallising' moment took place.

An obstetrics and gynaecology professional within the multidisciplinary participants of the per-birth case conference spoke about internal world of the developing child in utero. She detailed the level of risk to the unborn from the mother's illicit drug and alcohol use. She talked about the possible lifelong implications for the child. She mentioned the possible neurocognitive and neurobehavioral outcomes.

And there you have it – a light-bulb moment for yours truly. We had lots of kids in our system with neurocognitive and neurobehavioral problems, but I never had in undergraduate social work education or in the many years of practice which took me to Principal Social Work practitioner, heard anyone before suggesting that the neurocognitive and neurobehavioral in our child welfare population could have started before birth.

Yes, indeed, I had a lot of education at undergraduate and post graduate level about the “external” world of domestic violence, mental ill-health and substance misuse – the toxic trio. This toxic trio was very prevalent in my education at the time. Indeed, the vast majority of child welfare cases were firmly linked to one or all three of the trio combinations. And yes, many of the children arriving in our social work in-tray, coming from the “trio” had behavior presentation directly attributed to the toxic environment. In the days, weeks and months that followed I began to question why are we not discussing the fetal brain impairment from substance misuse as a possible etiology of the behaviors I was witnessing in the foster care and residential care services? Oh, so many were diagnosed with ADHD, and Ritalin was administered like a candy of the day in response to behavior management needs. I was troubled. We were not talking about the fetal brain development stage, as having an impact on the post-birth development of children in our care. There was no natural outlet for my questioning mind – the pre-birth risk assessment in 1999 was implanted in my thinking. The words and thoughts of the OB-GYN were still ringing in my ears – the ‘internal world’.

It wasn't until 2005 that an opportunity to study for my M.Sc. for this implanted thinking to have an outlet. For my thesis part of the program, I opted to ask the question if drug and alcohol use/misuse was a child welfare concern. The question was asked, the data collected, and the answer rendered. Within the 15 allied health professionals of the study, there was a palpable level of concern for the unborn within the context of maternal drug and alcohol use and misuse.

Suddenly, my research and its finding took on new meaning and identity. The study findings were partly published (15,000 words) by the Society for Knowledge in Ireland and the University of Limerick in a book examining the issues of the unborn and Article 40.3.3 of the Irish Constitution.

I was asked to speak at conferences; I had representations from caregivers who were struggling to care for children with neurobehavioral and neurocognitive presentations that were looking for a holy-grail direction that would magic away the presenting behaviors. It was 2008 when the above publication took place. Between 2008 and 2011, I wrestled further with the issue of fetal brain development and its impact on the post-birth trajectory of children and adolescents. It was in March 2011 that I undertook another defining identity decision by traveling to the University of Wisconsin to conduct further study to help with the multiple questions now cascading around in my mind. Here, I undertook an intense program of education to become a Certified Educator of Fetal Alcohol Spectrum Disorders (FASD). This program was developed in conjunction with the Center for Disease Control and Prevention (CDC).

Why alcohol and not illicit drugs, you might ask. Well, in the journey of knowledge accumulation, I learned to my surprise that it is indeed alcohol that poses the most significant risk to fetal development. With alcohol having such a common place in society and especially within my own Irish culture and society, this drove me further to better understand the multiple competing and complex factors at play when addressing the needs of the unborn. With the qualification from the CDC, demand for my services as an educator increased. I lectured, trained and offered consultancy across many jurisdictions. I also went on to publish further thoughts and experiences from my work with families and professionals. What struck me in my encounters with caregivers is the isolation they experience when coming forward in a help-seeking mode. Birth parents, and adoptive and foster parent families routinely find themselves lost and in crisis

when confronted with the emergence of an FASD in their children. The parents, often uneducated, don't know where to turn to locate the help vitally needed for their child.

It is perhaps much easier to put fingers on a keyboard when it comes to FASD; after all, we are saturated with the scientific, medical and social texts. Yet, even in 2019, I was regularly confronted by delegates in a training activity who are scratching their heads when it comes to the social context of living with an impaired brain due to prenatal alcohol exposure (PAE). It is equally perhaps shocking, that after an avalanche of publications over the past half-a-century, that social workers are confused, shocked, vulnerable and even angry about why this information is not more widely known and understood in social work education. It has troubled me that my profession of social work is absorbing a substantial number of children born of parental alcohol exposure, yet the professional skill development of the profession is woefully lacking in understanding this burden.

While using effective strategies that rigorous research has shown to improve outcomes for those living with an FASD and may not solve all the problems of caregiver burnout and frustration, it is a step in the right direction. I get very frustrated when I think of the many caregivers I have talked with who are so grateful to be pointed in the right direction. My experience to date has often witnessed parents and families finding themselves in fear and crisis, often uneducated and not knowing where to turn to find the help vitally needed for their children and young adults living with an FASD. I get frustrated when I think of the number of publications that fail to achieve knowledge translation in our public health and social structures. It is equally troubling and upsetting to see my colleagues struggling to work with these children, and, in the words of one, traveling a long winding road with no real direction of signposts for help.

I have been teaching, lecturing and training at Continuing Professional Development

(CPD) level for over ten years now concerning the psychosocial needs of those living with an FASD. My primary focus has been allied health professionals and a more focused lens on my own profession of social work. These CPD full-day level programs (in Ireland, United Kingdom and Poland) were very well received and evaluated very positively by delegates. It's important to note that the vast majority of delegates attending these events were female and of child-bearing age, yet never once did I experience a negative rebuke for disseminating the information on prenatal alcohol exposure and FASD. This again is testament to the fact the child welfare social workers know they are dealing with FASDs and want the professional education to aid their practice. There is an indisputable body of scientific and social texts citing the impact of FASDs on our child welfare services, especially the foster care services. However, we are still suffering a paucity of knowledge and understanding on how social work responds in such casework.

It is for this reason that I have undertaken identity number three on this journey of answering the question/s posed in 1999. Can this doctoral study effectively amalgamate all three identities? My doctoral study is motivated from my 1999 experience, and it was here as a social work practitioner that my inquiring mind took root during a pre-birth risk assessment activity. It is here in this study that I again ask how my social work colleagues are intervening in such cases of fetal alcohol on their caseloads. I am convinced from over ten years of the work that social workers need to be equipped with enough air in their tanks if they are to dive into the murky waters of FASD advocacy for children in child welfare. I say "murky" 'in that my experience has also brought me to a realization of perhaps an over medicalization of FASDs has left of child welfare services and the profession of social work within a subservient status within the current narratives of fetal alcohol. I am shocked, saddened and upset each time I read yet another sad obituary of a child in care with an FASD coming to a premature tragic death.

Writing this memo brought up emotions I was unaware existed, such as the anger at ineffective knowledge translation and the poor acceptance of FASDs impact on the social work profession within the child welfare services. More so, the emotions of reflecting on the families and individuals living with this preventable disability, their isolation in society, and their 24/7 care giving duties are all reasons to continue. Accentuating the role of social workers, will, I hope, lead to better education, and provide them with a navigable path within the global narrative of FASD. There is a need for a straight road, with clear signposting for my colleagues in social work practice. What is also a great need, is for allied health professionals to grasp a better understanding on the needs of children living with an FASD as social work cannot do this alone. It was Carl Jung in 1939 who said, “If there is anything that we wish to change in the child, we should first examine it and see whether it is not something that could better be changed in ourselves” (p.285). This goes to the heart of seeing these children in our child welfare services living with an FASD. Through effective knowledge translation we can learn to do things better. And as Maxwell (2012) stated “Any view is a view from some perspective, and therefore is shaped by the location (social and theoretical) and the lens of the observer” (p. 46). My own perspectives have deep roots in my prior knowledge and experiences, roots that will continue to bear fruit in my research life as I strive for societal betterment in my research endeavor.

Chapter 2: Literature Review

Introduction

I aim to explore the role of CWSWs operating within Irish Child Welfare Service and understand how FASDs have impacted the child welfare services in Ireland. It should be noted, however, that FASDs' impact on Ireland's child welfare service is not formally acknowledged in research outside that of previous research conducted by myself (Curran, 2008, Catterick and Curran, 2014). To fully grasp the impact of FASDs on child welfare service and the social work profession, it is necessary to look at more international literature, where the awareness of FASDs and the responses of child welfare service is discussed.

The purpose of this chapter is to organize, present and critique the literature on FASDs, and the roles of CWSWs and child welfare service in addressing FASDs. The study methodology Constructivist Grounded Theory (ConGT) (Charmaz, 2006, 2014, 2017) is discussed in Chapter 3, which includes the relevant literature of both the methodology and the theoretical framework of symbolic interactionism which underpin the study. There is a body of scholarly work concerning the use of grounded theory, which advocates approaching projects without conducting a prior literature review. According to Dick (2014), it is thought that avoiding the literature review limits the researcher's prior conceptualized theories and the previous knowledge of research evidence concerning the topic under inquiry, allowing the researcher to develop an approach that is pure and influenced solely from the study data.

This review of the literature discusses the phenomena of FASDs in society in general and the escalating social and monetary costs and the implications for Child Welfare Services. As outlined in the context chapter, FASDs are shown to place a significant burden on both the child welfare services and the front-line CWSWs. The review will focus primarily on the interlocking role of FASDs, child welfare, and the CWSW profession. Thus, I draw upon literature from the

pre-data-collection phase, concerning FASDs and their impact on child welfare service and CWSWs. However, it is worth noting that literature focusing specifically on child welfare service and CWSWs is somewhat limited when compared alongside the considerable amount of medical and scientific publications on FASDs. The literature discussed in this chapter comes from a comprehensive global base concerning FASDs, as there is limited research available within the particular site of the inquiry. The topic of FASDs which is still not formally recognized within state policy or procedural documents at the site of this inquiry. As such, Ireland has an unknown level of FASDs within society, given the published rates of alcohol-exposed pregnancy within Ireland (Barry et. al., 2007; Mullally et. al., 2011; O’Keeffe et. al., 2015). However, a broadsheet media report in national newsprint in 2019 stated that "Tusla protects 350 children deemed to be ‘at risk’ of harm before their birth" (Deegan and Byrne, 2019, p. 13). This is likely an extremely low guesstimate when considered alongside documented international prevalence rates.

An initiative of upskilling social workers and some allied health staff is part of a wider approach was introduced on January 15, 2019, under a national strategy entitled *Hidden Harm* (HSE and Tusla, 2019). This joint approach taken by Tusla and the Health Service Executive (HSE) to address the needs of children living with parental alcohol and drug use is a positive step forward. In the foreword of this document it states, “problematic use of alcohol and other drugs is a complex issue and continues to be one of the most significant health and social challenges facing our society” (p.5). What is also a welcome development from these two national leads in health and child welfare, is the formal acknowledgement of FASDs (p.8). Listed in the glossary of the publication, alongside definitions of neglect, attachment, child development, FASDs are clearly identified as a child welfare need of recognition. However, for CWSWs to know about

FASDs will not be sufficient in delivering on safe care. Understanding FASDs and all the multifaceted needs it spans will need substantive education to achieve the goal of safe care.

Prenatal Alcohol Exposure: The Historical Context

In 1962, the world got its first clear insight into how certain substances can cause debilitating neurological and physical disabilities in unborn children when the first babies were born to women who had used thalidomide drug during their pregnancies (Chasnoff, 2011; Curran, 2007). It was the thalidomide tragedy that opened a visible window of the risk to fetal development from substances ingested during pregnancy. Indeed, it was not substance abuse, but a prescribed medication for morning sickness, which led many women to unknowingly inflict a severe disability on their unborn child (Dally, 1992). Society is well versed in this public health failure to support the welfare of mothers-to-be and to understand the devastating impact of how a substance ingested during pregnancy can derail the development of the unborn. Society is not so well versed in understanding the risk that alcohol poses to the developing fetus in utero. It is important to note that alcohol as a teratogen is just one of many neurotoxins that can disrupt the central nervous system in the developing fetus (Olney, 2004). It is noted repeatedly in literature that alcohol consumption during pregnancy by the mother is the leading cause of intellectual disability in children and is 100% preventable, although such claims are seen as placing the onus on women solely (Bell, Andrew, et. al., 2015).

The prevention of FASDs, therefore, needs to be encapsulated within a more comprehensive strategy concerning public health needs of prenatal care, when seeking to understand the best outcomes for further generations. Such ‘understanding’ concerning the consumption of alcohol during pregnancy is still somewhat misunderstood in public health efforts, leading to ongoing preventable tragedies of children born with brain impairments (Raja Mukherjee et. al., 2016; Olney, 2004). A recent study by Sher, Frank, Doi and de Caestecker

(2018) talks of a societal 'blind spot' when it comes to engaging the body of significant evidence that alcohol as a tetragon has such destructive properties when it comes to the unborn child. They offer that "FASD remains a professional, cultural and governmental 'blind spot' allowing fetal alcohol harm and its lifelong consequences to continue unabated" (p. 2). Evidence in literature suggests that CWSWs can see this 'blind spot' it but have no policy, protocol or pathway to acknowledge it, which concurs with Badry and Choate who offered a finding of a systemic failing in child welfare services addressing FASDs.

It was articulated by Stratton et. al. (1996) that "of all the substances (including cocaine, heroin and marijuana), alcohol produces by far the most serious neurobehavioral effects on the fetus" (p. 35). This was reiterated by the Academy of Pediatrics (2013) when it stated that "of all the illicit, non-illicit, and non-prescribed compounds, alcohol had the most significant impact on the development of the fetus "(Behnke, Smith and Abuse, 2013, p. 1009). Although society is awash with prevention efforts for illicit drugs, there is a difficulty in imparting the prevention message of alcohol. Urging caution with a legal drug (alcohol) that has social acceptance at every level in society is problematic for those seeking to advance the knowledge as offered by both Stratton et. al. (1996), and Behnke et. al. (2013). The following visual on the statements of alcohol harm to the unborn is a graphic representation of the above statements (Table 1).

Effect	Alcohol	Marijuana	Cocaine	Heroin	Tobacco
Low Birth Weight					
Impaired Growth					
Facial Malformation					
Small Head Size					
Intellectual and Development Delays					
Hyperactivity, Inattention					
Sleeping Problems					
Poor Feeding					
Excessive Crying					
Higher Risk for Sudden Infant Death Syndrome					
Organ Damage, Birth Defects					
Respiratory Problems					

<http://www.faslink.org/DrugEffectOnPrenatalDevelopment.html>

Table 1. *All substances that impact Unborn*

It is now just over 50 years since Lemoine et. al. (1968) published the first paper demonstrating the causal link between the teratogenic properties of alcohol and the potential for congenital disabilities in the unborn (Smith and Jones, 1973). However, as will be discussed below, the history of concerns about alcohol exposure during pregnancy has been documented well before 1968, even dating back to biblical times. This review synthesizes a significant body of literature documenting the history and contemporary research findings concerning prenatal alcohol exposure leading to fetal alcohol syndrome (FAS) through to the current terminology of fetal alcohol spectrum disorders (FASD)s.

Knowledge, awareness, and concern about prenatal alcohol exposure can be traced back to biblical times, with the entry in Judges 13.7 "Behold thou shalt conceive and bear a son; and not drink no wine nor strong drink", and even further back to the philosophical writings of Aristotle (384-322 BC) (Warren, 2015). Perhaps the first recorded research activity on the

causality of prenatal alcohol exposure was conducted in 1899. It was then that Dr. William Sullivan, who found that women incarcerated in a Liverpool prison gave birth to children with a pattern of congenital disabilities and higher rates of miscarriages (Sullivan, 1899). He noted that women incarcerated for prolonged periods to include the nine months of gestation gave birth to healthier offspring, suggesting that incarceration was responsible for total abstinence during pregnancy (Warner and Rosett, 1975).

It wasn't until 1968 that we saw a more validated research study under Dr. Lemoine and colleagues in France (Lemoine et. al., 1968). In this study, researchers observed the direct causality of prenatal alcohol exposure to distinct features in 127 children who had been reviewed. The study failed to ignite any significant response for two reasons. First, the paper was only published in the French language, limiting its impact on the English-speaking world, and, secondly, Lemoine et. al. did not offer any diagnostic framework or guidelines to be applied in such cases of prenatal alcohol exposure. The study was published in English much later, in 2003.

Jones and Smith (1973) introduced the diagnostic term fetal alcohol syndrome. was shown to produce a specific pattern of growth retardation, malformations and CNS defects in children with prenatal alcohol exposure. Unlike Lemoine's study this study had just eight children. These eight children had been referred to the Washington Clinic of Ken Jones and David Smith by social workers for "failure to thrive". This is the first direct link to the child welfare system and perhaps the inspiration for this doctoral study. It is generally accepted that this paper was pivotal in bring western understanding of prenatal alcohol exposure and the effects, as it offered guidance on how to diagnosis the disorder of fetal Alcohol Syndrome a component missing in the published work of Lemoine et. al. back in 1968. Fetal alcohol syndrome was the single diagnosable condition linked to prenatal alcohol exposure at this point in time and literature.

In 2004, the Center for Disease Control (CDC) coined the term “FASD” to collectively describe all the conditions now emerging from prenatal alcohol exposure (Bertrand et. al., 2004). FASD is not a diagnostic term, but merely an umbrella term to encapsulate the constellation of effects stemming from an alcohol-exposed pregnancy. Perhaps the most significant development in the history of FASDs occurred in 2013: The publication of the Diagnostic and Statistical Manual for Mental Health Disorders (DSM V) (2013). The DSM V offered a new diagnostic term to try and encapsulate all of the hidden impairments from prenatal alcohol exposure. The term introduced in 2013 in the DSM-V under point 315.8 was Neurobehavioral Disorder as a Result of Prenatal Alcohol Exposure.

Neurobehavioral Disorder associated with Prenatal Alcohol Exposure is particularly challenging to define, as developmental problems and behaviors due to its hidden nature within the CNS and that it offers no visible features. Neurobehavioral Disorder associated with Prenatal Exposure further challenges the role of CWSWs and allied health professionals in their interventions of understanding the FASD disability in service delivery (Brown, Rich and Freeman, 2016). One of the major conflicts within all professional understanding of FASDs and identification which abounds today, is the challenge of confirming a history of alcohol exposure for all the other conditions associated with parental alcohol exposure outside that of fetal alcohol syndrome (Hoyme et. al., 2016, Petryk, Siddiqui, Ekeh, and Pandey, 2019). This point will be discussed in more detail, with the synthesizing of FASD literature within the study.

Only one of the conditions within FASDs, namely fetal alcohol syndrome can be diagnosed without confirmation of prenatal exposure due to the visible features (Bertrand et. al., 2004). The task of seeking evidence of prenatal alcohol exposure is an emotive task challenged by ethical, moral and social values and one which is poorly developed in current ethical

education standards of CWSWs. Confirmation of alcohol use in pregnancy may be obtained from maternal self-report of alcohol use in pregnancy, medical or other records, or clinical observation. (Chang et. al., 1998). Therefore, it is imperative to remember that results found in medical and other records are not a true reflection of prevalence rates of FASDs in any given culture. (Chasnoff, 2011) cited the task of seeking confirmation as a ‘great controversy ... as the lack of information’ is a major barrier to diagnosing due to the absence of evidence concerning prenatal alcohol exposure (p.28). The lack of routine recording of prenatal alcohol use in pre- and post-natal medical interventions is a major weakness within the dialogue on FASDs. Given this weakness, it will be necessary for a comprehensive assessment to be undertaken by a range of professionals within the multidisciplinary setting of service structures to reduce inadequate and inaccurate assessment of FASDs (Lange et. al., 2017; Hoyme et. al., 2016).

Outside the medical and scientific developments over the past 50 years, a vast profile rate of FAS and FASD information has appeared in social forums and social texts. One such author that gained traction within the dialogue, *The Broken Cord* (Dorris, 1989). This book is a vivid and emotional account of an adoptive parent (Dorris) raising his adopted son (Adam). It became an international success as Dorris captured the unique parenting challenges of caring for a child who was born of an alcohol-exposed pregnancy. This was seen as one of the first texts to explain the outcomes of prenatal alcohol exposure in layperson terms, as up until its publication, FAS was dominated in a very medical and scientific dialogue and written texts.

Alcohol in Pregnancy

Alcohol is widely consumed by women of reproductive age with the cultural site of this inquiry in Ireland (Reynolds et. al., 2019). Alcohol use within pregnancy continues to be a contested area of public and social policy health discourses (Lee, Macvarish and Bristow, 2010). Although significant evidence demonstrates the teratogenic effects of alcohol use during

pregnancy, there remains much debate and denial on the danger to the fetus, especially when it comes to the area of advocating safe levels of alcohol use in pregnancy (Domeij et. al., 2018).

The idea that there is a safe level of alcohol consumption during pregnancy comes against a backdrop of extensive literature which states that abstinence is the only safe approach in mitigating against cases of fetal alcohol exposure (Hoyme et. al., 2016; Mukherjee et. al., 2016; Mullally, Cleary, Barry, Fahey and Murphy, 2011; Public Health Agency of Canada and Health Canada, 2012). Turchi and Smith (2018) offer that the best practice message currently approved at government level almost universally is:

- There is no amount of alcohol during pregnancy that is risk-free.
- There is no kind of alcohol (beer, wine, spirits, etc.) during pregnancy that is risk-free.
- There is no time during pregnancy when alcohol consumption is risk-free.

(p.1).

As a teratogen, alcohol can travel unobstructed through the fetus's bloodstream and into the fetal brain (Mullally et. al., 2011). As a toxic substance, it disrupts the delicate process of fetal formation, leading to a wide range of neuropsychological deficits (Dobson et. al., 2016; Riley, Infante and Warren, 2011). The neuropsychological deficits found in children prenatally exposed to alcohol include deficits in visuospatial functioning, verbal and nonverbal learning, attention, and executive functioning (Chasnoff, 2011; Mukherjee et. al., 2016; Petrenko, 2015).

Subsequently, these children will also exhibit a variety of behavioral problems that can further challenge their daily functioning and structural compliance with rules and regulations (Catterick and Curran, 2014; Malbin, 2002). It must be understood that alcohol, as a teratogen, has the ability to affect all the organs of the developing fetus, with the brain being the most sensitive to this potential damage (Riley, Infante and Warren, 2011, Dobson et. al., 2016)

Any discussion of alcohol use/misuse needs within pregnancy needs consideration alongside multiple underlying factors that can influence the development and functioning of the human brain. In the past decade, neuroscientists and cognitive psychologists have begun delving into childhood brain development from multiple perspectives. It is also worth noting that the social detriments of health play a significant role in the prevalence of FASDs within society (Bertrand et. al., 2004). Low socioeconomic status, lower educational levels, partners who consume and abuse alcohol and use of other illicit drugs are all contributing factors to the level of FASDs in society (Salmon, 2008). Such toxic environments also add to the complexity of recognizing the neuro-disability of FASD and provide other etiologies of impaired cognitive and brain development maturation (Riley and McGee, 2005). Such environments, although common to CWSWs, will provide major challenge of differentiating neurodisabilities and seeing FASDs. Hemingway et. al. (2018) found that twins exposed to the same levels of parental alcohol exposure had very different outcomes “Despite virtually identical PAE, 4/39 (10%) dizygotic twin pairs had FASD diagnostic contrasts as large as PFAS vs ND/AE”

(p. 16). This study further determined that:

“despite virtually identical prenatal alcohol exposures, two fetuses can experience vastly different FASD outcomes. So which fetus is genetically vulnerable? We currently have no way of knowing. Thus, to protect all fetuses, especially the most genetically vulnerable, the only safe amount to drink is none at all” (p. 23).

As no two children with an FASD present the same needs, the CWSW must prepare individualized plans and respond appropriately. This provides the CWSW with assessment and intervention challenges within a plan of safe care. Not having sufficient education and knowledge to understand the breadth and scope of FASDs may leave the CWSW inadvertently making incorrect assessments. Equally, the fear of offering stigma in seeking information

regarding alcohol use in pregnancy is likely a further paralyzing fear within intervention activities.

It's further noted in the empirical literature that 'stigma' is potentially one of the most evident and dominant forces now impeding professional practice in prevention work and developing interventions for the improvement of maternal-child health (Choate and Badry, 2018). The issue of stigma has become somewhat of a paralyzing force in responding to FASDs, which was further highlighted by Bell et. al. (2015) who stated “ There is a lack of knowledge about the factors that contribute to stigma for FASD individuals and how it impacts their lives in spite of the potential harm of stigma” (p. 74).

The relationship between stigma and discrimination against individuals with an FASD and their caregivers is multifaceted. Adopting a unique cultural lens to the public health issues of alcohol in pregnancy is essential within the site of this inquiry. A cultural sensitivity lens is a lens through which the specific opinion of alcohol is viewed, how maternal rights and needs are respected and what services exist and what services are needed to address parental alcohol exposure and the needs of those born with an FASD. The need for professional competency-based education, which encompasses the many components of maternal and child health within the cultural lens, is essential to tackling stigma and ensuring equity in access to treatment and service delivery of care (Domeij, Hulterantz et. al., 2018). It is vital to understand the many and varied origins of stigma when it comes to FASDs. It is only when we fully understand the dynamics surrounding stigma and FASDs, that we can strive to address and prevent stigmatization within society, and thus prevent FASDs.

Alcohol in the Irish Cultural Context

When discussing any aspect of alcohol harm within Irish society, it has to be contextualised into the wider and historical placement of alcohol in society. In general

classifications of alcohol harms, Ireland tends to figure as having one of the highest levels of alcohol consumption in western culture (Martin et. al., 2010). It is common for many people within Irish culture to regularly exceed safe alcohol limits and partake in binge drinking. In a national survey by Long and Mongan (2014) of 5,991 respondents in 3,897 households found a “75% of the alcohol consumed was done so as part of a binge drinking session” (p. 11) in the week prior to the survey. Alcohol, as a substance, originally brewed for pleasure and leisure by our forefathers, is an ancestral product which has become a major detriment to health and wellness within Irish society.

Indeed, a description by Monaco et. al., (2019) may best sum up how alcohol is viewed when they described alcohol as “Both divinized and demonized, it is nowadays at the heart of a great controversy at health and social levels” (Monaco et. al., p.1). Its causal effect on the human body of multiple health conditions cannot be denied by the mounting medical and scientific levels of evidence now available to policy makers. As noted by Mongan et. al. (2009) alcohol permeates all sectors and services of Irish society when they noted the consequences “include spouse/family problems, public disturbances, violence, and reduced work performance, which impact on all facets of society” (p.7).

The implications of alcohol’s hold on Irish society is shown to severely impact the public health system within the site of inquiry. Long and Mongan (2014) stated “it may be concluded that we, in Ireland, consume alcohol in an unhealthy pattern ... and do not realize that they consume alcohol in an unhealthy manner ... that harmful drinking is the norm in Ireland, in particular for men and women under 35 years” (p. 50). It is within this culture where alcohol harm is considered a ‘norm’ that the issue of parental alcohol exposure has struggled to gain any momentum in Irish public health approaches. In a study in 1992, Daly et al, noted there was a worrying level of ignorance by pregnant women about the dangers of alcohol. Further concern

expressed around this time was offered by Walsh et. al., (2007) who found that 58% of a study group concerning alcohol use in pregnancy “did not want to alter their consumption behavior even after being informed of the risks by health professionals” (p.7). In 2007, Barry et. al. (2007) offered that it is “time to investigate the extent of alcohol and other substances consumption in pregnancy in Ireland” (p.1). In this seminal Irish longitudinal study, Barry further articulated “that the issue of alcohol harm in pregnancy requires ‘collaboration of pediatricians, child psychiatrists and other health professionals’” (p.18). It was a study by Mongan, Hope and Nelson (2009) that offered one of the first descriptions of FASDs in Irish literature when they offered that:

“The most devastating effects are the intellectual disabilities associated with the negative impact of alcohol on fetal brain development and the central nervous system. Fetal alcohol spectrum disorder (FASD) is the umbrella term used to describe the various developmental disorders associated with maternal alcohol use during pregnancy” (p.19).

Although multiple calls have reverberated in Irish society over the years concerning prenatal alcohol exposure and FASDs, little has moved in terms of collective agency responses both to prevention and management of FASDs. What is further evident is the lack of “dot joining” between the empirical evidence on FASDs and the pragmatic reality of this neurodisability impacting child welfare services and the profession of social work. Evidence is mounting in the international dialogue on FASDs of the real and present reality of children living with this neurodisability requiring state systems of health and social care services but experiencing systemic barriers (Petrenko, Tahir, Mahoney, and Chin, 2014).

Ireland continues to have a difficult relationship with alcohol, with one academic recently noting “ Irish consumption levels remained high by international standards as did the prevalence of adverse consequences of such consumption” (Butler, 2015, p. 107). A recent study by

O'Dwyer and Mongan (2019) further found that “public awareness that alcohol can increase the risk of developing a variety of health conditions is low” (p. 21). The high level of prenatal alcohol exposure being one such ‘adverse consequence’ and with low ‘public awareness’ of alcohol health risks is a concerning view of Ireland's relationship with alcohol. Together they pose a major challenge in addressing the prevention of FASDs

The Current Picture of FASDs

Although significant efforts have been made throughout the western world to educate people about the risk factors associated with prenatal alcohol exposure, such efforts have mixed results in achieving prevention goals (Warren, 2015). Scholars continue to predict a rise in FASDs (Petrenko and Alto, 2017), and findings indicate that the prevalence of the FASDs may now be close to 5% of the birth rate in the general population (May et. al., 2014, 2018). It must be noted that this prevalence of FASDs births is taking from within North American Culture, where the alcohol in pregnancy rates is lower than in Europe Union cultures. McQuire et. al. (2019) in a UK study in the south of England produced a prevalence birth rate of FASDs at 17%.

It was noted in this study that within the European Union, the UK had the fourth highest rate for alcohol use in pregnancy at 75%, 7 percentage points lower than the Irish documented rates of 82% produced by (O’Keeffe et. al., 2015). May et. al. (2018) found a prevalence birth rate of 20 to 28% in specific communities in South Africa. These three birth prevalence rates offer a wide variation from 5% to 28%, indicating a need to approach prevention of FASDs through a particular cultural lens. Investigators have demonstrated that alcohol's impact on the developing fetal brain, combined with environmental factors, is the source of a high rate of co-occurring mental health disorders Popova (2019), and child welfare populations (Chasnoff, Telford, Wells and King, 2015; Popova et. al., 2014). CWSWs are challenged daily to understand and plan for the needs of children coming from toxic environments will have children

with an FASD coming through the same service door. Planning a safe care package for the child with an FASD is poorly articulated in child welfare literature currently.

Rapid development of technologies within the medical sciences, such as magnetic reasoning imaging (MRI), have dramatically expanded the understanding of normal and abnormal brain development in utero (Thomason, 2014). Rutledge (2014) suggests that neuro-scientific principles provide "Insight and awareness into the bio-physiological processes that underlie traumatic experiences for children" (p. 2). This suggests that social work practitioners may need a specific education to understand the many origins and causes of brain-based behaviors and their impact on the child welfare service. Having such input will likely empower CWSWs to understand the variance of brain-based behaviors that are commonplace with CWSWs assessment activities.

Despite scientific advancement and evidence on the risk that alcohol poses in facilitating fetal brain impairment, there remains significant cultural denial of such risk and harm in western cultural settings. Riley and McGee (2005) offered that alcohol-induced brain injury derives long-lasting cognitive and memory consequences. However, a significant body of literature has shown that the denial of the toxic effects of alcohol use on health outcomes in society persists even within many health domains (Rehm et. al., 2009; Stewart and Wild, 2017).

Recently, a causal relationship has been established between harmful alcohol use and the incidence of infectious diseases such as tuberculosis and HIV/AIDS. Beyond health consequences, the harmful use of alcohol leads to significant social and economic losses for individuals and society at large (O'Donnell et. al., 2018). The WHO Global study of alcohol harm (Organization and Unit, 2014), discusses the harmful effects of alcohol on individuals and those around them. What is not developed sufficiently in the mainstream literature is the causal link between alcohol consumption in pregnancy and the derailment of fetal brain development,

with lifelong consequences (Curran, 2007; Dobson et. al., 2016; Streissguth et. al., 1996).

Understanding and acting on the public health issue of alcohol in pregnancy can bring significant economic and psychosocial benefits to society as a whole (Coles, 2003; Mukherjee et. al., 2016; Popova et. al., 2011; Public Health Agency of Canada et. al., 2012).

It is widely noted in the literature of both child and public health, that the first 1,000 days of life, starting at conception, are the crucial building blocks for a successful, healthy life (Louw, 2018). Fetal alcohol, as a result of an alcohol-exposed pregnancy, is a significant detriment to the goal of 1,000 days of healthy development and continues to be written about in the context of lifelong neurodevelopmental and cognitive impairments originating during pre-birth gestation (Badry and Felske, 2011; Cook et. al., 2016; Dobson et. al., 2016; Hellman's, Sliwowska, Verma and Weinberg, 2010).

Previous studies have also highlighted the destructive effect that alcohol-exposed pregnancy can have on the fetal brain and its development (Abel, 1988; Olson, 2009; Riley and McGee, 2005; Bertrand, 2009). All those concerned with child development from preconception to adulthood will need to engage in the prevention of FASDs to achieve a healthy and prosperous life. The unborn does not have a voice to speak up on the dangers of prenatal alcohol exposure, it therefore falls to all who seek healthy children and prosperous society. Niccols (1994) wrote in the *Clinical Psychology Review* that "it has become apparent that alcohol, like other teratogens, gives rise to a spectrum of defects, with affected children shown much individual variation in both the extent and severity of their involvement" (p. 107). This demonstrates that there has been knowledge of the effects of alcohol-exposed pregnancy within the medical professions for some time, but CWSW do not transmit this knowledge as effectively as perhaps other pregnancy health information, such as the risk of smoking in pregnancy.

This is also evident when comparing the knowledge transfer of alcohol-exposed pregnancy with the knowledge transfer on the effects of smoking on pregnancy, as in the pregnancy health information strategies currently applied in many western cultures. In Canada through the *Tobacco Products labelling Regulations (Cigarettes and Little Cigars)* which came into force in September 2011, all tobacco products are mandated to carry health information messages both on and in their products (Hammond, 2011). On the Health Information Cards inside packets of cigarettes, one now finds explicit language outlining the risk that smoking presents to fetal development. The universal application of these health messages has seen a considerable decline in smoking during pregnancy in Canada (Health Canada, 2013). However, it was two years earlier that Society of Obstetricians and Gynaecologists of Canada (SOGC) issued a *Practice Guideline* instructing that all pregnant women who smoke should be provide with counselling services (Wong et. al., 2011). It may suggest that both initiatives have proved successful in changing societal norms concerning smoking in pregnancy, offering signposts for potential societal changing on alcohol use in pregnancy.

When discussing the effectiveness of prevention labels concerning alcohol in pregnancy, most labels originate from the United States approach adopted in 1989. The United States health label is fixed rather than rotating and has not changed since its first introduction in 1989. The label reads:

“GOVERNMENT WARNING: (1) According to the Surgeon General, women should not drink alcoholic beverages during pregnancy because of the risk of birth defects. (2) Consumption of alcoholic beverages impairs your ability to drive a car or operate machinery and may cause health problems.” (U.S. Congress, Alcohol Beverage Labeling Act, 1988).

Although very small print is used on many alcohol products, the display of such warnings in bars in the U.S. tends to be very vivid.

Unfortunately, it is still challenging to find an equal application of health information on the risk posed by alcohol to fetal development and brain function with the cultural site of inquiry. The lack of political will to address the public health issue may be one of the most significant impediments to prevention strategies. Where government approaches have attempted to address the problem, they tend to fail in universal application and enforcement. Warren and Chezem, (2018) note that "To be most effective, policies for the prevention or mitigation of FASD should be grounded in explicit statutory provisions" (p. 14). It will also be necessary where statutory approaches are taken, that such approaches are monitored to ensure full implementation of such statutory directives. As noted in Chapter 1, Ireland recently introduced legislative directives on labeling and public notifications regarding alcohol use in pregnancy. This may suggest we are finally seeing some political will to address this major public health issue in Ireland.

FASDs and Child Development

The development of the central nervous system starts in utero and continues through adolescence and early adulthood (Archer, Kostrzewa, Beninger and Palomo, 2010). Much has been written about how both genetics and the environment can derail the developmental trajectory of human life (Archer et. al., 2010; Riley and McGee, 2005; Jones and Smith, 1973). It is now known that various substances can affect neurodevelopment negatively and can alter the developmental trajectory of specific abilities, processes, and functions (Chokroborty-Hoque et. al., 2014). A well-established knowledge base of recent advances in the science of early childhood development and its underlying etiology, provides a better in-depth understanding that can inform and improve policy and practice initiatives and can help develop new ways of thinking about what needs to be done (Chevalier, Finn, Harmon, and Heckman, 2006).

Acknowledging, assimilating and disseminating scientific knowledge of the fetal brain should be integral to any strategies seeking to promote safe, healthy children in the future (Drabble et. al., 2011).

As a teratogen, alcohol is a toxic element (Mattson and Riley, 1998; Dobson et. al., 2016), that is shown to disrupt fetal development severely. The multiple effects of fetal alcohol exposure are likely due to a combination of direct and indirect interactions of alcohol with biological processes occurring at the time of exposure. It, therefore, must be acknowledged that ethanol, as a teratogen, is just one of the many causal factors impacting brain development in utero and leading to irreversible neurobehavioral, neurocognitive and neurodevelopmental presentations in early childhood development. (Warren and Chezem, 2018, p. 14). One such causal factor discussed in literature is that of air pollution where “exposure to air pollutants during fetal development and early postnatal life has been associated with adverse birth outcomes” (Wang and Pinkerton, 2007, p. 144). Such risks to fetal development provided by the air a pregnant woman breathes may prove difficult to prevent due to the lack of personal control over the environment.

As demonstrated by Wang et. al., (2018) the broad application of synthetic chemicals now commonly used in everyday products such as soap, shampoo, perfume, deodorants, pose an equal risk to the developing fetus. Such “risks” giving their pervasive use in society will further challenge society in its efforts to protect the development of the fetus. The primary difference between alcohol and other toxins influencing development is that we have the ability to prevent alcohol exposure to fetal brain development (World Health Organization, 2014)

Due to the diffuse teratogenicity of alcohol on the brain, the impact of alcohol exposure on the developing child can occur across physical, cognitive, behavioral, and psychosocial domains (Mattson, Crocker and Nguyen, 2011). The work of Mattson et. al. (2011) and the work

of others (Dobson et. al., 2016; Popova et. al., 2016; Riley et. al., 2015; Jones and Smith, 1973) challenge society to formally acknowledge that the fetal brain maturation stage can be disrupted and impaired by exposure to alcohol, with significant consequences for the individual, the family and society.

One of the more acknowledged aspects of brain impairment in the child with an FASD is the gap between chronological age and their developmental stage of cognitive and behavior presentation. (Fast, Conry and Loock, 1999). Anderson, Harding, Reid, and Peia (2018) showed inappropriate sexual behaviors due to impairment in the cognitive and development maturation to be a risk factor for children with an FASD. Inappropriate sexual actions are just one aspect of the many secondary disabilities and difficulties to stem from FASD (Streissguth, Barr, Kogan and Bookstein, 1996). Like the majority of secondary disabilities stemming from FASDs, inappropriate sexual behaviors either as a victim or a perpetrator is a high precursor for the involvement of CWSW who have the opportunity to respond and support individuals in managing their secondary disabilities and preventing negative outcomes (Olson, Oti, Gelo and Beck, 2009)

An FASD translates into daily challenges for children, adolescents, and adults, and in across multiple domains of functioning, including behavioral, academic and social functioning (Riley and McGee, 2005; Streissguth et. al., 1996). Although widely and succinctly demonstrated in scientific findings, society still views the risk of alcohol derailing development with skepticism and sees the FASD disability as an enigma to be dismissed (Huitson, 2014).

However, what is known is that children with an FASD experience both cognitive and social function impairments which curtail childhood developmental and the ability to conform and to succeed in society (Brown and Rodger, 2009; Chamberlain, Reid, Warner et. al., 2017). Developing interventions in early childhood is shown to be effective in maximizing the potential

of children with FASDs by assisting them in adapting to cognitive, behavioral and functional difficulties, and reducing secondary disabilities (Streissguth et. al., 1996).

The lack of substantive structured pathways to services continues to be the primary objective advocated by caregivers who are tasked with maintaining and developing children's developmental milestones and expectations (Mukherjee et. al., 2013). FASDs need to be incorporated into mainstream service provision to meet this childhood development goal, a point repeatedly stressed in research findings and Government advocacy strategies (PHAC, 2019). Any such inclusion of FASDs into the mainstream service provision of child welfare services will need to fully incorporate the knowledge and skill development needs of social work personnel (Meekosha and Dowse, 2007; Wilson, 2013, Durkin, 2016). Kislov et al, (2014) state that "It is becoming increasingly recognised that the translation of research evidence into practice has to be supported by developing the internal capacity of healthcare organisations to engage with and apply research." (p.166). Developing capacity and confidence within CWSWs and allied health colleagues is essential to delivering on FASD-informed interventions and supports and services. This will require allied health educators of undergraduate university education to bring a psychosocial model of FASD education into that university lecture halls.

Literature addressing the needs and skills of CWSWs in delivering on their statutory role in managing the neurobehavioral presentations of FASD is lacking. Ultimately a situation where the caregiver is educated and the CWSW is not, will potential lead to strained relationships in the collective efforts of planning safe care for the child with an FASD. It is therefore necessary that CWSWs must be educated equally, as they carry the statutory duty of keeping the child safe.

Having CWSWs at an FASD-informed level is an additional layer of protection that a child with an FASD does not suffer and level of maltreatment due to their disability. The FASD literature does not address the risk factors of maltreatment while in out-of-home care for children

living with intellectual deficits due to prenatal alcohol exposure. However significant literature exists concerning the issue of intellectual disabilities and child maltreatment (Hibbard, Desch, Abuse, and Neglect, 2007). CWSWs need to be mindful of this area of care in their case work with children living with this disability. Organised advocacy in the field of FASDs has grown very strong over the years. Many of these advocates will be foster parents whose knowledge and experience of FASD may intimidate CWSW while assessing plans of safe care.

Current Developments in Child Welfare Services

Substance abuse by parents is associated with the placement of at least half of the children in the custody of child welfare in the USA (Child Welfare League of America, 1997). In 2013, alcohol abuse by parents was listed as one of the reasons that approximately 16,000 of the 254,887 children who entered care that year were removed from their homes (U.S. Department of Health and Human Services, 2013). Similar statistics are produced across many other cultures documenting the issue of parental substance abuse and subsequent involvement of child welfare services and CWSW.

Children with parents who abuse drugs and alcohol are at high risk of becoming subjects of child protection investigations (Dubowitz, Kim, Black et. al., 2011). It is further noted by Kambeitz, et. al., (2019 that children with an FASD ‘are often exposed to abuse, neglect and foster home placements which have uncertain effects on the lifelong course of FASD’ (p.1). What is further acknowledged by child welfare research, is the role substance abuse has on the development of children living in environments of neglect and deprivation. As Stahmer and colleagues (2005) note:

“Children referred to child welfare, have high developmental and behavioral needs regardless of the level of child protection involvement. Both age and level of

involvement influence service use when controlling for need. Mechanisms need to be developed to address disparities in access to intervention” (p. 891).

The CWSW may be the first port of call for a family struggling with the behavior associated with prenatal alcohol exposure. Or it may be a schoolteacher saying that a child’s behavior is likely to result in expulsion and asking for social work involvement. Again, due to the range of possible behaviors and presentations, the referral to CWSW may come from a range of sources all of which will be seeking the CWSW to work a magic wand and mediate the presenting problem.

Currently, without policy and system awareness, FASD is rarely flagged in social workers’ interventions. Studies have repeatedly highlighted the presence of FASDs in child welfare, with Popova et. al. (2013) offering the insight that:

“based on the current Canadian and international literature, the prevalence of children in care with FASD is likely higher than in the general population, and thus, the fiscal burden associated with children in care with FASD in Canada is considerable” (p. 84).

A significant body of empirical research further documents the various impacts. Brown, Sigvaldason, and Bednar (2005) found that foster parents caring for children from the child welfare service needed ‘responsive professionals’ who were skilled and knowledgeable about FASD to aid them in their caring duties. Chasnoff, Wells, and King (2015) call for “early recognition of the child or adolescent with FASD” (p. 265) and for a referral to providers who can facilitate proper treatment and care planning and assessment. As child welfare services depend on many services outside its direct control, this need for services as part of assessment may prove difficult of partner agencies are not in an FASD informed mode.

Popova, Lange, Burd and Rehm, (2014) state that FASDs are placing a considerable economic burden on child welfare service in Canada, with the annual cost of care ranging from

\$57.9 to \$198.3 million. An additional study by Stade et. al. (2009) found that, including the cost of social services, medical care, and education, the cost of prenatal alcohol exposure related impairments to Canadian society is approximately \$5.3 billion annually. The fiscal burden appears to be increasing as time progresses, with Chokroborty-Hoque, Alberry and Singh (2014) finding the annual cost burden to be a staggering \$7.3 billion (p. 2). This fiscal burden has risen even further to 9.7 billion per year in Canada (Thanh and Jonsson, 2018). Interestingly, 40% of this total cost (3.9 billion) was associated with crimes stemming from FASDs, with social services cost 13% of the overall costs (p. 53). In the latest Canadian publication, the yearly cost burden of FASDs was said to be “costing about \$10 billion” (Jonsson, 2019, p. 162). The most recent available cost burden analysis for the USA is offered by (Sacks, et. al. (2015) who place the annual cost burden of “drinking while pregnant at 5.5 billion” (p. 73). Such rising socioeconomic costs related to FASDs need to be conceptualized and considered within the broader health service costs on society, at a time where such health budgets are under pressure (Sisko et. al., 2009). Within the site of inquiry, such costs are likely masquerading within mainstream health budgets and therefore not understood as an implication of prenatal alcohol exposure. It should however be considered that it’s not the government that is paying this cost burden, it’s the taxpayer as health budgets are directly linked to tax burden of society. This may be a further catalyst for societal change and seeking better prevention efforts if individual members of society understand the socioeconomic burden of pre-natal alcohol exposure is directly linked to personal tax burden.

Perhaps a more worrying aspect of Vignette 2, was the finding that, following a clinical assessment and a diagnosis of FASD, this 10-year-old had been returned to the child welfare service without a sufficient treatment and follow-up plan (Pringle, 2014). This finding by Pringle points to one of the most significant challenges facing child welfare policymakers as they search

for a systematic practice and a policy response to children suspected of having a condition that falls within the FASD Continuum and who are seeking or receiving services from Child Welfare Service. According to Badry and Choate (2015), the FASD community is in “urgent need of what social work can offer” (p. 29). They suggest that any policy or procedural development within child welfare service needs to engage the CWSW at its core. This will require a paradigm shift away from the current “epidemiological, diagnostic and behavioral containment” focus (Badry and Choate, 2015, p. 29). Such a ‘paradigm shift ‘will need to see the child with an FASD and address their presenting needs of adaptive, executive and sensory difficulties pre-diagnostically, creating an evidence-based practice in the process.

The equally troubling case of a child with an FASD residing in an Australian child welfare service foster placement was documented in 2018 (Vignette 1). Although diagnosed soon after birth, there was a lack of understanding of his needs within the system of care. Ultimately, the behavior management technique to move HLS to the Australian outback, as a mean of removing him temptations and distractions is ultimately shown to be a failed procedure in behavior management strategies.

An accumulative body of evidence demonstrates that children’s cognitive impairments, behavioral presentations and sensory difficulties stemming from an FASD, create significant challenges and stresses on caregivers charged with their care (Bakhireva et. al., 2017; Brown, Sigvaldason and Bednar, 2005; Mukherjee et. al., 2013; Murray, Tarren-Sweeney and France, 2011). Both foster and adoptive parents associated with the child welfare services are continually advocating for the children they care for who live with an FASD (Baskin et. al., 2016; Chamberlain, Reid, Warner, Shelton and Dawe, 2017; Mukherjee et. al., 2013). Gough and Fuchs (2008) argue that more research is needed to determine the unique developmental needs of children with FASDs. Such research could meet the needs of those caring for children from the

child welfare service who live with an FASD. There is an urgent and pressing need for officials of child welfare services to begin such research on the developmental needs of those living with FASD and to raise the skill level of CWSWs in administering interventions and sharing information with both adoptive and foster parents (Badry and Choate, 2015; Durkin, 2016; Gibbs, 2018; Pomeroy and Parrish, 2011).

Christine Petrenko and colleagues in the U.S. are fully focused on the needs of caregivers, especially foster parents, in the FASD dialogue. Petrenko has demonstrated repeatedly that caregivers need to have evidenced based education to manage the neurobehaviorally presentations of FASD (Petrenko, 2015; Petrenko and Alto, 2017; Petrenko, Demeusy, and Alto, 2019; Petrenko et. al., 2014). Stessguth (1996, 2004) demonstrated that caregivers who are supported in the caring task can successfully alleviate the trajectory of children sliding into secondary disabilities of addiction, mental illness, and school failure. Consistent, stable caregiving is an important protective factor in the lives of children with an FASD, highlighting the need to support birth parents and caregivers.

CWSWs can and should be in a position to assist and alleviate some of these challenges by delivering a holistic model of care planning for a child with an FASD. There is a pressing need to develop a psychosocial lens and neurodevelopmental screening tools for understanding the lived experiences of children who have an FASD (Astley, 2011; Charach, Bélanger, McLennan, and Nixon, 2017). There is a large body of literature concerning FASD, which focuses on prevention, scientific and medical diagnostics and the importance of seeking an early diagnosis (Group, 2016, p. 3). Meanwhile, we are still struggling to help children living with an FASD assimilate and manage the lifelong needs and the services required in the post-diagnostic environment (Badry and Felske, 2011; A. P. Streissguth et. al., 1996; Wilson, 2013).

Chamberlain, Reid, Warner, Shelton and Dawe (2017), documented caregivers lack of support beyond purely diagnostic services. Further, Doak, Katsikitis, Webster and Wood, (2019) identified “ongoing difficulties regardless of diagnosis” as a common belief for caregivers caring for a child with an FASD. So, we also need to ask what post-diagnostic services might look like and what would be required to achieve a holistic, system-wide response to children living with FASDs. Children in foster care are already at high risk for educational disruptions as well as behavioral and developmental issues Murray et. al., (2011), which are exacerbated when that child has an FASD (Dobson et. al., 2016).

Evidence continues to emerge on service shortfalls for children with an FASD – a common complaint emanating from caregivers in the post-diagnostic caring role (Mukherjee et. al., 2013; Sanders and Buck, 2010). Part of the shortfall in services may rest with societal denial of the disability and its needs. Chasnoff, (2011) noted that many professionals continue to dismissive of the presenting needs – seeing them as temporary variants of healthy development – i.e. "she is just a fussy child" and "boys will be boys" – (p. 71), with professionals believing they will grow out of the presenting behavior. Equally, Mukherjee et. al., (2015) found that there was a degree of arrogance operating within the unified health system, with evidence that individuals were refusing to accept the existence of FASDs. Refusing to recognize and acknowledge the disability associated with FASD, is to deny a significant legislative mandate enshrined most western countries, which is Article 3 of the Convention on the Rights of the child. Article 3 states: "In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration" (Assembly, 1989). Coveney, (2018) demonstrated that although Ireland does have obligations under the CRC, it is currently failing to ensure the best

interest of the child, who is living with prenatal alcohol exposure deficits. The need to incorporate visible protocols to address this weakness within the law is evident.

Exemplary Models

In recent years, there have been some systemwide responses to the problem of FASDs, in which child welfare services have played a central role. Perhaps the most noted of these responses has been the ten-year strategy developed in Alberta, Canada, from 2008 to 2018. A brief look at Alberta FASD Service Networks (2012) demonstrates a holistic province-wide approach to FASDs. What is not discussed widely in current literature is the fact that Alberta's leadership within the FASD child welfare paradigm is due primarily to social workers and foster parents coming together in the early 1990s to advocate for legislation ensuring recognition of FASD and services for people affected by it (Shankar, 2015).

To the year 2019, the government of Canada had invested 27 million dollars over the previous 20 years addressing FASDs (PHAC, 2019). It may be deduced that this spending is primarily on research and not on the provision of services and education. Currently, it is not possible to source any information on funding that supports CWSWs in their statutory role of intervening in cases of FASDs, which a weakness in the holistic response to FASDs, given the empirical evidence of the burden and failings with child welfare services when it comes to FASD.

A more recent systems approach is currently under development in New Zealand, where the government has initiated a three-year strategy for the period 2016 to 2019 (Group, 2016). What is encouraging in this strategy is its explicit statement of the impact of FASDs on child welfare service. On page two of the program report, it states that “FASD affects about 50% of children and young people in Child, Youth, and Family (CYF) care” (Group, 2016, p. 2). A

closer look at this strategy reveals that the CYF is a vital stakeholder in the holistic policy currently being implemented.

The New Zealand government has elected to approach FASD on four key platforms: Prevention, Early Identification, Supports and Evidence (Group, 2016, p. 3). What is further encouraging about this government strategy is the number of stakeholders from within the structures of the New Zealand government forming a collective and cross-government holistic approach to the management of the disability. A reading of this strategy clearly shows child welfare services as a key player within the overall approach.

A more recent development is seen with the Australian government, which also is moving on with a multidisciplinary and multiagency focus in addressing FASDs within Australian culture. One of the first government acts on their new 10-year action plan was to announce a \$7 million investment in the prevention and management of FASDs (Health, 2019). This investment is now showing promise with the development of multidisciplinary resources with Australia. Doak et. al., (2019) describe one such service:

“Children were referred to the Sunshine Coast CDS FASD clinic by medical practitioners. All FASD assessments were conducted as per the Australian Guide to the Diagnosis of FASD. The CDS FASD multidisciplinary team comprised of a pediatrician, psychologist, speech pathologist, occupational therapist, social worker, physiotherapist, and clinic management staff” p. 2).

This model is similar to that which is operating within the Alberta service in Canada, and exemplifies the scholarly literature denoting that FASDs must be addressed and managed within a multidisciplinary framework. The inclusion of social work in such approaches is pivotal to the broader psychosocial needs impacting the child and their caregivers. A multidisciplinary approach ensures that professionals from a variety of services can provide education to their

professions. Streissguth, (1997) noted in that "professional training was best accomplished by trainers from the same profession as those being trained" (p.254). This is a particularly relevant consideration to be applied to CWSWs, giving the complexity of their role and their mandatory responsibility to provide a Plan of Safe Care to children living with an FASD. By receiving training from a member of their own profession who understands the complexity of child welfare assessments, the CWSW is more likely to be able to assimilate the FASD messages professionally.

The Diagnostic Quandary - Ethical Challenges

The clinical approach to FASDs has developed considerably since the publication of the Jones and Smith paper (1973), which offered the first set of guidelines to diagnose FAS. From this point forward, the mantra of ‘receiving an early diagnosis’s (Carpenter, Blackburn and Egerton, 2014; Chudley et. al., 2005; Streissguth et. al., 1996) has dominated the discourse concerning FASDs. Currie, et. al. (2016) state that ‘early diagnosis leads to the receipt of more supports throughout childhood and contributes to a better understanding of FASD by families and caregivers’ (p. 37). What is less debated or discussed in the early diagnostic mantra, is that the many and varied presentations of FASDs, make it extremely difficult to identify, screen assesses, and diagnose an FASD (Brown, Harr, Morgan, Varga, and Fenrich, 2017). Literature calling for early intervention and diagnosis fails to encapsulate the need for a cultural lens when seeking early diagnosis to ensure that treatments and services are available in the post diagnostic life.

As noted in Chapter One, FASD is not a diagnostic term but merely a term to encompass a number of different diagnoses. These different diagnoses resulting from prenatal alcohol exposure present in varying in degrees. The most severe outcome of prenatal alcohol exposure is FAS (760.71) of the ICD 10. Others include partial FAS (pFAS) and more recently,

Neurodevelopment Disorder – Prenatal Alcohol Exposure (Neurobehavioral Disorder associated with Prenatal Alcohol Exposure (315.8 DSM-V), (Association, 2013). Currently, there are five diagnostic tools applicable to the assessment/diagnostic of an FASD. These are:

1. The Emory 4-Digit Diagnostic Code (Astley and Clarren, 2000)
2. The Washington 4-Digit Diagnostic Code. (Astley, 2004)
3. CDC, Guidelines for Referral and Diagnosis (Bertrand et. al., 2004)
4. Canadian Guidelines (2005) (Chudley et. al., 2005) (2016), (Cook et. al., 2016)
5. Hoyme Modifications, (2005). Update (2016) (Hoyme et. al., 2016).

Of these five, the Washington 4-Digit Code is by far the most validated and used in many American clinics and internationally around the world. However, Canada is running a trial on a new diagnostic guideline which aims to be more in tune with addressing the needs of those living with an FASD who do not have dysmorphic features (Cook et. al., 2016). A significant change offered by Cook et. al., (2016) is that the term FASD with or without sentinel facial features is now a diagnostic term. This conflicts significantly with previous diagnostic literature that noted FASD as an umbrella term and not a diagnostic category. The new guidelines from Cook et. al. does away with fetal alcohol syndrome, Neurobehavioral Disorder associated with Prenatal Exposure, etc. It must be however acknowledged that the umbrella terminology of FASD is still used in the United States and other parts of the world and is found in the majority of FASD literature including this study. The new approach has drawing significant critique with McLennan and Braunberger (2017) offering:

“The new guideline does not shed light on the extent to which mental health disorders seen in persons diagnosed with FASD ought to be considered part of FASD, rather than as comorbidities. It is also not clear how an FASD diagnosis will improve outcomes of persons with neurodevelopmental difficulties” (p.182).

Again, we are offered confusion and contradictions concerning diagnosis playing out in the literature, highlighting the competitive nature of the FASD diagnostic debate. Calls for clear, concise and universally applied clinical diagnostic are frequent within the dialogue with Burd and Popova (2019) noting and calling for development of “universal clinical diagnostic guidelines for clinicians who care for people with FASD” (p. 2).

As a new tool, the new Canadian guideline introduces further challenges within the diagnostic discussions. Although such tools exist and have done for some time, we are still in a position in 2019 where it is difficult to recommend anyone approach as there is still “an absence of a gold standard for diagnosis or a diagnostic biomarker” (Chudley, 2017, p. 232). It was noted by Popova that the total annual cost of diagnostic services in Canada ranges between \$3.6 million on the lower end to \$7.3 million at the upper end (Popova, 2013).

What remains a concern within the FASD world is that diagnostic guidelines suffer from a significant number of divergent views owing to the complexity of the diagnostic challenge to prenatal alcohol exposure. A consensus is evident on FASD owing perhaps to its clear guidelines offered in the ICD 10 and published reports (Bertrand et. al., 2004).

Many of the divergent views come from within the FASD dialogue and could classify as a “war within” on FASD. After a half century of research on the outcomes of prenatal alcohol exposure, there is still a lack of consensus on ‘diagnostic categories and conditions’ (Bastons-Compta, Astals, and Garcia-Algar, 2016). With the confusion on diagnostics, child welfare service and CWSWs are left without direction on the statutory duties of keeping children safe and understanding what services are needed. Domeij, et. al., (2018) showed that a diagnosis of FASD may increase stigma and isolation for the individual (p. 5).

Equally birth mothers talk of being “oppressed and stigmatized” when health professionals are at odds concerning FASD diagnosis and FASD knowledge (Salmon, 2008,

p.191). Mothers of children with an FASD talk of feeling abandoned by health care professionals and express much frustration concerning the attitudes of health staff (Sanders and Buck, 2010). Attitudinal actions by health staff and CWSW concerning alcohol use in pregnancy towards birth mothers is likely to further fuel stigma. However, it is imperative to consider that cultural norms of alcohol use and misuse will influence such attitudinal language. Indeed, Bagley and Badry (2019) noted that “allied health professional practice demonstrates that personal perceptions interact with professional decision making across various fields” (p.2). Together demonstrating that both stigma and practice decision are integrally linked to individual values when addressing FASD prevention and management within state services.

Also noted recently by Petryk et al (2019): “Emphasising a specific minimum level of prenatal alcohol exposure for an FASD diagnosis is problematic” (p.7). Demonstrating that the prenatal alcohol history which is essential, is woefully lacking in many cultures where parental alcohol use in pregnancy is not routinely recorded in antenatal charts. This sensitive area of practice will be a necessary action for CWSWs to undertake while seeking to establish the best Plan of Safe Care for a child with an FASD.

Chudley, (2017) suggests that the 4-digit code which is predicated on a multidisciplinary application carries “very complex diagnostic terms and categories; some terms only accepted in the State of Washington for funding purposes” (p. 233). Although Chudley has commented on the difficulty of applying the 4-digit code, the Code has become a primary tool of assessment throughout the world. One of the strengths of the 4 -digit code is the requirement of multidisciplinary approach to assessment and diagnosis (Astley, 2010, p. 132). However, some are seeing the inclusion of Neurobehavioral Disorder associated with Prenatal Exposure in the DSM -V as a new avenue to go with the vast majority of individuals who are living with this hidden brain injury from an alcohol-exposed pregnancy. It currently not fully

approved for diagnostic purposes as it requires further research. Brown, Trnka, and Harr, et. al., (2018) note:

“It is speculated that an inevitable refinement of new diagnostic criteria will allow mental health professionals the opportunity to diagnose Neurobehavioral Disorder associated with Prenatal Alcohol Exposure in the absence of specific medical input. Nonetheless, Neurobehavioral Disorder associated with Prenatal Alcohol Exposure holds promise improving the recognition and identification of prenatal alcohol exposure and help improve the case management and treatment of individuals with this affliction” (p. 4).

Taking the Neurobehavioral Disorder associated with Prenatal Alcohol Exposure side of FASDs into mainstream mental health services and provisions is likely to improve service availability. Also, a diagnosis under Neurobehavioral Disorder associated with Prenatal Alcohol Exposure is and will be less stigmatizing for the individual, as it can sit independent of the FASD debates in society. Neurobehavioral Disorder associated with Prenatal Alcohol Exposure is estimated to place a significant challenge on child welfare service, as it is estimated that the majority of FASD cases residing in child welfare service will be suffering from this invisible side of FASDs. Also, as noted, obtaining confirmation of the mother's alcohol use in pregnancy is problematic and ethically challenging for the CWSWs who are untrained. It is here where a lot of confusion enters the discourse for child welfare service and CWSWs, and the debate on the efficacy of seeking a diagnosis is warranted (Domeij, Hulcrantz et. al., 2018). Also, as noted in the vignettes, all four profiled cases were living with a diagnosis. Their tragic endings may be the most considerable evidence offered that post-diagnostic services and societal responses are woefully inadequate in 2019.

It is important to note what is fundamental best practice in diagnostics which was established by the CDC in 20004 and reiterated here by Astley who states “FASD diagnostic evaluation is best conducted by an interdisciplinary team of professionals, and 2) the team should use rigorously case-defined and validated FASD diagnostic guidelines” (Astley, 2011, p. 5). It’s further noted that an evaluation or input from a multidisciplinary team is the most efficient and effective approach to assessment and diagnosis along the full continuum of FASDs (Manning and Hoyme, 2007).

Evidence continues to emerge, that knowledge and service provision following a diagnostic is still lacking in many parts of the world (Alexander et. al., 2007; Caley et. al., 2008; Catterick and Curran, 2014; Mukherjee, Wray, Hollins, and Curfs, (2015), leaving caregivers and individuals living with an FASD little option on receiving the services needed to accommodate a clinical diagnosis of an FASD. In a study by Sanders and Buck with caregivers of children with an FASD, described getting a diagnosis for their child as a double-edged sword (Sanders and Buck, 2010). This double-edged sword may be best described as the diagnosis helps the caregivers understand what's wrong, but the search for services to right what is wrong is a problematic and lonely journey. While a study by Chamberlain and colleagues found that although caregivers found the diagnosis helpful, it was post-diagnosis services and knowledgeable personnel that was perceived as the most significant needs (Chamberlain et. al., 2017). The lack of FASD informed personnel within allied health systems of care is a repeated finding of social scientist seeking to address FASDs in the lived experience.

It has been acknowledged for some time now that diagnosis should ideally be accompanied by the increased availability of treatment and post-diagnostic care options (Day, Helsel, Sonon, and Goldschmidt, 2013; Moore and Riley, 2015). Unfortunately, the development of post-diagnostic treatment and care options are severely lacking in most western developed

countries, as within the site of this inquiry. This issue poses an ethical dilemma which needs to be addressed and discussed in the broader discourse (Domeij et. al., 2018; Price and Miskelly, 2015). Best Practices repeatedly articulates that an FASD diagnosis needs to be made by a multi-disciplinary team, composed of both clinical and psychosocial staff, such as psychologists, occupational therapists, and specialist social workers (Cook et. al., 2016; Hoyme et. al., 2016; Manning and Hoyme, 2007; Peadon, Rhys-Jones, Bower and Elliott, 2009; Price and Miskelly, 2015).

Such diagnosis offered within a collaborative approach of clinical and psychosocial personnel working together would likely aid a greater awareness of the post-diagnostic needs to both the individual and their caregivers. It will also help balance the diagnostic mantra by including service mantra within the process. A significant statement by the American Pediatrics Association (APA) in September 2018, signifies an acknowledgment and a need for the diagnostic physician to go beyond the pure diagnosis act. In their clinical report, they state:

“Supporting a patient and family after a diagnosis of an FASD is integral to a high-quality medical home. Often, families are distressed and need support and linkages to resources in the days after diagnosis as they begin to process and begin their journey to support their child.” (Turchi and Smith, 2018, p. 7).

A collaborative medical/social model of diagnostic and interventions care will likely reduce the ethical issues of children and families left isolated following a diagnosis. Children diagnosed with an FASD, need to have their health care needs to be recognized (Coles, 2003; Doig, McLennan and Urichuk, 2009; Nash, Stevens, Clairman and Rovet, 2017), thus ensuring that equal weight is placed on the post-diagnostic treatment and service needs of the child and their caregiver. As noted by Price and Miskelly, "the people we currently diagnose with an FASD need support and deserve comprehensive assessment and treatment" (2015, p. 424).

According to Cook et. al. (2016); Hellemans et. al. (2010) and A. P. Streissguth et. al. (1996), FASDs requires lifelong services provided by FASD-informed professionals of the allied health system.

This means that diagnostic decisions must be made with reference to the needs of those living with this disability and the services that can support them (Bakhireva et. al., 2017; Mukherjee et. al., 2013) in order to meet the ethical standards of patient treatment and care (Astley, 2011). Ultimately, what is needed within the FASD diagnostic dialogue is what Doak and colleagues call for which is global standard to be applied to the diagnosis of a child with prenatal alcohol exposure (Doak et. al., 2019). For a global standard to be applied within the diagnostic services of FASDs, government bodies will need to adopt clinical governance and oversight concerning the application and use of a single diagnostic method to be used with any specific culture site

Prevalence of FASDs in Child Welfare

It is accepted within literature that FASDs are still not widely recognized and that there is a stigma attached to them resulting in many children remaining undetected and misdiagnosed (Aspler, Zizzo, Bell, Di Pietro, and Racine, 2019; Bell, Zizzo, and Racine, 2015; Chasnoff, Wells, et. al., 2015). Furthermore, evidence is offered that FASDs are predicted to become more prevalent in coming years (Petrenko and Alto, 2017). Together these two facts offers even more urgent need for child welfare service to become more FASD informed, especially given the direct correlation between children with FASDs and children entering child welfare service (Blackstock, 2011; Brown et. al., 2005; Chasnoff, Telford et. al., 2015; Chudley et. al., 2005; Lange et. al., 2018; Svetlana Popova et. al., 2014; Streissguth et. al., 1996). Additionally, there is evidence that the failure to recognize FASDs leads to many undiagnosed cases throughout

society (Chasnoff, Wells and King, 2015; Knuiman, Rijk, Hoksbergen and Baar, 2015; Mukherjee, Cook, Fleming and Norgate, 2016).

This creates a fundamental challenge for child welfare service and CWSWs in conceptualizing, responding and establishing a Plan of Safe Care to FASDs within their responses to such cases. Understanding the prevalence rates of FASDs affecting children in care is a priority. Doing so will facilitate child welfare service to identify and meet the needs of children in care with an FASD through resources programs, supports to caregivers, training to staff and policy development (Badry and Choate, 2015). A further consideration for child welfare service is to prevent such incidents such as premature deaths relating to FASD (Linton, 2018, Badry and Choate, 2015) and potentially costly lawsuits, due to hidden disclosure of FASD especially in the foster care and adoption process. (Williams, Dubovsky and Merritt, 2011).

Social worker Prue Walker (2014) points to the alarming connection of children prenatally exposed to alcohol and the child protection system in Australia. The study demonstrated a strong correlation of parental alcohol exposure with an elevated risk of children entering the child welfare system. The study observed a direct link with prenatal alcohol exposure and entering the child welfare care services:

“21% of children in the study experienced prenatal alcohol exposure (1 in 5)

40% of Children on Protection Orders experienced prenatal alcohol exposure (2 in 5)

In some locations, up to 88% of children in care experienced prenatal alcohol exposure”
(Walker, 2014).

This offers an ominous sign to Ireland given the high level of alcohol use in pregnancy as discussed previously. As Walker's (2014) research directly shows, the issue of prenatal alcohol exposure is directly linked to the child protection service of legislation within the state. This

directly correlates the statutory role of CWSWs in planning safe care and uphold both human rights and the CRC rights of the child as described by Coveney (2018). Walker's (2014) study is yet another wake-up call to child welfare agencies to emerge from the subservient role and develop a strong psychosocial lens on this vulnerable cohort of children. This was reiterated recently by Popova et. al., (2019) who noted that monitoring levels of prenatal alcohol exposure within society is “crucial for understanding and identifying vulnerable populations” (p.19).

Popova, Lange, Shield, Burd, and Rehm, (2019) found child welfare service to be one of five most vulnerable sub-populations with FASDs at a rate 10 to 40 higher times than that of the general population(s). This study noted specifically the prevalence rate of FASDs within the U.S. child welfare system, was 32 times higher than that in the general population. Collectively, such research, statistics and findings offer a significant challenge to child welfare services globally to act and uphold the rights of the children impacted with by prenatal alcohol exposure. Popova and colleagues noted that “We now have convincing evidence that FASD is a relatively prevalent alcohol-related disorder that greatly increases the risk of long-term adversity” (Popova et. al., 2019, p. 18).

CWSWs will likely receive competency-based education to work with substance misusing parents and learn valuable skills to work within this situation. However, when turning to the issue of a possible FASD assessment for a child, CWSWs lack a pathway or a protocol to engage effectively. For any CWSW undertaking an assessment concerning parental substance abuse, consideration needs are given to children within that assessment and the potential that they may have experienced an alcohol-exposed pregnancy. Having the knowledge and ethical skills to do so is a significant learning need of all CWSWs.

Lange et. al. (2013) noted prevalence rates of FASDs in the Canadian child welfare service at 16.9% or 169/1000. More recent studies from an international perspective give further

evidence of FASDs on looked-after populations. Chasnoff et. al. (2015) found a 29% prevalence rate of FASDs in the Chicago Child Welfare Service. In the UK, Gregory et. al. (2015) documented a 27% incidence rate, while in another UK study recorded a 30% prevalence rate in mixed-race children in public care (Selwyn et. al., 2011).

Again, such documented evidence has direct and compelling implication for both child welfare service and CWSWs. Convincing and mounting evidence demonstrates that children suffering prenatal alcohol exposure are impacting child welfare service structures at substantial rates and by default the caseloads of CWSWs. Seeking to establish a Plan of Safe Care for a child living with an FASD will offer CWSW enormous challenges while operating without education, policy, procedure and protocols.

Part of the challenge facing child welfare service is grasping the challenge presented by FASDs will be the fundamental requirement to uphold both the CRC rights of the child as described by (Coveney, 2018). Kilkelly (2008) noted that “the Convention is a blueprint for the treatment of children in all areas of their lives and, accepted by 193 states worldwide, it reflects a universal acceptance of the best practice concerning children” (p. 8). It therefore follows, that children living with an FASD are fully entitled to have their disability recognized and to have services provided to mitigate the known implications of being born of an alcohol-exposed pregnancy.

Jamplosky (2018) described “the treatment of individuals with FASD outside of and within the criminal justice system is a human rights issue and should be expressly covered under Human Rights legislation” (p.108). It is also noted in research that youth with an FASD are at elevated risk of involvement with criminal justice system (Fast, et. al., 2009). Many of these “youth” will be also be either resident of involved with the child welfare services. Child welfare

services have to develop both a CRC and human rights lens in meeting the statutory requirement to deliver safe care to children living with an FASD and in need of services.

It is documented that the vast majority of children living with an FASD will reside within both foster care and residential services of both state and private providers (Popova et. al., 2014). Evidence clearly articulates the critical interface between juvenile justice and child welfare services (Kilkelly, 2006), but is poorly articulated in main stream research publication. In 2019, the UNCRC issued the following guidance to member states when it stated, “Children with developmental delays or neurodevelopmental disorders or disabilities (for example, autism spectrum disorders, fetal alcohol spectrum disorders or acquired brain injuries) should not be in the child justice system at all” (UNRC, 2019, p.7). This will be a significant area for child welfare services to ensure it advocacy of children with a neurodisability in their care is treated respectfully and have their rights upheld in juvenile justice settings.

Astley, Stachowiak, Clarren, and Clausen (2002) revealed that FASDs are 10/15 times more prevalent in foster care than the general population. The screening of effects of prenatal alcohol exposure is an important step in identifying FASDs. As prenatal alcohol exposure can affect the functioning of an individual across several domains, diagnosis is best made within the context of a multidisciplinary assessment of the individual (Manning and Hoyme, 2007). Currently such screenings and multidisciplinary approaches are not conducted in most child welfare services, again demonstrating a gap between research and best practice. All of this suggests that the child welfare social work profession is and will continue to encounter FASDs at a significant rate in the course of their intervention, screening and initial assessment duties for the Child Welfare Service, requiring a specific knowledge requirement in social work education (Badry and Choate, 2015; Caley et. al., 2008; Catterick and Curran, 2014; Durkin, 2016; Holleran Steiker, 2009; Wilson, 2013).

Quantifying Prevalence

Scholars continually remind us that FASDs are incredibly difficult to identify and to treat due to the many symptoms associated with the disability (Dobson et. al., 2016; Hedwig, 2018.; Mukherjee et. al., 2018). However, the latest guesstimate suggests “there are 11.3 million affected people 18 years old or younger” (Burd and Popova, 2018, p.1). What is also accepted is that the prevalence of FASDs may be significantly higher in sub-populations such as child welfare settings, justice systems, substance abuse and those in receipt of mental health services (Flanagan et al, 2018). The wide variance in FASDs symptomology and presentations likely means the individuals are represented across the allied health structures and engaging with allied health professionals on a regular basis but seen and treated under more traditional labels.

Such symptoms may be chronic and are often co-occurring with other impairments so that FASDs may not manifest until the middle or late childhood or the adolescent stage of development (Mukherjee et. al., 2016; Popova et. al., 2016). Indeed, such evidence of secondary disabilities later in development is well documented, as is their contribution to dropping out of school, mental health difficulties, substance abuse issues, homelessness, and involvement in the youth and adult justice systems (Fast, et. al., 2009; Catterick and Curran, 2014; Domeij et. al., 2018; Malbin, 2002; Streissguth et. al.,1996).

In the transition into the teen years, youth must navigate different social settings and peer groups while discovering who they are and juggling their responsibility on how to live more independently. It is at this stage in the trajectory of development that the neurodisability associated with FASDs becomes more pronounced (Senturias and Burns, 2014). It is a significant phase for a high risk of mental illness leading to suicidal ideation and suicide actualization in this adolescent stage (Dubovsky, 2009; O’Connor, Portnoff, Lebsack-Coleman and Dipple, 2019). Of interest to note in the O’Connor et. al., the study demonstrates a linkage to

child welfare service in that of 54 adolescents with an average IQ of 91.11 and demographics of “70% of adolescents were adopted, 24% were in foster or family guardian care, and 6% were living with their biological mother” (p. 2). It was previously noted by Streissguth et. al., (1996) that many livings with an FASD will have an IQ above 70 are at greater risk of suicidal ideation than those with more severe intellectual disability and falling below the IQ 70 benchmark (Streissguth et. al., 1996).

Mental illness and suicidal ideation are just two aspects that may become more visible in the adolescent stage as the young person transitions to adulthood. With current evidence describing a dearth of training, attitudes and competing priorities in healthcare workers in relation to suicide ideation in mainstream services as described by King, Horwitz, Cryz and Lindsay (2017), it is difficult to understand how this vulnerable cohort of young people with mental illness and FASD can be integrated into mainstream strategies of suicide prevention. Engaging mainstream mental health advocates on the needs of those living with an FASD is a major need within the FASD strategies of any cultural approaches. Children living with or suspected of an FASD, are at higher risk of suicidality, with the adolescent years being the highest time of vulnerability. Ignoring or denying the etiology of mental illness stemming from prenatal alcohol exposure is likely “detrimental to the success” of all strategic approaches to mental health/ suicide ideation and actualisation (Anderson, Mela, and Stewart, 2018).

Collectively, the global discourse concerning FASDs will likely provide significant challenges for child welfare service officials and practical difficulties for CWSWs in screening, identifying and providing services to those living with an FASD. For child welfare service officials, a significant task will be to try to quantify the magnitude of the problem within their systems. A difficult task from the outset by the poor case recording of maternal alcohol use during pregnancy (Riley et. al., 2011), which is particularly notable for children within the child

welfare services (Aronson, 2000). A further potential difficulty for child welfare service officials at a policy level, is breaking with the traditional views of neurocognitive, neurodevelopment and neurobehavioral antecedents of such presentations. The traditional view that illicit drug use during pregnancy is the only concern in protecting the unborn at the expense of considering the legal drug of alcohol (Lloyd, Luczak, and Lew, 2019), which is shown to inflict significant damage, is perhaps the greatest cultural paradigm shift needed in addressing alcohol-exposed pregnancies and the prevention of the FASD disability.

Interestingly, Whelan (2018) in her doctoral study within Ireland found that “Drug and alcohol treatment services were more likely to report children’s “behavioral problems” and parent’s struggling to manage their children’s behavior than any other issue (p.168). It is highly probably that some of these children within the demographic would be living with unassessed prenatal alcohol exposure, but here they are being to refer to Tusla child and family agency by professionals of other agencies within the site. Again, the lack of dialogue and education concerning prenatal alcohol exposure within Ireland is facilitating professionals to potentially misread the signs of FASD presentations and offering a missed opportunity for intervening on the needs of children living with an FASD.

One novel approach to addressing this weakness in the discourse was acted upon in the UK. Diageo, one of the world's largest suppliers of alcohol products, has funded a UK-based NGO (NOFAS) to specifically train British midwives to record prenatal alcohol use during pregnancy (Fleisher, 2010). Such an approach is vital, in that it may not be for 10 or 12 years following the birth that screening for an FASD is warranted. Currently, it is only possible to diagnose fetal alcohol syndrome (FAS) without confirmation of prenatal alcohol exposure (Bertrand, Floyd and Weber, 2005), while all other categories of diagnosis (especially Neurobehavioral Disorder associated with Prenatal Alcohol Exposure) needing clear evidence of

alcohol-exposed pregnancy (Domeij et. al., 2018; Mattson et. al., 2013). However, engaging with the alcohol industry in prevention of FASDs has many challenges and seen by many as a no-go area of public health strategies. Lim, et. al. in 2019 note in their study that “findings suggest that alcohol industry corporate social responsibility bodies may use strategic ambiguity and other informational tactics to “nudge” women toward continued drinking in pregnancy to protect the female alcohol market” (Lim, Van Schalkwyk, Hessari, and Petticrew, 2019, p. 532). Of note, was the inclusion of Ireland within this assessment of the alcohol industry corporate responsibility on prenatal alcohol use. This study further advocates that the public agencies should be aware that the alcohol industry may not be totally genuine in their public actions of alcohol in pregnancy.

This failure to accurately record prenatal alcohol exposure on prenatal records is a fundamental weakness in the current allied health practice interventions with pregnant women who consume levels of alcohol in pregnancy, which significantly restricts the ability to diagnose accurately, beyond just FAS at a later development stage of the child (Burns, Breen, Bower, O’Leary and Elliott, 2013). It is suggested that the majority of children affected by prenatal alcohol exposure are children that do not meet the diagnostic criteria of FAS (Bertrand et. al., 2005), thus leaving many children undiagnosed or misdiagnosed (Chasnoff, Wells et. al., 2015) and potentially entering the child welfare services because their specific needs have not been met (Chasnoff, 2011; Popova et. al., 2014).

Chapter 3: Methodology

Introduction

This chapter describes the rationale for conducting a qualitative research where I applied a constructivist grounded theory method to the following research question:

How do child welfare social workers respond with children who are living with an FASD or who are suspected of having an FASD?

The study applied a Constructivist Grounded Theory methodology (ConGT) (Charmaz, 2014, 2017). This qualitative method was selected, as it was believed it could explore the research question in more detail. Kegler et. al., (2018) describe qualitative research as "Qualitative methods help us understand the context, explore new phenomena, identify new research questions, and uncover new models of change" (Creswell, 1998, p.1) describes qualitative methods as essential to understanding context, exploring different perspectives, and for generating and extending theory.

ConGT was chosen due to the sensitive and ethical aspects of the research topic in this poorly understood area of public health within societal discourse (Bell et. al., 2015; Domeij, et. al., 2018). Within Ireland, understanding and awareness of FASDs remains inadequately addressed within society, which further underpins the challenges of CWSWs in responding fully to the needs of this vulnerable cohort of children. A prerequisite underpinning this inquiry is adopting a theoretical and philosophical framework as the "researcher's theoretical orientation has implications for every decision made in the research process, including the choice of method" (Mertens, 2005, p. 7).

My choice of ConGt was therefore more salient with exploring an area of practice where there is little known. As a methodology it provided a focus to explicate how CWSWs are currently responding to FASDs. As a methodology it allows for constructivist interpretations of the data in seeking to develop a theory encompassing the responses of CWSW to FASDs. As a

methodology it also facilitated my tussle with prior knowledge, in that it calls for clear procedural actions of constant comparative analysis of the data, theoretical sampling and member checking. All these processes do not prevent me from imposing theory on my findings, but rather to find theory as it emerged from the data.

ConGT offered a flexible approach to answering the research question, supported a developmental lens of social construction and facilitated the consideration of the socio-political context of FASD within Tulsa's child welfare services. It also acknowledges both my social and cultural position within the research process, as I was returning to a site where I had previously delivered FASD education

As I came to the study with significant prior knowledge in the area of FASD education, I have included a research identity memo (Maxwell, 2012) directly following this context chapter. In this research identity memo, I document my history of coming to this field of research. I also document my interactions and experience of engaging with fellow social workers and caregivers who are dealing with the phenomena of FASDs on a regular basis. I felt it was important to situate myself within the methodology due to my prior experience of FASDs.

This is a delicate balance for the novice researcher with prior knowledge. As Charmaz (2014) states: "Grounded theorists evaluate the fit between their initial research interest and their emerging data. We do not force preconceived ideas and theories on our data" (p. 32). Memo-ing, reflexive practice and peer debriefing sought to offer checks and balances on my prior knowledge to prevent overly influencing my decisions or interpretations of the data or influencing the grounded theory of the inquiry

Additionally, I acknowledge biases and assumptions stemming from prior knowledge and work in the area of FASDs education. By continuing to memo, write personal journal entries and debrief with peers within academia, I was able to understand my biases and how these biases

interacted with my doctoral journey. Remaining reflexive, using many years of social work, and practicing skills of reflection and analysis stemming from my work in child protection duties further also in managing my biases and assumptions. This further helped me gain awareness on when my bias influenced my interpretation of the data in this study. Considerations of trustworthiness are considered near the end of the chapter. This chapter focuses on the qualitative methods utilized for data collection, transcription and data analysis.

Theoretical Foundations

The ontologies and epistemologies which underpin this study inform the methodological framework and channel how the research led to the gathering and analysis of data

In my prior experience of facilitating FASD education, CWSWs, allied health professionals and foster parents communicated a high degree of uncertainty, confusion and frustration in relation to interventions with FASDs (Badry and Choate, 2015; Blackburn, 2017; Landgraf et. al., 2018.; Mukherjee, Wray, Curfs, and Hollins, 2015). These have a direct impact on child welfare service and CWSWs carrying out their interventions within specific communities. Consequently, these are essential fundamental concerns that drive this inquiry, seeking to understand how CWSW respond to FASDs from a statutory duty perspective.

FASDs impact on child welfare service may be described as:

1. The documented prevalence rates within child welfare service provision (Lange, Shield, Rehm and Popova, 2013)
2. The complex breath of neurobehavioral, neurocognitive and neurodevelopmental profile of FASDs within service provision (Badry and Choate, 2015; Dobson et. al., 2016; Popova et. al., 2014)

3. The absence of substantive education concerning FASDs concerning the cognitive and behavioral profile within CWSWs undergraduate and postgraduate education (Catterick and Curran, 2014; Durkin, 2016).

This is the case in many jurisdictions and especially within the European Union (Manthey et. al., 2018) and the site of this inquiry within the Irish Child Welfare Service. Ireland has one of the highest rates of alcohol use in pregnancy in the world (82%). This likely places Irish children at an elevated risk of FASDs, compared to Canada, where the national alcohol use in pregnancy is 10.4% (Lindsay, Royle and Johnston, 2008). This suggests an elevated impact on state child welfare service and CWSWs within Irish Child Welfare Service. It also suggests that it will take courage and conviction on the part of Tusla management to address the needs of CWSW in carrying out their statutory duties.

Ontology

Ontology refers to the way people view and understand the social phenomena they encounter. What is the form and nature of reality? What can be known about it? Also, what is the nature of the relationship between the knower and what is known? In this approach, knowledge is seen as hard and objective and can be gained through direct experiences and rigorous scientific inquiry (Robson, 2011). Guba and Lincoln, (1994) see ontology as the form and nature of reality, how it can be known and its epistemology as the nature of what can be known by the knower. Both the ontology, and epistemology which follows, are key underpinnings of symbolic interactionism, which is served as a theoretical framework in this inquiry.

Epistemology

Epistemology is a philosophical view concerned with how knowledge is attained and what constitutes meaningful knowledge (Guba and Lincoln, 1994; Willig, 2008). As a philosophical lens, it is generally agreed that epistemology offers three positions: positivism,

phenomenology and social constructivism (Guba and Lincoln, 1994). The ontological beliefs about the existence and the epistemic relationship between the knower and the known are essential determinants of how a phenomenon is approached by social researchers (Lincoln, Lynham and Guba, 2011). Questioning the nature of reality is an essential feature of this inquiry, as the theoretical approaches underpinning social research call into question how reality is understood and how meaning is shared (Ritche and Spencer, 1994).

One's personal philosophy is very important as it defines what we consider to be real and how we can legitimately acquire knowledge about the world. As such, Birks and Mills (2015) define philosophy as "a view of the world encompassing the questions and mechanisms for finding answers that inform that view" (p. 18). The aim of GT is to generate or discover a theory or a theoretical explanation for a process, action, or interaction. A theory is grounded in data that is inductively generated by the participants who have experienced the process. Constructivism and interpretivism emphasize multiple subjective realities and the impossibility of objectivity capturing inner worlds, thoughts and perspectives of participants as an ultimate test of reality and personal understanding. An aim of this study is to put knowledge into action, advance social justice, empower the powerless. Research is not value-free and uses praxis as an ultimate test of knowledge (Bryant and Charmaz, 2010; Charmaz, 2014).

Symbolic Interactionism Theory

Symbolic interactionism is "a micro-level theoretical framework and perspective in sociology which addresses how society is created and maintained through repeated interactions among individuals" (Carter and Fuller, 2015, p. 1). Charmaz (2006) describes symbolic interactionism as "how people create, enact, and change meanings and actions" (p. 7).

According to Blumer (1969), symbolic interactionism contains four central tenets, which are summarized here:

- (1) Individuals responses are based on the meaning objects have for them
- (2) Interactions take place within a cultural and social context, where physical and persons, as well as events, must be defined or categorized based on individual meanings.
- (3) Meanings develop and emerge with other individuals and society
- (4) Meanings are continually developed and recreated through the interpreting process during interactions with others.

Symbolic interactionism is very closely aligned with grounded theory, with some scholars suggesting that grounded theory origins are linked to the founding fathers of symbolic interactionism theory (Oktay, 2012). Charmaz (2014) further explicates how constructivist grounded theory links to symbolic interactionism by stating: “a theoretical perspective that assumes that people create reality or realities through individual and collective actions. Rather than seeing the world as a given, constructivist grounded theorists take a reflective stance towards the research process and product” (p. 240). Thus, instead of assuming realities in an external world including global structures and local cultures, social constructionists’ study what people at a particular time and place take as real, how they construct their views and actions when different constructions arise, whose constructions become taken as definitive, and how the process ensues. Symbolic interactionism is a constructionist perspective because it assumes that meanings and obdurate realities are the product of the collective process (Charmaz, 2014 p. 344).

Grounded Theory

Grounded theory is a systematic approach of qualitative research that seeks to generate new theory to explain phenomenon (Strauss and Corbin, 1997). Its original development by Glazer and Strauss in (1967) saw it as a method to develop middle-range theory. It is a commonly used method of use by researchers within the social sciences (Gilgun and Sands

2012). Grounded theory has two central characteristics that set it apart from other qualitative research tools: first, the constant comparison method, which aims to iteratively develop codes, categories and themes through data analysis; second, theoretical sampling, which involves the identification and selection of rich data sources to explain the social phenomenon (Charmaz, 2006, 2014, Glazer, 1967a, 1967b). Another component of the method theoretical saturation. All four components “are used in combination to develop theory from data “(Gilgun and Sands, 2012, p. 15).

These approaches aim to develop a substantive theory that explains an inherent process within a particular social context through the experiences of the people operating within a particular setting (Creswell, 2007). Grounded theory is professed to be inductive research due to a systematic method of analysis it draws on to highlight social process within reoccurring data patterns. This iterative process of data collection, analysis and comparison is known as the constant comparison method and aims to develop an explanation of how the phenomenon operates through observations grounded in data (Strauss and Corbin, 1997, Charmaz, 2014). This differs from deductive methods of analysis that rely on testing a priori theory and hypothesis (Charmaz, 2006). Although widely used and applied in social settings of research it is not without various critiques that have developed since its conception in 1967.

Gilgun (1994c) advocates and promotes grounded theory (GT) as a hand-in-glove methodology for social work research. GT Challenges standard methods of inquiry into issues presented within societal research. GT is a challenging methodology to master, leading scholars to described it as having a checkered history. In discussing GT, Walker and Myrick (2006) offer the following by saying “it is the most frequently discussed, debated and disputed of the research methods” (p. 547). While another described the devotes of GT sharing a “war of sorts” (LaRossa, 2005, p. 835) when defending or articulating the different strands of GT applications. A further

rebuke of GT was offered by Wacquant (2002) when describing GT as “an epistemological fairy-tale” (p.1481). Urquhart (2016) further describes the history of the grounded theory method as having “a major intellectual dispute and consequent split between its founders, Glazer and Strauss. Understanding this split helps us understand grounded theory” (p. 1). This “diverging” and splits” within ground theory methodology has primarily evolved under three methodological approaches of grounded theory. These are Glazer and Strauss, classic grounded theory (1967a 1967b); Corbin and Strauss (1990), Straussian grounded theory; and Constructivist ground theory, Charmaz (2006, 2008, 2014). Each of these methodological approaches offers the researcher something uniquely different in application.

Area of Choice	Glazer	Strauss and Corbin	Charmaz
Philosophy	Positivistic perspective implied. Believes in one reality.	Postpositivist perspective implied. Acknowledge implausibility of seeing reality as it “really” is.	Constructivist perspective. Believes in multiple perspectives of reality. Researcher passionately engages in interpretation.
Analysis Process	Passively attending to emerging data. Constant comparing for a core category, inductive approach – open and selective coding	Action orientated microanalysis through structured process. Constant comparing to select a central category – inductive and deductive, open, axial and selective coding	Actively unitizing researcher’s creative interpretations. Constant comparing for relevant categories, deductive, and abductive approaches – initial and focused coding
Useful viewpoint for researcher when—	Researcher believes in one reality of a phenomenon of interest.	Researcher is hesitant to apprehend reality as “really” is.	Researcher is aware of changing context or competing perspectives of reality.

Table 3. *Overview of divergent approaches within grounded theory*

There are many interpretations and diverging views in applying GT since its conception by Glazer and Strauss (1967a, 1967b), leading to new methodological alterations and developments. As Kenny and Fourie (2015) state, "despite sharing fundamental GT tenets, classics, Straussian, and constructivist GT are not homogenous or interchangeable entities" (p. 1272). However, what all three these methodological approaches concur, is that all the methods have a central goal of developing a theoretical understanding of a social phenomenon (Charmaz; 2014, Glazer, 1978, Strauss and Corbin, 1997).

As such, GT has become a valuable methodology for social researchers, who seek to understand the human experiences and respond to real-world problems. As Strauss and Corbin (1997) state, "If someone wanted to know whether one drug is more effective than another, then a double-blind clinical trial would be more appropriate than a grounded theory study. However, if someone wanted to know what it was like to be a participant in a study, then he or she might sensibly engage in a grounded theory project or some other type of qualitative study" (1997, p. 40). Despite the contested nature of grounded theory, the method is valuable in contributing to research addressing complex social problems that are manifested in everyday life. Its application to an inquiry with a social work lens is even further validated by what Gilgun (1994c) who describes GT as having a hand in glove relationship to social work practice. Its application to social work research is further discussed by Oktay (2012), who clearly demonstrates the close relationship of GT with symbolic interactionism, a core theory utilized in social work practice from its origins in the early 1900s (Oktay, 2012, p. 8).

Strauss and Corbin (1997) point to the critical value of conducting a GT study when it comes to an understanding of 'why' questions of social needs within practice settings. As GT was developed to be of 'USE,' it has significant value in assisting social work researchers in

developing mid-range theories “ that can be applied in practice situations” (Oktay, 2012, p. 5). Glazer and Strauss (1967) emphasize that data can be collected from many sources using the GT method. Although interviews remain the most common form of data collection, observations and documentary analysis are also favored within the GT data collection approach (Egan, 2002; Glazer and Strauss, 1967, 1968). Charmaz (2014) suggests that "grounded theories may be built with diverse kinds of data – field notes, interviews, and information and reports" (p. 23), while Strauss and Corbin (1990) state that data can come from “many alternative sources” (p. 27), including televised news reports (Ralph, Birks and Chapman, 2014).

The divergence in opinions and views about ‘what is’ and ‘what is not’ grounded theory challenges researchers in adopting GT as a method of choice (Nagel, Burns, Tilley and Aubin, 2015). This study provided by Nagel et. al., 2015 (Figure. 1) was a significant aid in helping me to decipher and understand the myriad of challenges the study presented within ConGT lens. As Birks and Mills (2015) suggest, “For beginning researchers, including graduate students, the magnitude of information that exists about grounded theory methods and findings has made engaging in a grounded theory study a complicated endeavor" (p.10). Ralph et. al. (2015) also argue that "awareness of what is, and what it is not, GT is essential to preventing the perception that GT lacks boundaries or limitations on how to use it" (p. 2). All of which can leave the novice researcher facing many crossroads when adopting a grounded theory methodology, as shown here by Ralph et. al. (2015).

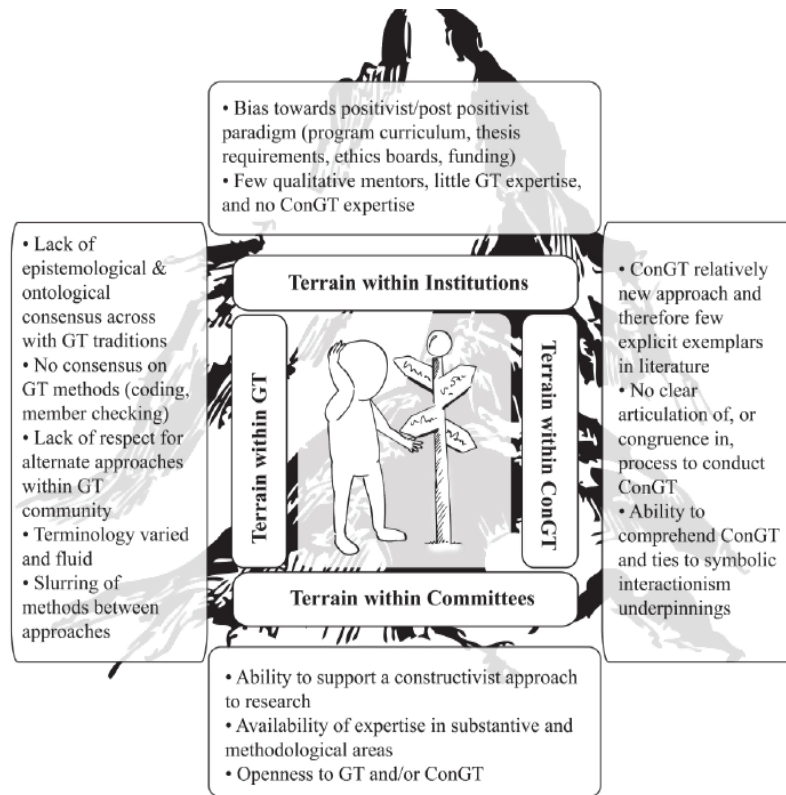


Figure 1. *Crossroads when adopting grounded theory*

The rationale for the application of Constructivist Grounded Theory method

I used a Constructivist Grounded Theory (ConGT) approach for all methodology, methods, and analysis of data in seeking to construct a theoretical finding to explain social work interventions with FASDs. ConGT is a methodology encompassing a number of methods to facilitate the construction of theoretical finding, which is a key objective of this study.

Applying a ConGt method offered the best mechanism to facilitate the generation of theory from data supplied by the professionals who contributed to this study. Current approaches on managing FASDs are very heavily viewed in a medical lens of diagnostics, resulting in continuing frustration for both professionals and caregivers. Within Tusla, professional knowledge translation on the complex issues presented by FASDs is absent in allied health education. Employing a ConGT method provides insight on the lived and practical skills of

professionals grappling with casework and care duties for children and adolescents in need of service delivery. My epistemological stance in gaining insight into experience, views and beliefs is very aligned with a constructivist approach. ConGT says that people construct their understanding and knowledge of the world, through their experiences, and by reflecting on those experiences (Bloomberg and Volpe, 2016). Applying a ConGT approach to data analysis as the data emerged allowed for a generation of new knowledge to appear through a reflexive discourse.

Grounded theory and the application of the constructivist method is, therefore, an appropriate and beneficial method to accentuate the professional needs and wants in a social lens of responding to FASDs through answering the research question of this inquiry. It is believed that the theory generated from a grounded theory method is a theory created from the lived experiences of participants in this inquiry. FASD literature over the past fifty years has mainly focused on medical and scientific explanations of the causation of FASDs. In contrast, this study is seeking to hear the psychosocial views and experiences of practitioners and caregivers charged with intervening and caring for children suffering from this neurodisability in everyday life. Therefore, the application of the grounded theory method is believed to be the best approach to explicate a process and develop a practical theory to describe CWSW responses to FASDs and to address the research question of the study. It was important to hear directly from social workers, as a means of ensuring the credibility of seeking to answer the research question posed within the study. It can then serve to offer a grounded theory finding in response to the research question that can be utilized to assist the education of CWSWs' in their interventions on cases of FASDs.

Research Question

Due to the large body of scholarly literature pointing to the prevalence and impact of FASDs in the Irish Child Welfare Service, the study sought to answer the following research question:

1. How do child welfare social workers respond with children who are living with an FASD or who are suspected of having an FASD?

Research Procedure

Ethical Approval(s)

Major ethical issues abound for CWSWs, allied health professionals and foster parents when responding to children suffering from an FASD (Bell et. al., 2015; Domeij, Hulcrantz et. al., 2018; McCormick, 2016). Giving the recognized body of literature on ethical aspects of FASDs, I needed to be mindful of respondent's knowledge, experience and stories relating to FASDs within an ethical framework of awareness on the sensitive topic. FASDs have become a major ethical challenge within the professional ranks of social workers and allied health professionals in recent years, especially now the public health coroners are documenting the premature deaths of children with an FASD in child welfare settings. As such, this needs to be taken hold of by state bodies of public health and social service at a professional level owing to concerns the FASD dialogue is concerning through social media (Mukherjee et. al., 2015). As Domeij et. al. (2018) explain, “The Province or State has substantial social, legal, financial and ethical interests in protecting children from the harm that results from the use of alcohol by their mothers during pregnancy, for the sake of the child and of the family” (p. 15).

It is acknowledged that qualitative research facilitates and empowers participants to talk about sensitive topics and share their stories, which have the potential to cause emotional distress

and anxiety (Birks and Mills, 2015; Dempsey, Dowling, Larkin and Murphy, 2016). My study involves human subjects (CWSWs, allied health professionals, foster parents) and offers insight into their personal, social, professional and caring world. It was, therefore, essential to obtain ethical approval before engaging with participants, thus ensuring the safety and welfare of all participants. Ensuring that their identity and contribution would remain confidential in all aspects of the study assured that any risks of speaking out on the concern of FASDs were minimized.

Ethical Approval Process

The study required four ethical approvals in total. Two ethical approvals were required at the initial stage of collecting the initial data. It was a requirement of my university protocol that I received ethics approval from the agency where I was collecting my data first before applying for university approvals. A two further approvals were needs in order to return to data collection for theoretical sampling. The sequence of these approvals are as follows:

<u>First Approvals</u>	Approval Date	Appendix
Tusla Child and family Agency	January 2017	Appendix: B
University Ethics Approval	June 2017	Appendix: E
<u>Second Approvals</u>		
Tusla Child and Family Agency	August 2017	Appendix: C
University Ethics Approval	November 2017	Appendix: D

Informed Consent

From the beginning of this inquiry, ethical considerations were a significant component to wrestle with due to the sensitive nature of the topic under inquiry. When a participant contacted me from flyer information, they were sent an information sheet concerning the study and given seven days to consider their participation. Once they agreed to participate, they were

sent a copy of the Consent Form (See Appendix: I). In this communication, they were asked to review the consent procedures carefully. I brought two copies of the Consent Form to the interview. Once signed, one copy was given to the participant, and I retained one copy. Before signing the Consent Form, individuals were asked if they have any questions/concerns. Under EU data regulation 95/46/EC (Directive, E, U, 1995) it was not possible for me to transport these identifiable data out of the EU region and back to Concordia University in Montreal, Canada. To accommodate the EU data regulation, the school of social work, Trinity College, in agreement with the ethical approval given to the study by both Tusla, Ireland and Concordia University, agreed to store identifiable data in locked storage at the School of Social Work. The data was lodged in the school on November 30, 2017, with a destroy data on November 27, 2022 (five years) attached to the sealed envelope.

Note: This landmark Data Protection Directive (Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data) in 1995, the Union established what is probably the world's most comprehensive system of personal data protection.

In order to ensure informed consent, individuals were asked to indicate yes or no (do they agree) to each of the following:

- (a) To be interviewed for the study
- (b) To the interview being audio-recorded
- (c) To the use of anonymous quotations from this interview to be used in presentations, doctoral thesis or other publications that emerge from this research
- (d) To being contacted up to six months following the interview date, should I require any clarification of my data.

Distress Protocol

Furthermore, speaking on this emotive and ethically challenging area of public health policy, risked some level of emotional discomfort. Participants might face certain risks by participating in this research. However, we anticipate that the level of risk will be minimal. Possible risks include feeling some discomfort in discussing practice challenges that social workers encounter working with children and caregivers where FASDs exist. Participants will not personally benefit from participating in this research. An information sheet concerning FASDs will be given to participants if they request information that is outside the scope of the interview. Participants were encouraged to discuss with the principal investigator (PI) if any aspect of the process causes them any emotional distress. Participants are fully aware that they do not have to answer a question if they find it distressing. Participants are free not to answer and withdraw from the study. If a participant were to become distressed in any way, the PI is confident in his social work skills to comfort and promote the well-being of the participant. The PI will not leave any respondent who is visibly distressed. If necessary, the PI will refer the participant to the HSE counseling service at http://www.hse.ie/eng/services/list/4/Mental_Health_Services/The_Mental_Health_Team/ at 1850 24 1850.

Participant Recruitment

There were 18 participants in this study. This was made up of eleven social workers, three foster parents, one psychologist specializing in child development, one midwife, one occupational therapist one staff development officer of Tusla. There were fourteen female participants and four male participants. It is important to note that this sample was engaged in two different stages of initial and theoretical sampling. The first stage, 'Initial Sampling'

constituted meeting with social work practitioners operating the front line of state child welfare service interventions. As Charmaz states, "initial sampling, " gets you started; while theoretical sampling guides you where you are going" (Charmaz, 2014, p. 197). Initial sampling was essential to establish research criteria by going directly to the participants that could best articulate the complex issue of FASDs with casework interventions.

In the first stage of the study, the participants who were registered CWSWs with the state registration body of Health and Social Care Professions Council (CORU) (2011). It is within this registration and statutory framework that CWSWs receive their professional development and ongoing skill needs and deficits are identified. All participants held a master's degree in social work (MSW) and were qualified level CWSWs currently employed in the Tusla state agency and had a minimum of two years' experience. Participants were not reimbursed for their time in order to ensure that there was no real or perceived coercion.

Specific Recruitment

I was granted site permission to meet with CWSWs by the service director of the Dublin North East division of Tusla on December 5, 2016 (see Appendix F).

It was anticipated that social workers of DNE division of Tusla responding to this study call would be social workers that had undergone some level of education awareness on FASDs with myself in previous years (Purposeful Sampling). This purposive sampling strategy as one that would bring forth volunteers to that study that may already have an interest in FASDs given their past participation in professional development. DNE child and family division employ 311.45 social workers in whole-time equivalent posts as of 2017 (Tusla, 2017). As the recruitment flyer was circulated in DNE, respondents began to contact the researcher from beyond the initial designated area. I then clarified with the national office of Tusla if I could

engage with such respondents directly. Approval was granted by Tusla to engage with participant from outside the initial catchment area under the ethical approval previously granted.

In the second stage of the study, two groups of key informants were sought, these being foster parents who provide care to children with an FASD and allied health professionals. This purpose of this stage was to further develop the categories identified during phase one of the data analyses. This action of returning to the site is known as theoretical sampling CITE. Foster parent caregivers were registered foster parents with the Tusla Child and Family Agency and register with the Irish Foster Care Association, who is the main provider of foster-care services to Tusla. I interviewed three individual foster parents (from different families) within this study. The allied health professionals recruited were a child psychologist, a male midwife, an occupational therapist and a staff development officer. All allied health professionals held their own specific qualifications to their own profession and were registered to that profession. They had or have had a current or recent involvement with children and families where an FASD was/is a presenting factor of their involvement, and they also have active links with CWSWs.

Participants were not representing an organization but speaking on their own behalf to the study. The following criteria for participants were established before engagement in the field and to comply with the ethical requirements of filed practice.

Summary of Criteria for Social Workers:

- Be a fully qualified social worker who has their CORU registration
- Hold a bachelor's degree in social work (BSW) or master's degree in social work (MSW)
- Have current employment in the Tusla child welfare agency
- Have a minimum of two years' experience employed as a CWSW
- Have a position in their agency where they currently have contact with clients including children and families.

Summary of Criteria for Foster Parents:

- Be a registered foster parent with Tusla
- Be a member of IFCA
- Have experience of caring for a child with an FASD
- Have a minimum of two years of duties as an approved foster parent completed.

Summary of Criteria for Allied Health Professionals:

- To be a registered professional of their own professional body
- To be or have been involved in a child case of suspected or diagnosed FASD
- To have active links with social work in addressing the needs of a child with an FASD.
- Have a minimum of two years of professional service in their profession.

All participants were screened for the above inclusion criteria. When a person responded that did not meet the inclusion criteria they were excluded. All persons excluded from the study were excluded sensitively and respectfully. Anyone who was excluded from the study, but who sought information concerning FASDs in child welfare service was offered selected information and resources (See Appendix H.).

Data Collection - Interviews.

The collection of data for this inquiry consisted of between 45 to 65-minute interviews with each of the eighteen participants. Semi-structured interviews were conducted with all participants responding to the call for contributors to the study. In these semi-structured interviews, I followed the protocol as laid down in the interview guide (Appendix J) but varied sequence and questions to accommodate the specific participant. This allowed for a more open discussion around FASD and allowed for a more natural exploration of the participant's views,

experiences and perceptions of participants contributions. In total, the study had three interview guides, which varied as the study progressed.

Unstructured interviews happened when participants came to the interview with a high degree of knowledge concerning the topic under inquiry. A number of the interviews followed an unstructured format where after the initial open question, the participants willing to talk about the topic was fuller. Here, I sat back, allowing for a free-flowing dialogue. I would intervene casually at times, asking the participant questions such as “You said you were unsure about working with the child?” or “What you mean by ‘unsure?’”. This was to try and develop the interpretative objective of eliciting raw data grounded in the day-to-day experiences of social workers intervening with cases of FASDs.

Data Collection Methods

Having received full ethical approval(s) as just discussed, the collection of data began on-site in Ireland on June 10, 2017, when the recruitment flyer (Appendix: A) was circulated through the director of services of Dublin North East (DNE) Ireland. All data collection proceeded following the ethical standards approved by each of the institutions mentioned. Following initial coding and analysis of this initial batch of data, I sought a modification of the original ethical approval(s) so that I could returned to the site for the theoretical sampling of foster parents and a mix of allied health professionals engaged with child welfare service work. Again, this modification of the original approval(s) required me to apply for a fresh ethics approval as I would be engaging with participants outside of the original participant group who were all CWSWs working for the state system of Tusla. In this second stage, foster parents and allied health personnel of other services were interviewed

Foster parents were recruited through the national support body of the Irish Foster Care Association. I was granted provisional access to state-registered foster parents by the Irish Foster Care Association (IFCA) (Appendix G), who manage the day-to-day needs of foster parents on behalf of Tusla. These foster parents were not necessarily aligned to any one specific division of Tusla, as IFCA is a stand-alone national body. All interviews were carried out individually.

I applied the following sequential steps of the ConGT s (Charmaz, 2014).

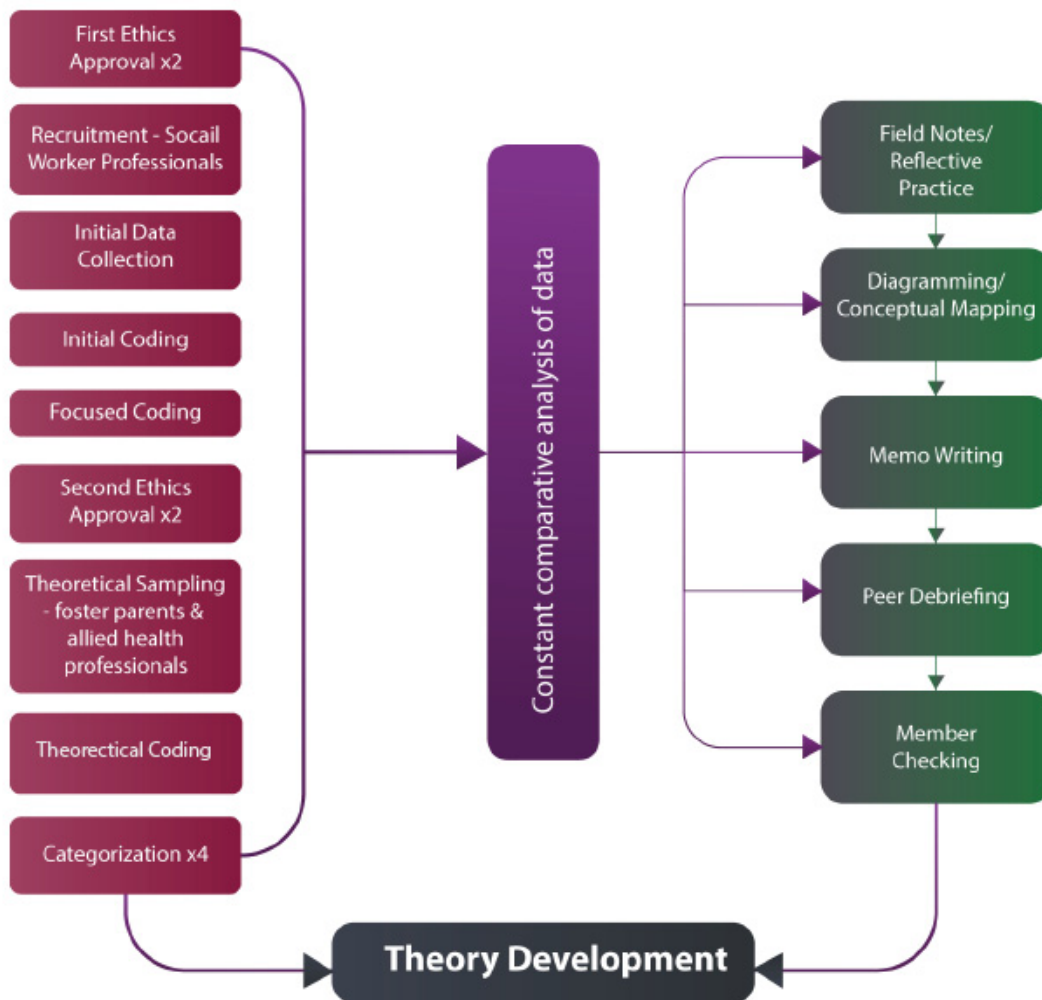


Figure 2. *Sequential steps of constant comparative method*

Constant Comparative

One of the most established and essential components of grounded theory is the action of comparing data constantly throughout the process (Charmaz, 2014; Glazer, 1967). As noted above in Figure 2, the central column, this process involved comparing each transcript. This was so that I could begin the process of creating theory from the data as it presented in the transcripts, a core target of the research. This action was in the initial stage (the first five transcripts) where I compared data with data looking for similarities and differences and coding the data along the lines of similarities and differences emerging within this initial phase of data collection. This line-by-line coding helped me to situate myself close to the world of the CWSWs. Through coding, I was able to identify gaps in the data, reframe my focus – the early data gave me new ideas and ones that I had not conceive of prior to entering the field of data collection. I refined my interview guide and introduced new questions to become more in tune with ideas and concepts that were emerging with the data.

This early coding was significant in that it helped to formulate a vision. By studying the data in this early stage, I was able to, as Charmaz (2006), states “make fundamental process explicit, render hidden assumptions visible, and give participants new insights” (p. 55). This was enriching for me as I moved into further transcripts, as new insights and concepts emerged. The data was showing evidence of knowledge and understanding of the wider implications of alcohol use in pregnancy, with some respondents having clear understanding on fetal alcohol syndrome but limited understanding on the wider implications of FASD. I began to move for initial coding to create focused codes as concepts were becoming clearer. Conceptual categories were specified and described based on the data of the inquiry.

Simultaneous Collection and Analysis of Data

During this phase I recorded theoretical ideas in memo form, as ideas emerged from the data. The theoretical ideas recorded on these memos were central to the later process of generating a theory that ultimately flowed from for the process. I began to create focused codes as conceptual categories were becoming clearer as the data analysis progressed. By transcript eight clear concepts were beginning to emerge allowing the early formation of conceptual categories. These conceptual categories were provisionally established at the end of eleven transcripts coming from the CWSW. I then moved to theoretical sampling by seeking a second round of ethics approvals in order to return to the field and interview both allied health professionals and foster parents, all who interact and collaborate with CWSWs when responding to FASDs in practice. Within this phase, I began to create theoretical codes which aided the cleaning up of the emerging conceptual categories within the data. As noted by Charmaz (2014), this process supports the elaboration and refinement of the initially categories, through to the establishment and refinement of focused codes. Through development of more robust conceptual categories, I believed I had reached theoretical saturation following analysis of the eighteenth transcript. The data was not saying anything new at this point. Throughout this process I also reviewed documents from within Tusla services. This analysis of documents combined with the data from my interviews helped to expand my understanding of the evidence as it emerged. Participants spoke of in-house documents and procedures but lamented the lack of documents or procedural pathways to respond to FASDs within their practice.

Memoing

Bryant and Charmaz (2007) advise that the researcher begins memo writing as soon as the initial ideas and thoughts begin to flow from the data. Memos help the researcher to

formulate abstract ideas and thus to help and ultimately assisting in the goal of theory generating. Memos help to explicate the underlying concepts and assist the me in critiquing any assumptions that may be emerging in the interpretation of the data (Bryant and Charmaz, 2007, p. 119). Furthermore, Clarke (2005) describes memos as “intellectual capital in the bank” (p. 85). I found this to be true, as the early interviewees presented heavy emotional and indeed angry emotions from CWSWs on the front line, who felt isolated in responding to children living with an FASD. By memoing and using reflective practice, I was able to situate this anger and emotion and critique it in a way that it could be articulated within the data findings. A further useful aspect of memoing was it contributed to a plan for theoretical sampling in the second part of the study. I was able to identify potential participants that would aid and possible provide theoretical possibilities later in the study. As the interviews progressed, memos helped to provide an audit trail within the data collection process.

This was helpful, as I halted interviews after the fifth interview, to review and take stock of what was happening in the data. As per the advice of Charmaz (2014), I revisited my memos continually during my constant comparison of the data. I have placed a memo in Appendix N Having prior knowledge, however, needs to be understood and conceptualized within the research task. Charmaz (2014) suggests that “the researcher’s scrutiny of the research, decisions, and interpretations in ways that bring him or her to the process. Reflexivity includes examining how the researcher’s interests, positions, and assumptions influenced his or her inquiry” (p. 344). I therefore also wrote reflective accounts as thoughts and concerns emerged during data collection. Situating myself not just as a researcher but also a male asking questions on a very female issue of pregnancy. A sample of this reflective practice is contained in Appendix M

Memoing Within the Process

Alongside the data collection process and interview activities, I scribed field notes or memos (Charmaz, 2014). These notes included notes on observation aspects of the interview, initial impressions, and dialogue that occurred both before and after the audio recording of the interview. As Gilgun (2015) describes, "descriptions in field notes are free-flowing accounts of what happened during data collection" (p. 5). This was an invaluable exercise in situating me within the context of the respondent's world. Understanding the situational experiences of child welfare service was imperative. Although this was the practice location of my own work in previous years, significant organizational change had taken place since I left the area. Coupled with this, the child welfare service was dealing with a substantial increase in workload pressure due to the national and global financial crisis which was incurring higher demands on child welfare service within society (Albert, 2017)

During the first few interviews in July 2017, I scribed multiple pages of summaries and reflections on what he was hearing and experiencing within the field. This is considered necessary by Padgett (2009), who suggests that such summaries are essential in managing and distilling the data. All summaries were written in word and exported to Dedoose. Memos written following each interview were saved and linked with each interview within Dedoose, allowing for higher analysis of each transcript. These memos helped in conceptualizing the data offered by the respondent. Analysis of the data began immediately once the first two transcripts were available. I coded the first transcript (MARIE) using initial codes and in vivo codes within Dedoose while waiting for the second interview (NIAMH) transcript.

Transcription

For the purpose of this study, I sought professional transcription services. Engaging professional transcription services provided the opportunity for constant comparative analysis of the data. I was limited to the time spent at the site and had respondents responding relatively close together with proposed interview dates. The speed of professional transcription (two to three days) allowed me to analyze the transcripts between interviews giving greater credibility to the constant comparative method (Charmaz, 2008, 2014). All transcripts were imported into Dedoose once received, and initial coding was engaged almost immediately.

As noted, transcriptions were professionally transcribed, with a transcription agreement of confidentiality signed with a professional Transcriber (Appendix K). To ensure a solid connection to the data, I transcribed the first few interviews fully myself, and I listened to each audio recording over and over to ensure a connection with the participant and the data. All transcripts were scrutinized once received to check for any identifying information. Where identifying information was located, such as a private service or an individual, this information was redacted to ensure confidentiality of third parties.

Computer-Assisted Data Analysis (CADA)

I utilized Dedoose (7.3, 2016) and found this data management software to be very user-friendly and flexible for my needs. Weitzman (2000) argues that the researcher can benefit from using the software in research projects by writing up, editing, coding, storage, retrieval, linking data to memoing and is relatively inexpensive to use (Oktay, 2012). The task of data analysis, as stated earlier, is not just about coding information and linking that information to conceptual categories. Seidel and Kelle (1995) describe the coding of data that "represents the decisive link

between the original, 'raw data' that is, the textual material such as interview transcripts of field notes, on the one hand, and the researcher's theoretical concepts on the other" (p. 52). Dedoose software is supported with helpful, accessible tutorials accessible that assist the novice researcher in this task of the coding journey to conceptual findings. It is relatively intuitive and offers many ways of viewing data, including word 3-D clouds, which was particularly useful. The software provides multiple tools to allow me to code, create and organize excerpts, conduct analysis in stages. The dynamic representation of the data in graphs and 3-D visuals greatly assisted the reflection and analytic process of interpretation. Charmaz (2014) offers that "diagrams can enable you to see the relative power, scope and direction of the categories in your analysis as well as the connections among them" (p. 218). This proved to be very true as the visuals gave life to the codes, concepts and categories as they developed in the study.

Application of 3-D visual, distributing codes in a circular motion automatically assigned colour coding to the codes that were most frequently represented. For example –early on in the constant comparative actions Confusion showed strongest in the 3-D model. It automatically showed up in the circular motion as blood-red color indicating it is the strongest code at this stage in the analysis. Cluster diagrams proved a useful technique by which to identify natural groupings of data codes, raising the analytical level of categories to form unexplored connections (Charmaz, 2006).

I could export in word format at all stages, thus allowing me to take a second lens to the data in a standard form. A few other benefits of using the software is the speed and ease of locating participants quoted in the write-up phase, as well as the ability to share work with Ph.D. committee members. The many visualizations, which one can access within Dedoose software, are yet another supportive tool in this grounded theory study. Key benefits of the software include:

- Interactive Visualizations and Analytics
- Coding, Creating and Grouping excerpts (visualization)
- Open Import/Export Migration
- Secure and Integrated
- 24/7/365 web-based access to tutorials, user guide, and other digital supports.

All of which further aided the conceptual and theoretical thinking along the data analysis journey. This was extremely valuable, as I moved towards identifying a grounded theory, sourcing the excerpts to support the finding with ease and using the conceptual images which Dedoose provides. A snapshot of the home page of this study with Dedoose is contained in appendix O.

Data Analysis

Glazer (1992) states that “the grounded theory researcher has three important characteristics: an ability to conceptualize data, an ability to tolerate some confusion, and an ability to tolerate confusions” (p. 838).

Each individual was assigned a code at the time of signing consent. These codes were for social work SWIRL and a number (*SWIRL7*) for allied health professionals AHPs and Number (*AHP5*) and for foster parent FCIRL and number (*FCIRL3*). This assigned code was used from the very beginning of the audio recording. This ensured an added level of confidentiality and further assured that the professional transcript was not privy to the participants identifying detail. For the purpose of writing up and creating a smoother reading experience for the reader I have

given all coded participants a pseudonym name. The following chart links codes to pseudonym name within the study.

Gender	Research Code	Pseudonym
Male	SWIRL11	John
Female	AHP5	Sharon
Female	SWIRL10	Marie
Female	SWIRL4	Niamh
Female	SWIRL7	Carol
Male	SWIRL3	Patrick
Female	SWIRL6	Joyce
Female	FCIRL3	Fiona
Female	SWIRL8	Rachel
Male	FCIRL5	Harry
Female	SWIRL2	Jane
Male	SDSW1	Bobby
Male	AHP4	James
Female	AHP7	Ann
Female	SWIRL15	Roisin
Female	SWIRL5	Mary
Female	SWIRL14	Kathleen
Female	FCIRL7	Ruth

Table 2. *Codes to pseudonym name.*

Initial Coding

Initial coding is the preliminary stage of data analysis, where labels are systematically assigned to segments of data to allocate units of meaning. Line by line analysis was employed to fragment participants data with tags, highlighting the significance underlying the dialogue that would frequently escape the researcher's attention (Charmaz, 2006, 2014). For example, trying, fighting, trying to support, trying to respond, working in isolation - Gerunds, the noun forms of verbs, were used to label blocks of text to preserve action and make meaning explicit as it unfurled within the data (Charmaz, 2014). Initial labels were mostly descriptive, recounting the

action of a line in concise terms. These expose the “implicit processes, to make connections between codes, and to keep their analyses active and emergent” (Charmaz, 2008, p.164)

Exceptions occurred when gerunds were substituted for in vivo codes, the words or phrases used by social workers such as ‘nobody is listening’ or ‘just putting up with it.’ In vivo codes acted as a significant feature of coding, derived directly from the language of the social workers to extenuate, describe and emphasize problems in a way that was meaningful to them (Charmaz, 2006). In vivo codes were useful as they progressed theoretical insight into the direct experience of social workers engaging with the phenomenon under inquiry without requiring further abstraction (Strauss, 1987).

During this early part of the analysis, my audio recordings and field notes were revisited to ensure the analysis was intuitive and that I was developing correct meaning to the stories that social workers were sharing. This provided an additional lens on the analysis and assisted in drawing implicit meaning from the interview context. By returning to original sources, initial assumptions made by the coding process can be challenged, and possible bias addressed (Strauss and Corbin, 1997). Revisiting data also encouraged new interpretations of social work dialogue, encouraging new codes that encompass a plurality of meaning (Charmaz, 2006). Deep immersion in data and repeated reading of transcripts fostered sensitivity towards the social work attitudes dealing with the phenomenon of FASDs. Allied health professional interactions also assisted in this task, enabling a full picture to develop of the beliefs of the participants, and how such beliefs impacted on their interventions with children and families living with an FASD.

Constant comparative analysis of preliminary data transcripts facilitated the early emergence of conceptual categories, identifying features specific to each interview transcript dataset (Charmaz, 2006, 2008, 2014). Dedoose highlights feature was a useful tool in forming early categories by using a simple system of colour coding. This allowed large amounts of data

to be reduced into general descriptors of responses, facilitating comparison between different features of data. The following excerpt (Fig 4) offers insight into the initial coding of transcript data within *Dedoose* on the process of coding, which helped manage, code, and analyze the qualitative data supplied (Version 7.0, 2016).

MARIE	
<p>Well, this child, <u>I'm still in the role of the social worker</u> to this young man. He is aged nine now I think, need to just double check that, he's around 8 or 9. <u>He had a range of complex needs. So, he has the visual signs of a child with FASD.</u> Fetal Alcohol Syndrome <u>he has difficulty at school, speech delays.</u> Not so much speech delays but more understanding, communication programs. <u>He has some sensory issues,</u> and they plan movement breaks within the school for him, which are quite helpful. <u>He can be quite hyperactive.</u> He is a very good child and wants to be a good child, and he is <u>a good-hearted child.</u> However, he can get in trouble. He plays with children, and he will tell me he tells them don't get annoyed, don't lash out but <u>he has hit his peers, he has hit is siblings.</u> More because they wanted to take a break from play whereas he wants to keep going. Once he gets into the role of something, he finds it <u>difficult to self-regulate and calm</u> down and wind down before bed, for example. So, there has been, from the years that I've been working with him, we've accessed <u>quite a lot of services for him.</u> But there's been much confusion around accessing services for him. At the moment there is quite a debate between like we put a lot of</p>	<p>Challenging Practice Interventions</p> <p>Advocating for the child</p> <p>Child Development</p> <p>Conflicting Response from CAMHs</p> <p>Professional Positioning</p> <p>Quantifying Children</p>

<p>time and energy into getting this child the right services. He is linked with CAMHS, the <u>child, and adolescent mental health services</u>. He has also been linked with the child development team. Now he <u>has been pushed from one service</u> to the other. They're saying that he would benefit from occupational <u>therapy, speech and language, psychology services</u>. The child <u>development team have discharged him</u> or were holding him <u>until he was accepted by CAMHS</u>. And CAMHS were saying <u>this child isn't relevant to us, he doesn't have a psychiatric or mental health illness</u>. So, we've now tried to have multidisciplinary meetings where we're <u>saying this child is entitled to a service, and we need someone or some service to take responsibility</u> for service provision for him. Moreover, it looks like they will co-work the case now and provide what is needed.</p>	<p>Contesting Medical Privilege</p> <p>Understanding the needs of the child</p> <p>Challenging Behaviors</p> <p>Confusion concerning FASDs</p> <p>Committed Social work practitioner</p>
---	--

Figure 3. *Example of Initial Coding*

Theoretical sampling

Theoretical sampling is an essential feature of grounded theory and one that distinguishes it from other forms of qualitative approaches and is considered by some theorists to be paramount within grounded theory (Gentles and Vilches, 2017). Theoretical sampling is described by (Glazer and Strauss, 1967b) as a process for collecting, coding, and analyze data and then decides, "what data to collect next and where to find them" (p. 45). In this case, 'theoretical sampling refers to sampling for theory construction' (Gentles and Vilches, 2017), using the initial social work data as a guide in directing me to individuals that could extend my initial data findings and give additional supporting evidence to addressing the research question

of social work interventions. Initial data spoke a lot of the relationship of the CWSW with foster parents, and how this relationship was sometime strained due to needs of planning safe care and provide much needed resources. It supported the development of theory through an emergent process.

I returned to the site and conducted seven further semi-structured interviews with a mix of participants coming from allied health and foster-parents caring roles, as I believed these participants could aid the development of categories and bring a higher level of abstraction to the data analysis (Charmaz, 2014). I engaged in theoretical coding only after some analytic and abstract categories were developed through initial and focused coding of the first data bank. Engaging in theoretical sampling at a later stage (October 2017) is considered safer than early theoretical sampling, in order to avoid analytical pitfalls, particularly as the researcher was a novice in the field (Charmaz, 2014).

Document Analysis

Charmaz (2014) encourages the use of documents, policy or otherwise, to aid the researcher in a ConGT study to support the process of analyzing the interview data. A starting point here for the study was to seek to understand how FASDs were viewed and defined from a policy perspective. One of the most noted aspects of FASDs impacting Child Welfare Service, is the paucity of policy or procedure to guide social workers in their interventions with this disability (Wilson, 2013). Although a large body of literature documenting the disability of FASDs in Child Welfare Service is available in society, it was difficult to locate specific research to understand the role of the CWSWs. I also sourced documentation from both the Irish Department of Health, Tusla child and family agency and some NGOs. Although this did provide some generic evidence of FASDs, it again yielded poor results of any systematic approach to the

needs of children and families living with FASDs. Interviews with CWSWs and AHPs revealed that they craved a need for more robust, holistic and focused approaches to be initiated to support their psychosocial interventions with children living with an FASD and their caregivers, a need repeatedly highlighted in literature (Mukherjee, et. al., 2013).

I found various documentation within the study site focusing on prevention (Barry, Kearney, Lawlor, McNamee and Barry, 2007; Gill and Sharif, 2017). (Later documentation on FASDs emerged within the site after this stage of analysis). Such documentation is helpful in seeking to contextualize the role of social work and how their interventions can operate successfully within this particular location. I found some internal documentation within Tusla concerning child welfare service and the role of social work, all of which assisted in the analysis and aided me in formulating to the role of social work interventions with FASDs.

The majority of the literature concerning child welfare service and the profession of CWSWs regarding FASDs comes from international experts (Badry and Choate, 2015; Badry and Felske, 2011; Popova et. al., 2012, 2014). Also, the doctoral study by Durking makes a unique contribution to child welfare understanding on FASDs due to its direct focus on CWSWs (Durkin, 2016).

Saturation

The study sought to adhere to what the founding fathers of GT described as the point in an inquiry where the data is not saying anything new (Glazer and Strauss, 1967). Saturation was reached with the eighteenth interview while conducting theoretical sampling, in that I was confident that the data was not offering anything new. Furthermore, given the specific and focused nature of the research question (Charmaz and Belgrave, 2012), within the specific cultural site where FASD is somewhat of a controversial topic, this number of 18 interviews was

sufficient to give rich, valuable and robust data.

Collectively, all participants offered a coherent and unified message of palpable concern on the issue of FASDs and were unified in their acknowledgment of the impact FASDs was having on child welfare service. In reaching “saturation,” I further analyzed documentation, such as publications, government statements or state bodies policy documents.

Trustworthiness

A central question to be answered in any qualitative research activity is to deliver a trustworthy study at completion. Lincoln and Guba (1985) ask "how can the inquirer persuade his or her audience [including self] that the findings of an inquiry are worth paying attention to, worth taking account of"? (p. 290). In the beginning this inquiry, I was mindful of the complexity, sensitivity and ethical considerations concerning the topic under investigation and thus understood the need to deliver a study that is reliable and valid in its reported findings. I sought to apply rigor to all actions of the research process within the inquiry. To be neglectful of adopting a strategy of evaluating rigor runs the risk of without rigor, research is worthless, becomes fiction, and loses its utility (Morse et. al., 2016).

A rigorous qualitative study tends to be associated with what (Guba and Lincoln, 1994) refer to as trustworthiness, credibility, transferability, audibility, and conformability. Many versions of Guba and Lincoln's criteria have evolved within the qualitative paradigm. Charmaz's (2014) evaluation is slightly different: a) credibility, b) originality, c) resonance and d) usefulness. In achieving trustworthiness, it must be acknowledged that these criteria are interrelated.

I was very mindful of the enormous ethical and sensitive challenges faced by participants coming forward to the inquiry. Having submitted all ethical approvals to Tusla, the state employer, I sought to assure participants that their contributions and their identity were very

protected procedural within the research process. This was important, as the disability of FASDs in Irish culture is highly stigmatized owing to the cultural acceptance and normalization of alcohol consumption. In one Irish longitudinal study (Barry et. al., 2007) addressing the issue of illicit drug and alcohol use during pregnancy, the authors found awareness and acceptance of illicit drugs, but little awareness or acceptance of the risk's alcohol posed during pregnancy. This was also a finding of a qualitative study I conducted with Irish allied health personnel linked to CWSWs where there was a palpable level of concern in the professionals contributing to the inquiry. In this study, (Curran, 2007), I found a heightened level of concern for both maternal and child health within the specific problematic culture of alcohol use/misuse.

Achieving trustworthiness with participants was sought through careful preparations in the formative stage of this inquiry and ensuring that all paperwork, ethics and committee

approval stages are complete before engaging in fieldwork activity. Developing a verification strategy was paramount from the outset. An audit strategy was adopted to continually review that adherence to methodological coherence, theoretical sampling, sampling adequacy, an active analytical stance, and saturation (Morse et. al., 2002). Such adherence woven into the inquiry sought to validate inquiry study findings (Creswell, 2013), thus upholding rigor and trustworthiness at all stages of the investigation process.

Chapter 4: Findings

Introduction

Child Welfare Social Workers are Advocating against the Tide when responding to Children living with or suspected of having an FASD

I identified *Advocating against the Tide* as a core category and therefore the grounded theory of this study. The grounded theory is supported by four sub-categories derived for the data. These four subcategories are subsequently supported by focused code data excerpts from the participants to the study.

Alignment of Data

Theoretical sampling indicates when early categories need further exploration (Charmaz, 2014). I found a compelling alignment between the data collected within theoretical sampling and data from the initial phase of the study. Although the participants within the theoretical phase of the study were not CWSWs, allied health professionals supported the participants in their interventions for children living with an FASD. All initial focused codes, and theoretical focused codes were merged using Dedoose software. After further analysis on the merged field of initial and theoretical codes, codes posting the highest values formed the categories.

Category/Sub Categories

Based on the findings from the analytical process, I offer *Advocating against the Tide* as a core theoretical finding in the study, as it was a recurring phenomenon observed in the setting. CWSWs feared advocating for a child with an FASD due to potential conflict within professional groupings of the wider allied health system. The core category was developed based upon sub-categories (Charmaz, 2006). Please note the sequential steps of data analysis outlined in Fig 3. In building towards this core category, four sub-categories of 1) Professional Position, 2) Intellectual Haze, 3) Broaching Difficult Conversations and 4) Disabling the Enabler emerged,

supporting the overall core category of Advocating against the Tide. The use of memos supported the data analysis by strengthening ideas, concepts and categories within the data. The substantive and core categories are outlined in Figure 3:

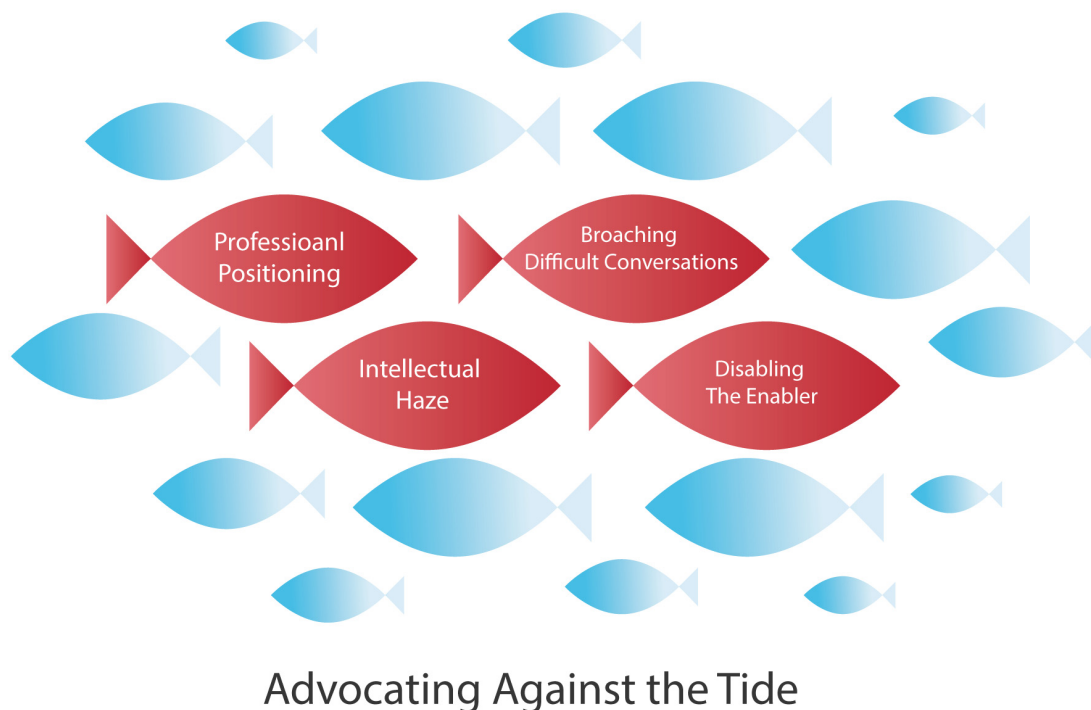


Figure 3: *Grounded theory and sub-categories -The blue illustrations (fish) represent CWSW when planning safe care. The red illustrations (fish) represents the four conceptual categories of the study demonstrating the dominant forces of the tide impeding the statutory responses to FASDs.*

The study found that basic principles of open communication and flow of information structures are fundamentally weak and even non-existent when responding to cases of FASDs. CWSW who are tasked with a mandated duty to plan safe care for these children are *Advocating against the Tide* in responding to cases of FASDs. Advocating against the Tide is a lack of professional recognition granted to the CWSW, resulting in barriers when planning safe care.

The tide further impedes CWSWs practitioners in their responses on cases of FASDs which is likely to create a vulnerability for the CWSW. This lack of professional recognition compromises the statutory duty of CWSWs and additionally strains their relationships with caregivers. The four sub-categories of Professional Positioning, Intellectual Haze, Broaching Difficult Conversations and Disabling the Enabler offers that analysis of the data is suggesting that CWSWs are struggling to effectively respond to children living with or suspected of having an FASD. Evidence also indicates that CWSWs are heavily restricted in carrying out their mandated role of ensuring the best interest of the child, owing to a prevailing culture of alcohol adoration within the Irish cultural.

Advocating against the Tide, CWSWs are bereft of the necessary knowledge, skills, policy and practice standards for intervening in this complex neurodisability. JOHN highlights the issue of ‘side-stepping’ the issue and sending children into repeated assessments. Side-stepping may be seen as a direct action resulting from the tide of disrespect offered the CWSW within FASD dialogue. Side-stepping appeases the dominant forces and maintains the status quo resulting in the advocacy of CWSWs being blocked when seeking a response to a child’s needs. Assessment processes that miss the underlying ethology of the behavior will not indicate interventions that yield expected change in behaviors. CWSWs are not in a strong professional position to effect change in repetitive assessments owing to multiple barriers as documented in the sub-categories of the study that ultimately leaving them Advocating against the Tide.

While CWSWs remain excluded within mainstream literature, it is perhaps understandable that they will succumb to the tide by not advocating fully for a child’s needs. Again, this places the statutory obligation of state law in doubt, as current systems do not favor CWSWs, leaving them to advocate against the tide in isolation with poor outcomes for children.

PATRICK talks of the potential number of cases of FASDs within the Tusla services, which may create fear owing to a lack of education and policy among CWSWs in acknowledging the FASD disability.

PATRICK: A high proportion or a significant proportion of the young people we deal with would have come from circumstances where alcohol and substance misuse were quite high factors, but FASD doesn't get mentioned very much.

A lack of education and policy and practice guidance leads to caseworkers to muddle through each aspect of the intervention process. This may 'inhibit' successful outcome, resulting in unsafe care for the child with an FASD. CWSWs and allied health professionals employed very stressful strategies in their response to coping with the demands of children with an FASD and their caregivers. Evidence supports the finding that the CWSW is "Advocating against the Tide" was present when MARY offered 'we have no real idea' and how this can result in ineffective interventions restricted by fear.

JOHN: So, you know, but you do have speech and language, you have occupational, you have psychology, you'd have schools, everyone trying their best and giving input. And carers, of course. And I personally find, you know, I'm looking at all this different information and trying to find the path, but what is the path? Who is directing it?

JOHN epitomizes the struggle of "trying to find the path" do the right thing – searching for a path to follow but also seeking someone to direct. This again may suggest that the absence of agency policy and practice standards is leaving JOHN vulnerable and Advocating against the Tide. Again, be mindful that JOHN is trying to activate his statutory duty of ensuring safe care.

The "we have no real idea or picture of what's going on for them" was a common concept reoccurring within data and in the conversations while engaging with CWSWs in their office settings. This can be best encapsulated by the fear that arises when cases of FASDs appear

on a CWSW's caseload, followed by a confusing path when seeking to carry out a statutory duty of planning safe care. JOHN talks of the confusion that comes with prenatal alcohol exposure and finds that continued assessment is the best way perhaps to deal with the confusion.

JOHN: It's just the confusion comes with, you know, I think that sometimes there's a propensity to assess and assess and assess, you know, and reassess

As was documented in the literature of the study, confusion is still a major barrier impacting the professional understanding of FASDs. JOHN offers that due to the confusion, children will just continue to go around in a cyclical motion of assessments as the clarity around FASDs is lacking with the service structure. Again, the issue of undiagnosed and misdiagnosed is discussed in the wider debates of FASD.

Professional Positioning

This category was constructed from the initial analysis and code formation. Four defined subcategories were developed within this process. The codes are: Feeling Devalued, Not Knowing a Confused Journey, Being Subservient, and Contesting Medical Privilege. Ultimately, what CWSWs discussed was this feeling of being the unwilling participants of a "merry dance" where they have little say but can get lead in many different directions when seeking to offer services for a child with an FASD. Professional Positioning is where individuals exert power and influence within the FASD dialogue of meeting a child's needs. It may be best conceptualised as a type of turf war with individuals marking out their territory and creating exclusion zones around their services.

However, in many occasions within the data, such power influences were not based on knowledge of FASDs. Professionals may adopt a position out of ignorance concerning FASDs, or indeed adopt a position based on prior knowledge and education concerning more traditional socially acceptable neurobehaviorally and neurocognitive presentations, therefore denying the

reality of FASDs, while at the same time exerting power with the statutory responsibility to planning safe care for a child. It would offer that the lack of FASD informed education is a significant barrier in collaborative working to meet the needs of the child living with an FASD and their caregivers. This lack of FASD Informed professionals is a major hindrance to the CWSW approaches to Planning Safe Care and upholding the statutory obligation of the social work profession

Feeling Devalued.

Feeling devalued was a common occurrence throughout the data when CWSWs spoke of their advocacy for children with or suspected of having an FASD. Their advocacy was particularly devalued by other non-social work professionals who carried higher status and therefore offered a power over the CWSW role. As John notes: just speaking the word FASD can have the effect of wondering “oh my god, what’s going to happen?” To fear speaking up is a major devaluing of the response of the CWSW.

JOHN: So that was my decision to raise that. And it was fine, but I remember struggling with it. And even as I was saying the words thinking oh my god what’s going to happen, but it was alright. But you know you’re never too sure.

CAROL: And you might have a social worker then who is involved in like a therapeutic service, who comes into court and they would be treated entirely differently. Like an expert. Whereas we’re not.

Participants spoke about issues of Professional Positioning in intervening with children where FASD was diagnosed or suspected. CWSWs articulated that they were devalued and had their interventions dismissed in a hierarchical system of care. This was a phenomenon and a recurring undercurrent of the data. CWSWs expressed feelings of not wanting responsibility. This was more evident within the allied health personnel who saw the CWSW as responsible.

However, the CWSWs were equally struggling to respond due to lack of holistic working relationships. MARY discussed this devaluing experience within her work:

MARY: I'm the doctor, or I'm the psychologist; you are only a social worker. And you can't question me."

"Only the social worker" indicates self-deprecation in how she views her role. MARY's excerpt may offer the extenuating circumstances on how the role of CWSWs is compromised within the dialogue on FASDs. Without the skills of education and framework of policy to guide, the role of the CWSWs may become 'just a social worker' with no power of self-belief of power to design and/or implement a plan of safe care. MARY's statement indicates that she feels no other option but to take the road of least resistance.

Another participant reflects on the challenging aspect of seeking an assessment. Carol spoke of the double jeopardy when seeking to plan safe care. Firstly, discussing with the parent caregiver her concern that the child may need an assessment but then having the medical response that they won't do an assessment and to come back in six months. This has a devaluing experience on both sides of trying to respond to the needs of the child. CAROL says:

CAROL: We'll consider it again in 6 months' time. And you might have had a conversation, a difficult conversation with a parent or a foster carer about the fact that this is something you're concerned about, and you're going to raise it. And then it damages your relationship further because like a doctor says no, no too early to consider that.

JOYCE: And again, there's a real resistance to, they're too young, we can't consider that now (laugh), kind of a stop asking us kind of an approach at times, you know in terms of the doctors in the hospital.

Again, here, the professional positioning between the medical and social worlds is evident. Noting that JOYCE gave out a ‘laugh’ during her response may signify a sense of hopelessness in her advocacy for a child on her case load. She states that as a CWSW she has to “stop asking” as the medical doctor is dismissive of her role. Joyce is seeking to advocate in a statutory mandated way for the child on her caseload, the data offers further evidence of the CWSW Advocating against the Tide due to professional hierarchies taking a superior position over the CWSW.

It shows a devaluing dialogue that CWSWs must engage with, in order to try an advance a plan of safe care. CAROL also notes how the dialogue can and does damage the relationship with caregivers. Having had the ‘difficult conversation’ with the caregiver concerning FASDs, the CWSWs is then caught between a rock and a hard place, resulting in fractious relationships with the caregiver. This supports the grounded theory of the study in that CWSWs within this particular setting find themselves positioned to Advocating against the Tide. CAROL, in a later excerpt, crystallizes the ambiguous role of the CWSWs on interventions for a child with an FASD when she says:

CAROL: Because there is a real disrespect, you know, from our court system and you wouldn't go in and disagree with the doctor because you'd end up regretting it. And it's really hard to, even within the organization, if you disagree with other disciplines. Also, I've been down that road, you know with another part of the agency may be where there's a multidisciplinary team who want one thing, and you're being asked to sign off on this care plan because the other person is responsible and in the whole of my being I know that it's the wrong plan and I'm saying no I'm not doing it and I disagree with it. And then you get a phone call to say well you're going to have to agree with it because

we're going into court and you can't go into court and have disagreed with somebody else who is in Tusla.

This excerpt crystallises the devaluing of the CWSW advocacy. Although Carol tries within the multidisciplinary arena to advocate, her advocacy is ultimately silenced by a more senior power within her own organisation. Again, if the CWSW is tasked with a legal mandate of planning safe care and when this legal mandate is disrespected within the service responsible for upholding this mandate it does not bode well for CWSWs to deliver on safe practice. Devaluing of the CWSW role with FASD advocacy is a serious matter which the state system needs to address. Devaluing of a legal mandated professional will likely end with poor planning and potentially lead to a child suffering a negative trajectory in life.

Not Knowing: A Confused Journey

The sub-category of Not Knowing a Confused Journey was a recurring concept within the data. CWSW talked openly on the lack of education, policy and procedure to guide them when responding to cases of FASDs. The CWSW confusion is more often caused by the professional positioning of others especially within the medical model of responding to FASD. Her Joyce laments that being a social worker and advocating for a child with an FASD is laughable

JOYCE: Yeah, absolutely and that constant questioning of yourself that you have when you're a social worker (laugh) and that thing of why I didn't do psychology, then they'd listen to me.

RACHEL: Certainly, think it should be because look the statistics are telling us that there's a huge problem. And if a lot of our case load is working with children who have been exposed to this, we need to have the knowledge.

JOHN: So, it's a difficult path to tread I think. I think it becomes Yeah, the more you read the file the more confused you become because, well fetal alcohol syndrome, there's the diagnoses, but that doesn't really get you anywhere unless you know what that is, what the effect is.

A further aspect of the professional position is the diagnostic belief that many believe to be the greatest need or the only option for meeting a child's need. CWSWs are often more interested in developing a service-led approach to the disability of FASDs. As demonstrated in the vignettes, mounting evidence suggests that for many children receiving a diagnosis does not offer clarity about service provisions. JOHN speaks of the difficult path for the CWSW with a feeling that diagnosis is essential in order to understand the path to follow.

MARIE speaks to the confusion that CWSWs experience when confronted with trying to find a pathway

MARIE: I think that I did use the word confusion earlier, I think that there is nothing that comes with a diagnosis of fetal alcohol spectrum disorder that accesses better services or benefits or seems to clarify things for professional services.

Although MARIE is offering an insightful view that the diagnosis does not offer any new or offer professional clarity on treatment planning for children or carers. As noted in Chapter 2, evidence continues to emerge that rushing to a diagnosis is ultimately not a golden bullet to solve the presenting difficulties. MARIE is indicating that they would like to have more options or a different pathway to follow, as she does not feel the diagnoses will offer a child what is needed. The lack of education offered to CWSWs concerning options to choose in their interventions is evident in the data, as CWSWs talk of not knowing which way to go when dealing with an FASD case.

Being Subservient.

The sub-category of Being Subservient is offered to explain how CWSWs have little option when responding to cases of FASDs due to the organisational approach to the issue. “Being” subservient is different from “acting” subservient and denotes that the CWSWs can only operate the status-quo of the service structure -- allowing others to control the dialogue and ultimately control the care planning tasks, a plan that may not be something the CWSW feels is correct in meeting the child’s needs.

PATRICK: I think you know because of who holds ownership of the potential of FASD, is it a model that can be used within social work or is it a model that can be used within psychology or CAMH psychiatry.

CAROL: I find it difficult at times that sometimes it’s a concern that maybe a social worker, or I and the allocated social worker might have, but other professionals aren’t wanting to consider it, they’re suggesting it’s too early in the child’s life to consider it.

A diagnosis should not be the only criteria to access a particular service. The foster parent notes a frustration with the social work service when she states:

FIONA: They’ve nowhere to, they’ve nowhere to point me.

The foster parent offered data which suggested that they need to get the diagnosis in order to get the attention of the social work department:

FIONA: But now we're, we were thinking about going to the GP (doctor) maybe to get a diagnosis and bringing this to the social work department’s attention.

The caregiver felt that the social work department would only engage once a diagnosis is in place. This suggests that child welfare services and CWSWs operate in a subservient manner to the medical profession, allowing the caregiver to go directly to the physician and only coming

to the CWSW after a diagnosis. The concept of the cart before the horse comes to mind here. FIONA is trying to access a pathway of services for the child in her care. The data would suggest that FIONA is not feeling supported by the social work department and there's looking for something more concert – a diagnosis to get the social work department to listen to her needs as a caregiver. This again highlights the strenuous relationship between care giver and the statutory mandated social workers

Contesting Medical Privilege.

Contesting Medical Privilege is primarily offered to encapsulate the struggle that CWSWs have in walking a tightrope with medical directives. Hierarchies of medical superiority and control that does not engage with any psychosocial needs of the child was evident within the particular site of inquiry. This ultimately leaves the CWSWs in a difficult position, where contesting a solely medical model of FASDs is problematic.

JANE: And we do get to that point but there just are medical differences of opinion that I can't comment on. It's just the confusion comes with you know, I think that sometimes there's a propensity to assess.

JOHN: I don't want to feed into a stereotype but sometimes yeah, some doctors, they're the experts and they'll tell you what has to happen. But we're trying to put things into a wider context you know.

SHARON: But they talk to themselves a lot, you know GPs will consult with the experts, the psychiatrists and liaise and I find they do that a lot. And maybe I would talk through the GP and the GP would tell me oh this is what we're doing, you know. So that can be a bit uneasy. And not all GPs are helpful

The concept of the corporate parent was introduced and discussed by JOHN. Corporate parent again denotes the statutory responsibility of both the CWSW and the child welfare service to promote a child's welfare.

JOHN: Well, to doctors or medical people tend to - you know the term to be ridden roughshod over, you know not exactly ignored, but just you're not important maybe, you know? We do think we're important because we're the parent, you know"

The overriding experience of the CWSWs is that of being "ridden roughshod" while trying to deliver the corporate parent role for a child with an FASD who needs services. Contesting a medical privilege is a major challenge of the CWSW to carry their statutory responsibility to the child. However, JOHN does acknowledge their responsibility by stating, "we are the parent," suggesting an element of conflict between being devalued but wanting to offer the parenting role. How CWSWs can uphold the statutory duty to plan safe care while being experiencing being devalued is problematic.

The state parent was raised again by JOHN when stating:

JOHN: *You* know we can't be an expert on everything. I think social workers sometimes, we are the manager of the case, we are the state parent, but we can't be an expert on FASD or all the other things that affect a child, because do you know I could name things like attachment, that we have to know everything about.

In discussing the state parent, JOHN notes that social workers are "manager of the case" but that they can't know everything about everything. Again, noting that FASD is not on the education front, but things like attachment are higher priority. As noted by JOHN "we can't be expert in everything' denotes a major challenge facing the CWSW in engaging the FASD disability. The frontline of CWSW in the site of inquiry has many challenges and many

pressures. There are multiple and complex needs presenting to the CWSW on frontline interventions. Ultimately as CAROL notes, CWSWs are routinely left feeling completely powerless in delivering their intervention for FASD children residing in child welfare service.

CAROL: I think social workers can feel quite powerless in it (FASD).

Again, such data needs to be considered in terms of the statutory and mandated role of the CWSW's responsibility to plan safe care and uphold the best interest of the child. CAROL offers that a feeling of powerless will increase the vulnerability of the CWSWs in carrying out their mandated duty, but also likely to become a severe impediment to collaborative working in order to achieve the best outcome for a child living with or suspected of having an FASD.

A further significant concept to emerge in the data was the conflict between frontline duty for CWSWs and how upper management of the agency view this work.

PATRICK: So, it is straightforward to move into a middle management piece where you have lots of responsibilities but no accountability and look at an inexperienced social worker who has all the accountability and none of the experience to sit with the challenge of FASD's responsibility.

As noted in Chapter 2, child welfare management may have difficulty in accepting the prevalence and presentation of FASDs due to fears around the potential costs of addressing FASDs. This invariably leaves the social worker carrying all the responsibility of trying to secure a plan of safe care while the upper level of the organization is in denial of the reality that FASDs are in existence within its services. This places an additional burden on the CWSWs as they are mandated to ensure safe care but not feeling or experiencing support from the very agency that is required to ensure the mandate is upheld.

CAROL: I find it difficult at times that sometimes it's a concern that maybe a social worker, or I and the allocated social worker might have, but other professionals aren't wanting to consider it, they're suggesting it's too early in the child's life to consider it.

CAROL talks of trying to access services or assessments where a concern exists for a child but getting rebuffed by the other professions. Again, we see a CWSW's "concern" around fetal alcohol exposure being dismissed within the interdisciplinary group of professionals. It's unlikely that a CWSW's concern around neglect or physical abuse would be rebuffed in the same way. However, a child with or suspected of having an FASD is of equal concern and should be viewed as such within state systems of care.

In the same way, the needs of planning safe care must be met, and the best interests of the child upheld. Also, early interventions and assessment of need are showing to be the most beneficial approach to children with an FASD or indeed, any child who is experiencing difficulty. For CAROL to be rebuffed, devalued and have their concern dismissed or told it is too early, is potentially renegeing on the principle of a child's best interest, a principle clearly established in legislation.

Intellectual Haze

The second theoretical category to emerge following data analysis is Intellectual Haze, which relates to the role of CWSW's discomfort with the challenge of managing and responding to FASDs. This category emerged from the following focused codes: a dialogue of fear, wanting to get it right, emerging knowledge, and lacking a procedural pathway. Intellectual Haze denotes a prevalence of misinformation concerning what FASDs are and what the needs of this of the children living with an FASD. Intellectual Haze was a feature across the study and was particularly evident within data of collaborative working.

Working within an Intellectual Haze is a precarious position for the CWSW who is tasked with the legal mandate of ensuring the welfare of a child with an FASD. As noted, following – having a dialogue around prenatal alcohol and FASDs is challenging within the particular culture of this inquiry. As CWSWs and allied health professionals fear speaking about FASDs, this significantly hinders knowledge translation, a process that could bring intellectual clarity and bring a CWSW to an FASD informed position within their responses to the needs of children living with an FASD. The truism that *knowledge is power* was sadly lacking within the data, power is the direct opposite of powerless, a view repeatedly represented in the data and a feeling expressed by many CWSWs within the study.

Dialogue of Fear.

A dialogue of fear may be best described as a feeling of insecurity and doubt that that's creeps in when addressing the needs of a child with FASD. Discussing Having to consider and discuss the sensitive issue of prenatal alcohol exposure can render the most secure CWSW helpless and fearful of discussing maternal rights versus the rights of the child. It is likely to weigh heavily on the CWSWs shoulders as they attempt to secure a child's welfare and respond to their needs. Rachel talks of not having the knowledge to do this crucial piece of work.

RACHEL: We're not talking about it. And I'm trying to bring, I've brought them to a meeting to gently bring them around, because you don't want to say to somebody, oh you don't know about that. And people are afraid to admit it. But because they don't have the knowledge then they can't support, so it's kind of the same thing, the fear holds people back.

JOHN: And it's a touchy subject when you mention alcohol I think, you know, with parents, they're the parents, they love their children. You know we have a job to do, but it's still trying to thread a fine line sometimes.

KATHLEEN: I don't remember talking about it in college, learning about it in college

The focused code of a dialogue of fear encapsulates a significant finding within the data. The vast and accepted culture of alcohol use within Irish culture presents significant difficulties in discussing and addressing its potential harm objectively. Moving the conversation to FASDs is fraught with multiple factors, which need significant investment in education to overcome. As RACHEL notes “fear holds people back.” Many respondents talked of the "fear, the not going there, not wanting to fight, better to say nothing," which together encapsulates this focused code of fearing the dialogue. Further, as noted by Jane, fetal alcohol is not currently addressed in social work undergraduate education. This is potentially a significant failure of the knowledge mobilizations needed with social work education. Jane offers insight on the culture of alcohol and how its impacts of the CWSW response to children.

JANE: I think there's also definitely a fear there that I mean we are, we're Irish, and there is a huge amount of drinking, obviously, in our culture. We do not like to think of the effects of alcohol on children or that they harm children. So, I think there's a protective thing there for us as well in saying that it's not to do with alcohol, or sure lots of people drink, or you know sure one or two wouldn't do any harm, and you know.

JANE grapples with how the role of social work operates within the “huge” alcohol culture and how it impacts her practice. It is also interesting to note that JANE talks of the protective role she carries within the culture of alcohol acceptance. Feeling the responsibility of protective role, which conflicts with the accepting alcohol culture, is a significant challenge for CWSWs. The complexity of CWSWs' role in interventions with families of substance abuse is problematic at the best of times. Seeking to respond in cases of FASDs heightens this complexity and renders the CWSWs experiencing fear. The particular culture's revered attitude toward

alcohol consumption has, in large part, denied and hidden the neurodisability associated with FASDs.

PATRICK: Well, to be fair, Ireland has absolutely no problem keeping its head in the sand, we are quite expert, I think, at that as a society.

PATRICK articulates the enormous challenge faced by CWSWs within the culture of the inquiry. Keeping one's "head in the sand" will continue to impact both the prevention and the effective supports to children with an FASD and those suspected of having an FASD. Perhaps this further acknowledges the unique cultural variants that the Irish child welfare service faces in publicly acknowledging the needs of children living with an FASD. It further acknowledges within the site of the inquiry, a need for a collective multi-agency response to effectively deal with the cultural denial. As a leading state agency Tusla, working collaboratively with other state departments, would offer greater hope of engaging the disability and protecting and promoting the CWSW's role while at the same time recognizing this public health need. JANE acknowledged that FASDs are suffering because of society misinformation. While BOBBY blames culture as a major factor in misdiagnosing FASDs.

JANE: I've heard people talk about things like, somebody said to me, "Well, you know, people don't drink during the third trimester," whereas actually I think that people think the third trimester is safer, so there are huge amounts of kind of like misinformation and if you have people whom themselves have used alcohol, it's quite hard for them to look back and then to change their stance.

BOBBY: So, I suppose everything I've said so far in terms of culture and that may be impacting on why it has not been picked up, you know.

BOBBY and JANE epitomise the failure of knowledge translation concerning FASDs and prenatal alcohol exposure. JANE talks about the “huge amounts” of misinformation swirling around within the particular culture of the inquiry. As noted by BOBBY this is leading to a barrier of not having FASDs “picked up”. Although child welfare services may feel it is somebody else’s duty to do knowledge translation, such belief will continue to allow the burden of FASDs on the CWSW and on the child welfare services in general. It is therefore pertinent for Child welfare services to engage with the prevention strategies within the culture under inquiry

Wanting to get it right.

JANE: I definitely got, for the early intervention team they didn’t want to take a look at it and then CAMHs then, we couldn’t there was a waiting list for CAMHs, it wasn’t that they wouldn’t take it on, but I think the waiting list was, was it two years, I think, with CAMHs as well. Yeah, it was a long time anyway.

MARY: It may give a better oversight and learning for the agency who were working with these children to see what the best ways is we can help these children and give them a more overarching approach between how much drink actually is needed to be consumed for these conditions to be in place.

FASDs present as an extremely complex set of neurobehavioral, cognitive and sensory profiles for a CWSW to grapple with in assessment activity. A vital requirement of any CWSWs is to assess need, which can facilitate the development of a Plan of Safe Care for a child within child welfare service. As CAROL notes, when discussing a child with an FASD, having the required knowledge awareness concerning the disability impedes the task of seeking a specialist intervention to meet a child's need.

CAROL: Moreover, I suppose my argument was the more we know about what a child's needs are and where their needs have come from, then we're in a better position to be able to meet those needs. However, I found it wasn't easy, like it wasn't an easy argument to make, that we needed to gain that I suppose specialist intervention.

This ultimately creates vulnerability on a number of fronts. First, as demonstrated by CAROL, this child will struggle to receive the specialist intervention they need because the CWSW does not have the knowledge that empowers the argument for such specialist input. Secondly, there is an element of vulnerability here for the CWSWs in not being able to advance a plan of safe care for a child. This again conflicts with the statutory and legislative underpinning of their role as a child welfare and protection specialist. This is further accentuated by MARIE who talks about the “confusion” that operates within professional ranks concerning FASDs.

MARIE: I think a lot of my learning would be through working through casework, through the opportunity to meet with professionals. And because of the confusion around fetal alcohol syndrome and the diagnoses of the children that I'm working with, it doesn't help my learning on fetal alcohol syndrome or spectrum disorder.

Social media will often report that a child who has received a FASD diagnosis bounces between a variety of services, professionals and programs. This ultimately challenges the CWSW in their interventions to plan safe care for a child.

"It doesn't help my learning" crystallizes the task that CWSWs face in having to rely on a type of ‘word of mouth’ education on FASDs. This may leave the social worker fearing that they will be found wanting in any inquires that may follow where a child suffers serious injury or even death due to their disability. MARY gives another observation on how the disability can be “miss-viewed” by social workers who are not equipped with the professional knowledge concerning FASDs.

MARY: Also, some social workers would say God that kid looks like they might; they have the features or whatever. It is interesting to see how different people would miss view it (FASDs).

Relying purely on visual observation, places the statutory child welfare service in a difficult situation, as the research is unequivocal in the factual evidence that the majority of children with an FASD disability will have no visible features. Therefore, many children living with the disability will go unseen and untreated. MARY gives a further where a social worker shares a picture with their colleagues who can then judge if the children they are working with have the disability

MARY: You would have come across it may be, I actually did one of my placements here so obviously in placement then you learn like oh these children have this or that. Other social workers might say to you I remember one social worker here was like these are two children, particularly bad fetal alcohol, and you know they have an extremely significant demonstration of the features. So, look at this picture, so you know you'd look at the picture, and you'd see them and oh right, and that is what they talk about.

The data offers that CWSWs are making determinations on a child's need based on photographic evidence of other children with the disability of FASD. As discussed in the literature, only around 15% of children will have the craniofacial abnormalities associated with an alcohol exposed pregnancy. There is no photographic diagnostic aid for the vast majority of children living with Neurobehavioral Disorder associated with Prenatal Exposure as now defined in the DSM-V. MARY highlights the level of misinformation that maybe be currently driving CWSWs interventions .The neurodevelopmental and neurobehavioral profile of neurobehavioral disorder associated with prenatal exposure presents fundamental complex and ethical challenges to CWSWs in their interventions seeking to meet their needs and provide services to ensure safe

care within a statutory requirement of the legislation. MARY rightly highlights the fear that other CWSWs will make determinations based on visual evidence. This will conflict with statutory obligations of the role.

Emerging Knowledge and Skills.

RACHEL: So, the child stayed at home. And I remember visiting the home and the mother and the child. And talking to the mother about how much alcohol she drank during the pregnancy. And just being, I suppose shocked at the amount of alcohol but then about the fact that she was pregnant at the time. But I was only learning about the damage that alcohol can do at that point. So, I think I was learning on the job.

JOHN: And there is, I suppose in terms of interventions OT is huge, but a lot of the things can't change, so they can't, when you have fetal alcohol spectrum there's some things that can't change, that are with the child in terms of the development, you know how they perform.

The data offered glimpses of emerging knowledge and skills. CWSWs seem to have knowledge concerning fetal alcohol syndrome but suffered with an intellectual haze when seeking to understand the wider implications of parental alcohol exposure. The definition of haze used is vagueness of mind or mental perception. This concept was evident throughout the data. Lack of intellect (knowledge) rendered practice into the realms of uneducated guesswork, where practitioners wrestled with their statutory duties, knowing and fearing that getting it wrong could have profound implications for their personal, professional life. Several participants focused their knowledge on fetal alcohol syndrome while failing to demonstrate a distinction between FAS and the range of

disorders associated with prenatal alcohol exposure resulting in FASDs. Navigating and resisting mixed messages concerning FASDs is a significant challenge for the CWSWs operating without competency-based education. Ultimately, this may result in a poor professional understanding of the presentation of a child with an FASD.

PATRICK: You know, and even the term, even the use of FASD, many people are still stuck on Fetal Alcohol Syndrome they are not, they do not even get into the whole pervasiveness of a lifelong disorder. And how that will impact on children's ability.

PATRICK highlights the cultural "stuck on" fetal alcohol syndrome at the expense of understanding the broader ramifications of a child living with a neurobehavioral, neurocognitive and neurodevelopment needs, but who do not display the physical features associated with FAS. This further accentuates the evidence of an intellectual haze prevailing with the specific child welfare service under inquiry.

There still is concern and evidence that the emerging knowledge is not strong enough to fully grasp the multimodal needs of FASDs and caregivers. Collectively, the needs of children and the understanding of the broad range of needs associated with an FASD may be the result of fear in addressing this public health issue. FIONA describes feeling let down by social work.

FIONA: I have to say that because "funny little thing," that's what, the way she was describing this child at meetings, so if this support was available for social workers and the children that the foster parents are caring for why was it not made available for us. This has been highlighted so many times to the social work department, yeah, I do feel let down by social work actually.

This foster parent describes a feeling of being not being important enough. Talks of both the child and the social worker being supported but not the caregiver. It is

perhaps surprising to note that Fiona perceives that social work has the services she requires saying “why was it not made available to us.” This would conflict with what CWSWs are saying in the data, as they articulate they are struggling to identify services and get organisational support for their efforts. This crystallizes how the collaborative approach of shared responsibility is not operating successfully, as the caregiver is feeling let down by the system. Providing stable and secure care to children living with or suspected of having an FASD. It is therefore in the child’s interest, the caregiver’s interest, the CWSWs interest and the CWS interest to ensure that placement stability is achieved for all concerned.

Another issue to emerge with the data is the belief that illicit drugs are the priority for CWSWs, and that alcohol is just a post-birth issue. Although education is society may be plentiful is addressing concerns of illicit drugs, evidence suggest that talking about the legal drug of alcohol is a significant challenge. Society is awash with the evidence that alcohol has a destructive ability on the fetal brain, this evidence is not transferring to general knowledge in society. Speaking about alcohol in the pre-birth stage is a significant and challenging practice issue for the CWSW.

JOHN: And we get the results from the clinics. Other drugs like cannabis and, you know yeah there’s a sort of maybe hierarchy of seriousness, clearness or how we deal with things, heroin is at the top of the list, that’s my experience. Alcohol is there, but it’s more, it’s post-birth we talk about alcohol.

As highlighted in the literature of this study, the fact the alcohol as a teratogen is more dangerous than illicit drugs, this has not been translated with social work education. The view that alcohol is a post-birth issue is likely a widely held view within CWSWs' knowledge base.

Lacking a Pathway.

Lacking a Pathway denotes the struggle of CWSWs to carry out their statutory duty of responding to a child with an FASD within the legal mandate duty of their role. As noted within the study, this offers a significant restriction of CWSW professionals' capacity to carry out their duty effectively. Although significant evidence exists documenting the prevalence of FASD in child welfare services, CWSWs talk of working with this cohort without policy, procedure or protocol to guide their response to FASDs. Knowing what to do and how to do it was a significant issue for the CWSW. Data suggests that FASD is lacking a pathway within child welfare services, rendering the CWSW to offer a response of guesswork in meeting the needs of children with an FASD.

PATRICK: No one has a clue what it is they must do or who should do it, but something should be done.

RACHEL: I certainly think we need procedure because look at what the statistics are telling us that there's a huge problem. And if a lot of our case load is working with children who have been exposed to this, we need to have the knowledge.

NIAMH: Because you could empower that foster, you know, you could help that foster carer in a real way you know. That might help, it depends on the foster carer if they're receptive to it as well. But outside of that, if we know about fetal alcohol syndrome that's great. But then what can we do, like what are we going to do with that information.

JOHN: You know there's no clear path for us to follow. I mean the clear path is protect the child or give support to the child and the family. So, we know that, but it's not quite as clear where, particularly if, it's easier where I am now, you've got a diagnosis and there's probably a treatment plan. But in the earlier stages it's much more difficult. And I

think it's because of the ignorance of, I mean that in the best possible way, I mean a lack of knowledge of parents and some other professionals.

Part of this fundamental complex challenge is the diverse and broad spectrum of symptoms that will confront the CWSWs when intervening to secure a child's safety plan of care. This emphasizes the urgent need for intellectual clarity in order to conduct risk assessments which fully meet a child's needs of care and protection. Such assessments are vital within child welfare service, as they can be key aspects of ensuring a child's placement stability and offering a caregiver the necessary information and tools to provide safe care. Joint multidisciplinary collaboration is the optimal approach when assessing a child or young person suspected of experiencing the effects of an alcohol exposed pregnancy, as noted previously in chapter 2. Seeking to do such assessments in isolation may leave CWSWs to "muddle through." Education concerning alcohol in pregnancy and the implications of an FASD was highlighted across all conceptual categories of the study. As MARY states:

MARY: Yeah, yeah, I think that we expect to give a general social worker education and those same group of social workers go out into all different types of roles. We don't actually receive specific training for the role you go into, and you learn absolutely you learn from experience, but that is not helpful in the first six months or a year in the role when you are trying to muddle through on understanding fetal alcohol.

Although the FASD dialogue has seen numerous calls of FASD to be educated at undergraduate and postgraduate level, this is still not translating to frontline CWSWs' education. MARY highlights a critical issue where the social work role has many roles in society. CWSWs don't get the specific impute to deal with FASDs while in training at university This is leaving CWSWs bereft of essential skills and knowledge to respond to children with an FASD on their

caseload. MARY's excerpt may suggest that employers are therefore better placed to deliver on the competency needs of CWSWs in respect of FASDs

Without education and a procedural pathway, it is only natural to understand how CWSWs can carry an element of having to battle against the tide to achieve positive outcomes in their interventions. As noted, CWSWs carry a statutory mandate to ensure a child's welfare and protection. A CWSW's duty in responding to a child with an FASD is no more or no less than when they respond in a case of child neglect – both cases are under a statutory mandate. This point offered earlier by RACHEL that she could talk about child sexual abuse and physical abuse of burning a child with a cigarette. RACHEL states that she “can talk about” these issues but “can't talk about” fetal alcohol or alcohol use in pregnancy. This is a key concern when viewing children with an FASD through a statutory lens. A CWSW saying that she cannot talk about ‘it’ signifies a significant weakness in the ability of child welfare service to ensure safe care for children living with an FASD stemming from an alcohol exposed pregnancy. This may offer legal ramifications for child welfare services who fail to acknowledge the rights of a child living with this disability. However, frontline CWSWs cannot be held accountable for failing the statutory obligations of their role if they are not provided the education, policy, procedure and protocol to deliver on the mandate of ensuring safe care for a child with an FASD and bring clarity to the intellectual haze surrounding FASDs.

Broaching Difficult Conversations

These four codes emerged from the early-stage analysis and initial codes constructed during the early coding of the data. The focused codes are: Hard to Go There, Ethical Dilemmas/Moral Judgments, Mother Blaming, and Fear of Stigma. It is without a doubt that broaching the subject of parental alcohol use as possible causation of a child's difficulties, is a sensitive and emotive topic for a CWSW to undertake. It is hard to talk about sensitive and

emotive topics at the best of times. Often, we shy away from these conversations because they may offer unexpected and challenging outcomes, outcomes we fear that we cannot handle. For the CWSW to carry out their mandated duty, they will need to broach such difficult conversations. Without a framework of protocol, information and knowledge to guide, it is likely that this vital piece of meeting a child's needs may be circumvented, resulting in the child being miss-labelled, miss-medicated and sent down the wrong service stream.

Hard to Go There.

RACHEL: There was a lot of reluctance to even go there because we understood that there wouldn't be much support afterwards. So, like you said what's the point in some way

PATRICK: The difficulty is that when we say intergenerational this generations drinking has definitely created a cohort of people who will function sub optimally for the rest of their life or below their potential capacity as a direct cause of the drinking. Because that notes the blame, it's almost like we don't go there and we're unwilling to challenge it.

Participants repeatedly presented the difficulty of "going there" when confronted by a case of FASD and the issue of alcohol use during pregnancy. Difficult and challenging conversations occur across multiple and different platforms and create discomfort and vulnerability for the CWSWs. As MARIE states – "there is a problem" this denotes the core of the challenging conversation.

Marie: We are placing children in the care of foster carers know that there is a problem, that the birth parents have had severe addictions, we avoid those difficult conversations.

In this case, Marie openly acknowledges, "avoiding those difficult conversations." This again highlights the conflict that CWSW can feel knowing information but unwilling to have

these discussions. Operating with procedural guidance ultimately places the CESW in this difficult position of not having difficult conversations as they do not feel supported in addressing FASD.

Ethical Dilemmas/Moral Judgments.

PATRICK: Because social work tends to label the behavior and not the child as a matter of ethical practice.

JOYCE: You know and then they're saying, "oh you jumped the gun and you were accusing me of this" and it can damage relationships then with parents because they're saying you're accusing me of damaging my child, do you know I never abuse my child.

JANE: I've been in situations where you're working with professionals and you might be out, and people will be drinking through their pregnancy and it makes me enormously uncomfortable that people feel quite judged and get quite defensive if an opinion is expressed around alcohol use in pregnancy.

The CWSW views the challenge of discussing FASD as an unpleasant activity and wants to protect herself. The concept of damaging working relationships with parents figured highly within the discussions of the study. The CWSWs need skills and vocabulary concerning alcohol use in pregnancy as a child welfare concern and seeking confirmation of alcohol use in pregnancy for current or future assessments of children's needs. The vocabulary is developed for the CWSWs when it comes to child sexual, physical or neglectful abuse, a point described by RACHEL:

RACHEL: It is very difficult, isn't it? However, we can talk about them burning the child with a cigarette, and we can talk about them sexually abusing the children, why can't we talk about them drinking when they are pregnant. We seem more comfortable doing the other two.

As acknowledged by RACHEL, CWSWs are well qualified and have demonstrated capability in so many areas of challenging practice and conversations – “we can talk about/why can’t we talk about” highlighting the challenging conflictual conversations of practice interventions. Culture normalization of alcohol use aids and supports the finding that CWSW are Advocating against the Tide while seeking to establish safe care for children living with an FASD. MARY addresses the concern of planning safe care by asking “what exact function” does the CWSW have:

MARY: So, you know them very well, but possibly there is a side where you know them too well, and you may not always see things that could be right in front of you. So, you would need to explore who as well is the best-placed person to do these pieces with these children and what is the social worker role and how much does actually, a lot of this actually pertains to what is the exact function you are meant to be doing which is to protect children.

MARY asking who is the “best person to do these pieces of work with these children” highlights the need for multidisciplinary involvement to do specific ‘pieces’ of work with these children.” This task may be significantly impeded and restricted, given the evidence in this conceptual category of CWWS struggling to have difficult conversations. Talking about FASDs is difficult – this conflictual responsibility impedes and restricts the collaboration of allied health professionals in meeting the needs of children living with an FASD. As Chapter 2 indicates, traditionally focused interventions do not work for these children. Where traditional interventions may have operated is silos of single disciplines performing single pieces of work with children. Evidence continually advocates that it is a shared responsibility that is required in order to be effective in care planning for children living with an FASD. This will require the breaking down of silos as part of the planning process to facilitate cross-organizational

collaboration. CWSWs need to be empowered with knowledge, in order to develop as a effective case managers, pulling the various allied health strands together to provide the best care plan.

Mother Blaming

CAROL: And it's, sometimes then there's almost this thing of you know are you trying to, are you worried that people are perceiving it as, look you know are you trying to blame the parent for everything. And you're being overly harsh on the parent.

As major concerns abound in society concerning the fear of stigmatisation against birth mothers of children with an FASD, this fear is yet another burden weighing on the CWSWs' response. Having difficult conversations that is loaded with ethical and moral components needs professional guidance. Giving literature discusses that prenatal alcohol and FASDs suffer from misinformation primarily due to social media, the lack of professional knowledge inputs for CWSW renders them vulnerable in their responses.

PATRICK: I think certainly the first point that they don't want to damage the relationship, or they don't want to go there. I think we live in somewhat, whether we like it or not we live in a blame free culture. So, the idea that someone is blamed as causing something, as a causative factor, is almost too terrible to comprehend

Perhaps the most significant challenge is the lack of information within society to empower CWSWs to talk about and have the awkward conversation concerning alcohol use in pregnancy. Patrick emphasises 'not wanting to damage the relationship' as a core objective of the CWSW when responding to child welfare concerns in the community. Responding to FASDs as noted is loaded with complex, emotive and ethical challenges that have great potential if not discussed correctly can lead to damaged relationships.

MARIE reflects personally on her own pregnancy, saying:

MARIE: I think my medical professional would tell me not to, to be honest, they are pretty good. But it's not a message that comes out in a leaflet like we have had many leaflets, a lot of information, you get a pack as soon as you go to the hospital. Not one of them was on alcohol in pregnancy.

Having the awkward conversation of whether a child was exposed in pregnancy to alcohol is complex, emotive and challenging for any professional. CWSW want to work proactively with parents, so talking to a mother about alcohol use in pregnancy is a big ask. As noted here by MARIE reflecting on a personal level that not having the information to discuss the implication of an alcohol exposed pregnancy, but also the challenge of seeking the confirmation of an alcohol exposed pregnancy for possible or further clinical assessment. JANE, in discussing the national HSE Alcohol in Pregnancy guide, noted how difficult it was to access the state information on alcohol in pregnancy.

JANE: I was saying this recently in my class, and my class is looking at a kind of... Population health and health services research, so we're very much health-orientated, and I said about the HSE guidelines, and they were a bit disbelieving, so then we had to look for them and they couldn't find them easily, that was the first thing, so it seemed that they weren't, kind of, accessible in an easy way, they needed to do a bit more searching because they will find these things in another way and found them, and then we're saying, "Yeah, it says here, zero alcohol, zero risk."

Again, evidence suggests that the response of the CWSW is significantly curtailed in meeting the needs of children living with an FASD when addressing prenatal alcohol exposure. As discussed, cultural normalization of alcohol use renders the CWSW in a difficult professional response role. Talking about alcohol use in pregnancy is fraught with difficulties. As discussed

by JANE above, just accessing health promotion information is a mammoth task while PATRICK below says that discussing alcohol use in pregnancy is a “bridge too far.”

PATRICK: I suppose it became quite apparent that in one respect to consider that parents who have presented with significant alcohol issues, both prior to birth and since birth, in some ways managed to ameliorate or not consume alcohol during pregnancy or in utero was probably quiet, maybe it was a bridge too far.

Here the CWSW talks of discussing alcohol use in pregnancy with families they engage with as a bridge too far. This again is likely the product of not having the required skills to navigate the steep terrain of ethical pitfalls when addressing the potential that a child may be suffering from an FASD. As a bridge too far within initial assessment’s likely results in the child having a plan of safe care built on a weak assessment outcome as it fails to crucially acknowledge the ethology of neurocognitive, neurodevelopment and neurobehavioral aspects of the child’s needs.

Whether it’s religion, sexuality, race or politics, we are all confronted by the challenge of difficult conversations. In CWSWs’ practice, these difficult and challenging conversations are required without substantive knowledge to execute the conversation. As RACHEL noted, CWSWs can have challenging conversations on very emotive topics such as child sexual abuse. Although CWSW are well skilled to talk aspects of child abuse, be it physical or sexual abuse, they do not feel they have the skills to talk about alcohol in pregnancy and not wanting to mother blame due to knowledge weakness. The key difference here is that child sexual abuse knowledge is robustly delivered to CWSWs in both undergraduate and postgraduate education. FASDs, on the other hand, receive little to no attention in professional social work education in Ireland. This may be due to what is documented in conceptual Category B of **Intellectual Haze** that currently affects the vision of CWSWs in intervening in cases of FASDs.

Fearing Stigma.

As just discussed above, there is mounting evidence within the data that CWSWs without education and skills around FASDs are fearful of imparting stigma. This fear of addressing alcohol in pregnancy within professional dialogue has direct implications for addressing the needs of children living with an FASD. John as a male social worker talks of raising the issue with a mother but talks of his “nerves” when doing this task. It is a common challenge of the CWSW to address difficult and volatile situations. John shows a level of emotion in talking of his nerves while responding to FASD. Not wanting to be judgemental and imparting stigma would high on a social workers response too.

JOHN: But it was something, it was in my mind. I can remember I suppose one specific, even a specific incident where I would have mentioned it to a mother and feeling a bit nervous about it because you know I don’t want to be judgemental of people.

MARIE: So, I think it’s kind of a lack of truth being shared sometimes. I think there’s a shame there as well whenever you have a drink problem. When I have met people, I don’t think they want to be honest around saying that they drink heavily between their pregnancy either. Especially when the child presents as OK.

A major area of difficult conversations concern stigma and blame as an impediment to delivering safe care to a child an FASD in addressing both the prevention and the management of FASDs within society. Not wanting to “mother blame” was a strong belief coming through for CWSWs, with knowledge weakness the most significant concern in restricting CWSWs’ interventions. Fear of stigma may be responsible for suppressing the conversations that society needs to have in order to address and manage FASDs. CAROL states:

CAROL: Yeah, because it is not being diagnosed, you're not getting it in reports every day of the week. They do not hear schools saying I need support around this, and they're not hearing. So, it's almost like the lack of conversation about it.

The "lack of conversation" suggests that society is not willing to address the difficult issue of alcohol and pregnancy and the possible outcomes in children. If society is not talking about it, then this makes the CWSWs job more difficult in raising the issue in the best interest of the child. JOHN encapsulates the difficulty and challenging aspect of raising the possibility that a child may have an FASD with a parent:

JOHN: You're finding your own way of doing it though. Like that particular incident, I'm referring back to, and it's funny how you remember particular things, but I remember before the visit, I am thinking am I going to say this or how am I going to say this. Taking it upon myself to eventually decide, I am going to say this, and I'm going to because the child might get extra help. But it was a real struggle to because there were no diagnoses, it was a suspicion on my part. So, I had to be careful not to appear like a medical expert but give advice and at the same time not be accusatory. And you could get a very negative reaction, and I didn't get in that case. But it was a bit, you know what I do here. I could have easily not said anything and carried on managing the case.

I have underlined the gerunds within this excerpt to highlight the words that depict action. JOHN is recounting a professional intervention for a child suspected of having an FASD. Here we see the complexity and the fear of getting it wrong, in not wanting to be accusatory. This is a major concern for the CWSWs in that responding with limited knowledge, which could inadvertently impart blame and stigma while equally trying to achieve the best interest of the child in need of services. JOHN talks of the real struggle and having to be careful as caveats to

the statutory role while intervening. Ultimately, JOHN notes that she could have said nothing and carried on without raising the difficult conversation. Intervening in cases of FASDs is fraught with the type of professional anxiety demonstrated within this piece of data's do need to have the support of policy guidance and competency-based education to support effective interventions and reduce stress.

The complexity of the CWSWs' role in responding is multifaceted. CWSWs' conversations are more difficult due to the misinformation that operates in society. Social media offer conflictual and contradictory information increasing the likelihood of difficult conversations in ensuring a child's plan of safe care. JOHN clearly articulate the conflictual position of the CWSWs in intervention work.

JOHN: Yeah, it is difficult to confront that issue. Well, it's difficult to confront a lot of issues in this job. And I think it just becomes easier as you work. But you know people's human reaction can be upset, and you know shame or anger, or guilt, and you don't really want to make people feel like that. But at the same time, professional job says you have got to, you know act protectively for the child or get support for the child. So, it's a difficult path to a thread, I think. I think it becomes easier as you get used to it.

JOHN sees this "difficult to confront" task become easier as one gets more experience in the job. Again, this may be that difficult conversations become more manageable with experience. However, even with experience, engagement with FASDs are challenging. JOHN acknowledges clearly the role of being "a protector" of the child in line with the statutory mandate of his role, but equally acknowledges it a "difficult path to tread". The word tread denotes softness and quietness given the difficulty to confront feeling on FASDs. However, the conflict between carrying out a legal mandate task and not seeking to create shame, anger or guilt equally places a significant burden on the shoulders of the CWSWs' professional duties.

It will be necessary for CWSWs to have correct information both to aid the prevention and the case interventions needs of their mandated role. Preventing the transference of stigma will need to be a core value of the CWSWs' role which can only be achieved with the provision of competency-based education and protocol to guide their responses.

Disabling the Enabler

Disabling the enabler is offered as a category to encapsulate the professional gap between what is expected of the CWSW and what is feasible to deliver. The role of CWSWs as enablers of supporting, protecting and promoting the healthy development of children is intrinsically a core attribute of the profession. However, seeing the role of CWSWs advocating for children's needs in the context of FASDs is potentially challenging, given the evidence contained within these findings from the data provided. This final category was developed from several focused codes coming from the data analysis in the pre-conceptual development stage of the study. Disabling the enabler encapsulates further the uphill struggle of *Advocating against the Tide* when CWSWs seek to respond and provide safe care. Marie encapsulates this struggle to advocate giving the nonrecognition the disability within the service structure.

MARIE: I am talking like a year and a half of trying to get this child into services, and it is not a week or two. And this is many, many letters to both child development team, to both CAMHS and still, we're waiting to hear back from the child development team, we need to know where this child is placed. There needs to be some sort of efficiency or time efficiency

MARIE highlights the challenge of advocating across disciplines in trying to seek a service for a child with a suspected FASD. For a CWSW to take a year and a half to get a child a service, is clearly failing to promote the best interest of the child. This cannot and should not be placed against the CWSW for failing to provide as it can be argued that as a practitioner, they are

disabled in enabling service for the child. The participant further articulates that failure of collaborative working is a strain of efficiency of her work and the agency. Perhaps the most concerning aspect of this excerpt is that a child in need of services as identified the CWSWs is waiting 18 months for an identified assessment/service. Again, we are confronted with the statutory and mandated requirement of the CWSWs to respond and provide services but seeing allied health colleagues rebuff the participants' efforts. Focused codes underpinning this category included: Struggling to Access Services, Challenging Diagnostic Labels, Searching for Interventions, and Working in Silos of Service Provision.

Struggling to Access Services.

MARY: Whereas for me, if we had services we could be provide right from the beginning and clinical oversight from the time they are born that remains in place then I feel they would get a far better benefit.

MARY: Oh, I don't think we have the services to deal with it. But that's not to say that I don't feel it should happen. I mean I consider we don't have the services to deal with the mandatory reporting that's going to come in, but I still think it should happen. I don't believe that just because we don't have the provision in place to deal with something doesn't mean that we shouldn't try and move forward with it. Because I think in those instances' services should be made available.

A further challenge placed in front of advocacy within the particular culture is prescribed and acknowledged as medical model authority in the area of neurodisability and particularly for children with an FASD. RACHEL talks of the "fight" that is necessary to advocate for these children.

RACHEL: We do because I suppose we have come down to resources and sanctioning and money and if the medical model does not even recognize it, well what are we at. So that probably disempowers people, so they don't do the fight.

It is the word “fight” that perhaps gives the most unambiguous indication of the tide which CWSWs must encounter in seeking to secure a child's welfare and provide the necessary services. Perhaps equally concerning in the excerpt is that the fight is so great that CWSWs “does not do the fight” – thus evidencing that a child's needs are being neglected within the statutory provision of care. This has significant implications for the agency and indeed all child welfare agencies. Another participant again spoke of his fear on the over-prescribing by the medical model:

PATRICK: So, is there an overprescribing? I don't know, I don't work in that area, but I certainly anecdotally would have seen very, very high levels of prescription within young children in terms of Ritalin, Seroquel, Concerta. That you know developing brains, I'd have serious concerns that they're not doing anything, they're doing more harm than good.

Challenging Diagnostic Label

Many participants talked of the confusion surrounding the issue of diagnostic needs and services for a child. Participants were very mindful of the enormity that a diagnosis and the label places on the child. They were also mindful of the ethical issues and the potential of stigmatising parents that would come with a diagnosis. These concerns expressed within the study replicate a view that is also carried in literature concerning the issue of diagnosis. Literature in recent years poses major ethical questions concerning the validity of diagnosis, especially when culture cannot provide the post-diagnostic services. Clarity concerning diagnostics needs to be offered at

a state level in order to give CWSWs a more defined pathway to work with children suspected of or having an FASD.

MARIE: There's definitely, there's potentially misdiagnoses. I don't think that there's, I don't think people are particularly looking to diagnose for fetal alcohol syndrome or spectrum disorder. I think maybe it's because it doesn't benefit the young person. It doesn't, with ADHD you automatically do qualify for supports within school. There's an understanding of what ADHD is by teachers. There seems to be a lot more awareness round ADHD and autism than there is around fetal alcohol syndrome.

Marie touches on the social acceptability of more recognised neurodisabilities within the culture of inquiry. She questions if a diagnostic offers anything for the child and offers the as the disability is not within social acceptability, then potentially it does not give the child anything.

Jane on the other hand talks of the cyclical response to a child's needs as the child oscillates from service to service without really meeting the needs.

JANE: I think it would have been our experience that you can't get the referral through to Child Adolescent Mental Health, so unless the child is already known, but then they'll have another label on them anyway, yeah, and so you're, you're back to this kind of cyclic thing where you're kind of trying to break out of it and work with the child's needs, which is a resource kind of a thing as well because middle class families with resources probably follow what is the child presenting with, let's go and see what resources we can find to address that and if we could follow that same kind of model where it was non labeling, yeah.

In addition to concerns about missed and misdiagnosing of children living with an FASD are concerns about the mis-medication of children with an FASD. MARIE, when seeking to advocate against the medical model, may feel significantly devalued in trying to advance the

needs of a child with or suspected FASD and as stated by RACHEL may “give up the fight” of seeking services. A foster parent offers that social workers are not advocating for children with an FASD.

RUTH: I have no issues with social work, social workers do a really great job, they’ve got really high caseloads, they're doing the best they can and kind of challenging situations. But, you know, I've no issues but around fetal alcohol syndrome. I haven’t come across anybody in social work that kind of understands it or is advocating for it or anything.

This offers further insight into the role of CWSWs within the particular site. As noted in other excerpts of this category and indeed in all the categories CWSWs within the Irish culture are significantly challenged from both the medical model and from the caregivers of the child welfare service charged with caring for these children. There are many forces which can render CWSWs “caught between a rock and a hard place” when seeking respond in the provision of services to a child an FASD. The following excerpt repeated from Category A crystalizes how the CWSWs may be placed in a no-win situation in advocating for the best interest of the child:

Rachel: We’ll consider it again in 6six months’ time. And you might have had a conversation, a difficult conversation with a parent or a foster carer about the fact that this is something you're concerned about, and you're going to raise it. And then it damages your relationship further because like a doctor says no, no too early to consider that.

As a CWSW, Rachel is trying to uphold her statutory duty to the child and the support role to the career, but due to a lack of coordinated, multidisciplinary systems of care her advocacy is leaving her vulnerable and at risk of damaging the relationship with the foster parents.

Searching for Interventions.

The need to allocate services and support for the child with or suspected of having an FASD was a constant challenge for CWSWs. Giving the level of misinformation and the lack of cultural acceptance of FASDs, this left CWSW searching for services like a needle in a haystack in that the services were very hidden or non-existent.

RUTH: So, there's been, from the years that I've been working with him, we've accessed quite a lot of services for him. But there's been a lot of confusion around accessing services for him. At the moment there's quite a debate between, like we put a lot of time and energy into getting this child the right services.

Kathleen talks of the closed door in seeking services where services have thresholds that exclude anything got to do with fetal alcohol as a presenting issue. Ultimately, it leaves CWSWs with their hands tied in that they are trying to respond and establish a plan of safe care, but not getting the collaborative support of partner agencies.

KATHLEEN: That mightn't be the presenting issue, I suppose the presenting issue mightn't be something that's pointing to fetal alcohol, but they might just close the door before you can even go in there to discuss it because their thresholds are very, very clear.

In the following excerpt, Harry, a foster parent, recounts what the CWSW is advising him to do as a caregiver. This implies that some CWSWs within the culture are clearly advocating not to rush to diagnosis as there is no resources" to support a positive diagnosis

HARRY: Well straightaway, it's telling us not to go down the fetal alcohol road, there's no services out there, there's very little we can do, why label the child with something that there's no resources, that's, that's exactly the response we got, why label the child with something when there's no resources out there for it?

PATRICK: And the courts may not accept that view either. So, everything becomes about the organisations inability to meet the child's needs because our interventions or assessments are not robust enough and don't have enough explanatory reach. So, everything is an external focus, it's the child, it's the child's environment, it's the interaction of the child with services, it's the relationships, it's the lack of an allocated social worker. And again, there may be various factors within that, that have some sort of basis. But overall do they explain the consistency of this cohort of young people we're seeing.

One of the critical needs of a child with an FASD is a secure and stable home life and to receive appropriate interventions and services from the CWSW. As noted, CWSWs experience organizational barriers, and their interventions can be limited and frustrated, even refused. We see the same struggles coming in the account from JANE. Here we see the pressure of working within service structures of the organisation, that prove problematic when addressing the needs of a child an FASD.

JANE: Moreover, we have even had recently, like with one assessment that we got, it was an assessment of need. And I think the recommendation, because the child is in care, Tusla should f...ing fund services privately. Like that is like another state agency saying that to another state agency when they should be under the same remit. So, I think the stress of foster carers, maybe us not being able to put in the right type of support.

A mindset which presents on not providing services. A mindset which directs that service must come from another area, in this case, a private provider, only serves to isolate the child within service structures. This type of mindset will reduce efficiency in the overall efforts of securing a child's welfare and will likely further reduce the morale of the CWSWs efforts on interventions and may contribute to the demise of productive agency culture. What is evident in

this account is that JANE acknowledges that they cannot provide “the right type of support” to either the child or to the caregiver. This confirms a large body of research as discussed in Chapter 2, which demonstrates how caregivers feel isolated and rejected when trying to seek services for the child an FASD. It further accentuates the conflictual role operated by CWSWs with FASD service response. The “rock and a hard place” experience of CWSWs is a recurring phenomenon and one which serves to damage the professional collaboration of CWSWs with caregivers. JANE, who has a managerial role within child welfare service provision, goes on to say

JANE: finding a service provision is one of a piecemeal response to the child and caregiver: So then maybe thinking, well I have, I know now what this family or this young person needs but not being able to find it. Moreover, it becomes very sort of piecemeal then in terms of the support that we are giving. But I have no problem in terms of funding private services. If that is what we need to do, that is what we will do, like we have funded many, many private services and will continue to do that for children in care.

Clearly, that lack of awareness concerning the disability of FASD is placing a major burden on the shoulders of the CWSW. The notion that services are piecemeal, that is unsystematic and partial measures, are clearly not sufficient to meet the needs of a child with an FASD. Jane talks of using her senior status within the service of funding private providers in order to receive services. It again shows the struggle of finding services and adding to the tide that is impacting the CWSs’ response to a child.

Working in Silos of Service Provision

Working in silos denotes what many participants talked about in terms of disjointed service structure. The data speaks of service structures that are not conducive to working with a

child who has an FASD, Literature clearly denotes that collaborative working across agencies is paramount to providing the services needs for a child with or suspected of having an FASD.

SHARON: I suppose, at the moment it seems that services here are very siloed, even for children, you have psychiatry in one service, you have primary care psychology in another, you have speech and language, physio, OT, so there's no joined-up thinking, there's no multidisciplinary working in terms of these children.

MARY: Yeah, I would believe it's too modern for you know the service that's there, the service provisions that's there probably isn't the right model to respond to it. And it's the same as you know I'd make a huge comparison between maybe the mental health struggles that a lot of young people are facing now, because again no services because these conditions are probably you know a reflection on modern society, but we are still working with a service and with service provision that's probably ten or fifteen years behind where it needs to be.

SHARON: So, I suppose there is no clear pathway for these children and there is no supports going in. As I said, it's very siloed, it's very piecemeal, and there isn't that multidisciplinary service that will follow them through and will talk about I suppose what is going to happen to them at different developmental stages like or even transitions.

Working in Silos and Searching for Interventions are intertwined. One of the significant challenges facing CWSWs is knowing the needs of children with an FASD and then finding the responses to such a need are not in existence within the systems of health provision. As JANE offers, such services are frequently with the private sector, a costly additional burden on the child welfare service in an age of massive restrictions on health budgets. Another aspect which CWSWs encounter in their search for appropriate services is a type of quid pro quo agreement operating within different service structures. This is where services will argue that their

eligibility for accepting a referral is only if the child has a diagnosis. Meaning if you get a diagnosis first then we will offer a service.

SHARON: I suppose, at the moment it seems that services here are very siloed, even for children, you have psychiatry in one service, you have primary care psychology in another, you have speech and language, physio, Occupational Therapist, so there's no joined-up thinking, there's no multidisciplinary working in terms of these children.

RACHEL: Well that was, not as readily. I think professionals bend the rules a bit maybe to get them in, out of working relationships and things like that but if that's their only diagnoses I would say the door would be shut. But a lot of children with fetal alcohol would have other diagnoses and you might get the door open because of that.

Rachel talks of the "open door" if you have another diagnosis alongside the fetal alcohol concern. She also notes the concept of "professionals bending the rules" by perhaps playing down the fetal alcohol concern and accessing services through a more acceptable diagnosis that will open the door of that particular service. However, a CWSW who is operating under legal mandates may not feel comfortable in bending the rules.

This can cause major conflict for the CWSW as they may wish to try and avoid labeling the child but equally seeking an intervention services for a child's needs. It also poses major ethical issues for the CWSW, as receiving a diagnosis will provide the child with lifelong needs. Many other services may refuse a service based on the fact the child has a diagnosis and the services does not recognize the disability and fails to meet their eligibility for services.

The powerlessness is again evident, in that CWSWs genuinely want to offer social justice responses in enabling the child and caregiver to succeed but find themselves disabled in their advocacy by hierarchies within service structures. As noted in the literature, it is foster parents and CWSWs working together in grassroots advocacy for children living with this

neurodisability that has the greatest's potential to affect positive change with the specific culture of the study. As discussed in the Chapter 2, when CWSWs and foster parents work together they can reap significant systematic and structural change, which can lead to wide-ranging service provision in current service responses. It is this grassroots collective action that can best aid supportive advocacy, diminishing the tide of confusion and denial on meeting the developmental needs of children living with an FASD within this particular cultural setting. Rosin epitomizes the struggle of the statutory social worker role. Acknowledging the responsibility, she feels in meeting the needs of the children on her caseload.

ROSIN: I am working a specific caseload, and my responsibility is to those children on my caseload. And I have to learn whatever I can to ensure that all their needs are met.

Yeah, absolutely and that constant questioning of yourself that you have when you're a social worker (laugh) and that thing of why I did not do psychology, then they would listen to me. Moreover, you think oh my god I have all these great ideas and somebody who has more power than you say you know you're wrong, we are not looking at that until next year.

What is surprising is the very honest belief that social work has no power to enable change. This is reflected twice in this excerpt. Firstly, Rosin notes that she wishes she was a psychologist as then she might be listened too and respected. It is such experiences of the tide pressing on CWSWs that leaves Rosin disabling her own professional qualification in favor of a perceived hierarchy of power, control and siloed services at play within her caseload. engaging a safe care plan. Ultimately, for the professional wanting the best for a child but feeling restricted by the "bridge too far" barrier is feeding anxiety and powerlessness around the statutory responsibility and mandated responsibility carried by CWSWs. As data suggests, CWSWs are seeking a "kind of model where it was non-labelling," as offered by Roisin

Given the vast body of evidence on FASDs and their direct linkage to child welfare services, it is highly conceivable that many of these children are not receiving a Plan of Safe Care within the statutory requirements of the child welfare services. Children with highly complex needs and a history of neurobehavioral presentations which come into contact with CWSWs are routinely poorly responded to due to the complexity of their needs. As shown, the etiology of FASDs are poorly articulated with the site of this study, likely resulting in many children with or suspected of having an FASD being a bridge too far for many CWSWs to engage with due to a skills deficit in CWSWs education concerning FASDs. Also, for those that continue to advocate against the tide, they talk of it being an “absolute nightmare”.

JANE: I think like I said you know sometimes these young people fall between different services. And like no matter how much we advocate for services. Like it can just be an absolute nightmare, an absolute nightmare.

One must remain mindful that this advocacy, as talked about by JANE, is about ensuring safe care and carrying out the statutory responsibility of the CWSW role. To describe a statutory duty as an “absolute nightmare” is concerning, as no CWSW should have to carry nightmares simply for carrying out their duty as prescribed in law. Again, the tide becomes more acutely represented as this CWSW searches and advocates for services, services that are primarily not available or services that precludes the child with an FASD because the neurodisability of FASD is not part of the service criteria. This leaves CWSWs peering into different silos of service provision in the hope of accessing a service for the child. With CWSWs struggling against the tide to provide such much needs services which are not readily available, may leave these children drifting within the child welfare service to a more serious presentation of their secondary disabilities. As shown and discussed in the study, children can suffer the ultimate outcome of mortality as a result of service non-availability.

Again, data indicates a need for multiagency and cross-government agencies in addressing the impact of FASDs. It may also suggest that senior management in child welfare service could benefit from competency-based education, to help them in helping their staff. The highlighted aspect of the legal services such as courts, barristers and solicitors engaging with this significant public health issue, also signifies that children and youth due to their impairment may frequent such services. MARIE further highlights this need for a collaborative approach:

MARIE: Absolutely, we are responsible. But there is a shared responsibility with service providers as well -- because we cannot be medical experts and psychological experts and education experts. So that is why it is a team effort for every child, whatever the diagnoses are but in particular with fetal alcohol syndrome. Like some of the things coming up are medical issues as well, you know or specific, like specialist services.

MARIE again demonstrates that Irish culture has a significant challenge in addressing FASDs due to the dominant cultural awareness of FAS. As stated in Chapter 2, children with FAS make up around 15% of those impacted by an alcohol-exposed pregnancy, with the majority falling under the broader umbrella term of FASDs. MARIE also highlights the need for collaborative work in order to address the isolation of CWSWs having to take responsibility for an issue which requires a collaborative approach. It is interesting to note that the allied health professional, who contributed to the study in the theoretical sampling stage is also lamenting the lack of collaboration in responding to the needs of children with an FASD

SHARON: there is no joined-up thinking; there is no multidisciplinary working in terms of these children

This would suggest that there is a willingness within the allied health structures to work collaboratively with CWSWs in order to achieve better outcomes for those in need. Sharon is acknowledging what is not happening and by default acknowledging what is needed for these

children. Currently, however, due to a lack of policy, procedure and protocol, evidence also exists that barriers within the working relationships of CWSWs and their allied health colleagues due to system silos of service provision and structures. SHARON highlights a critical issue to be considered by the services within the culture of inquiry. All the best practice evidence points to joined up thinking and multidisciplinary shared responsibility. This lack of shared responsibility has emerged throughout the data indicating it as a major area needed in addressing FASD strategic approaches of state systems.

Chapter 5: Discussion

Well, listening to some of the comments there from the social workers you have interviewed, I think there is a hunger and a demand from social workers for some core induction training when they start within the agency. BOBBY 27246-27472

Introduction

This study was directed by the research question of asking how child welfare social workers are responding to cases of Fetal Alcohol Spectrum Disorder(s) in Ireland. Although the study focus was on the Irish child welfare social workers, evidence obtained at the pilot stage of the study in the Canadian culture indicates that CWSWs in Canadian culture may benefit from having this study recommendations applied in their education and development. The data suggests a vulnerability lurking with the professional mandated obligation of the CWSW in planning safe care for a child with an FASD. The data from this inquiry suggests a significant lack of knowledge and a wealth of misunderstanding about FASD among CWSWs and allied health professionals within the site of the inquiry. The requirement to increase clinical skills in social work profession has been called for over recent years by Badry and Choate, 2015; Pomeroy and Parrish, 2011; Wilson, 2013 and in the wider allied health professions by (Alexander et. al., 2007; Brown et. al., 2017; Payne et. al., 2011).

As noted in chapter 1, FASDs are contextualised as a lifelong disability offering a significant socioeconomic burden on both society and the child welfare services structure of the state providers with calls for professional education repeatedly made. Calls for education concerning FASD knowledge mobilisation is not new within child welfare service requirements of professional development. As discussed in Chapter 2, Badry and Choate (2015) and Wilson (2013) highlighted a critical need for CWSWs to be educated sufficiently to respond effectively in cases of FASDs. Similarly, Durking, (2016) reported a high degree of self-efficacy in child

welfare social works who had knowledge and experience but low self-efficacy in those lacking the education and experiences.

The data presented in chapter 4 offer a problematic picture of the difficulties on how CWSWs are upholding their statutory duties on delivering safe care and promoting the best interest of children living with an FASD. Children both diagnosed and undiagnosed are suffering significant life barriers and even fatality due to their neuro-disability hidden in plain sight within Child Welfare Service. A macro observation of where Child Welfare Service/CWSWs operate within the FASD dialogue is offered here in Fig 4. This visual emerged from the analysis as a second level of sensitizing concept has emerged while deeply mining the data. Such concepts as are described by Blumer (1954) as “whereas definitive concepts provide prescriptions of what to see, sensitizing concepts merely suggest directions along which to look. (p. 7). These concepts, as the study shows, are intrinsically involved within the interplay of the public health needs, prevention and management of FASDs in society, and therefore have to be considered when seeking to address the needs of CWSWs who find themselves Advocating against the Tide.



Figure 4. *Factors Influencing the Tide - Over Researched, Diagnostic Medical Model, Social Media and Advocacy Dominance is squeezing the statutory role of CWSWs.*

In the interviews for this study, CWSWs talked of their struggle to advocate and pursue the best interests of the child. Seeing and responding to the best interest of a child with an FASD is a fundamental requirement of a CWSWs intervention practice, as their role mandated in law to keep children safe.

The "Tide" is a significant struggle for the CWSWs within the cultural site under inquiry. If this struggle could be viewed within a microculture on the front line of child welfare, there is a macro culture that further impedes and restricts the CWSWs in carrying out the duties towards both a child with an FASD, and the child's caregivers.

The over-focus on diagnosis has a detrimental outcome on seeing the FASD child and caregiver through the lens of a social model that seeks to meet needs across the lifespan as the child grows and develops. Within the site of inquiry, evidence would suggest the children are diagnosed in isolation to holistic care planning strategies. The post-diagnostic needs tend to get inadequate discussion and lack collaborative working between the medical and social models of care. This glaring absence adds to the 'Tide' pressing down on the CWSWs, who are operating under the statutory duty of keeping the child safe and ensuring a best principle of care.

Child welfare service officials who may genuinely want to address the needs of children with an FASD, struggle to synthesize the vast body of sometimes contradictory intervention literature for FASDs. The lack of knowledge translation, especially on the difficulty of understanding and intervening with children, was evident within this study (Blackburn, 2017). The data spoke of the confusion about what to do within a void of guiding policy and practice standards.

The Influence of Social Media

Aspler et. al. (2019) suggests that social media negatively affects the public health needs of FASDs by promoting stigmatization, exaggeration, and contradiction. Research findings from the University of Canberra in New Zealand found that social media influences on the public health messages of alcohol in pregnancy were very confusing and even misleading (Holland, McCallum, and Blood, 2015). The study found that women were actively receiving and interpreting contradictory information on the risks of alcohol during pregnancy coming from multiple platforms within social media (Holland, et. al., 2015). In truth, society is being challenge on how information is provided on social media platforms, suggesting that CWSWs need to become more thoughtful consumers of FASD information with social media outlets.

The confusion from social media publication on FASDs over the past ten years further compounds the professional duty of both CWSWs and allied health colleagues in achieving plans of safe care while running the risk of imparting stigma (Bell, et. al., 2015). Social media posting is often critical of CWSWs and Child Welfare Service. Such social media posts are likely to override scientific evidence that is needed to empower CWSWs in delivery models of care more effectively.

CWSWs will need more advanced knowledge of the FASDs in order to deliver comprehensive models of care (Gibbs, 2018). The evidence offered within this inquiry suggested that CWSWs are relying on social media for education due to the absence of any formal Competency Based Education. Leaving CWSWs' education and professional development to social media is not likely to increase the skills of CWSWs sufficiently to administer the statutory requirements of their role as well as legal and ethical mandates of the profession. Within the site of this inquiry, Statutory Instrument (143) (2011), covers the code of professional conduct and ethics of social workers. The code states that Social worker will act “within the limits of professional knowledge, skills and experience” (Statutory Instrument, 143 p. 5).

As there is no specific skills or knowledge translation concerning FASDs currently offered within core professional development modules within Tusla, CWSWs may find it a difficult task to honour their professional code of conduct. Here again we see a further ‘critical gap’ between what is mandated and what CWSWs deal with in frontline interventions. Such a gap is likely to cause strained relationships with foster and adoptive parents of children living with PAE. Equally, the ‘critical gap’ creates a significant hurdle in the mandated objection of offering a plan of safe care, a requirement of all child welfare legislation in western societies.

Advocacy by foster parents and adoptive parents usually may be delivered through social media platforms. Such advocacy within the FASD dialogue can be very critical of the Child

Welfare Service (Mukherjee et. al., 2013). Such social media advocacy is more likely to create a complicated relationship between CWSWs and caregivers if caregivers believe the wider child welfare service to be failing or inadequate in meeting the needs.

Emotive advocacy offered through social media can also have a deliberating impact on child welfare service policy efforts. Shonkoff and Fisher (2013) argue that advocacy can be a destructive force on policy development stating, "Moreover, although compelling anecdotes and organized advocacy have little influence in the scientific community, they can overpower complex empirical data and generate enormous leverage in public policy." Indeed, as noted by Chasnoff (2011) "caregivers need to be aggressive in seeking help for their child" (p.71), as failure to secure such services and interventions is likely storing up problem further down the caring line. Collectively, the diagnostic-led dialogue, the tsunami level of publication and the anecdotal, emotive and aggressive advocacy all contribute to the CWSWs finding themselves Advocating against the Tide when responding to FASDs. Organised advocacy may inform child welfare strategies, but they should not lead or seek to control the FASD dialogue in relation to the statutory and mandated focus of CWSWs responding to FASDs.

Theoretical Model of Intervention

A key question emerging within this data is: how can CWSWs develop a theoretical intervention model to accommodate their work with children and families living with an FASD? Linton (2018) states that the coroner's inquiry concerning the death of HLS closes with the powerful reminder on the vulnerability of children living with an FASD, "The events surrounding his death were tragic and difficult to predict. They are a reminder of the vulnerability of children with FASD" (p. 42). Although a simple statement, it challenges all who work in and preside over child welfare services, that children living with an FASD, are

vulnerable and have complex needs. Responding to this vulnerable cohort through a theoretical lens is therefore called for.

Payne (2016) describes theory from two perspectives:

Theory is different from knowledge -theory involves thinking about something;

Knowledge is a description of reality.

Reality is a picture of the world that is accepted and true. Theory is different from

practice – theory is thinking about something; practice involves doing something.

As noted throughout this study of context, literature and findings, the neurodisability of FASDs is pervasive, costly and majorly impacting various systems of child welfare services provision. It is therefore warranted that CWSWs education needs to blend FASD knowledge within current social work theories that are focused on supporting, empowering and alleviating suffering within the community. Forder (1976) describes the systems model as an approach that meets the needs of a number of different disciplines from engineering to sociology to find a way of analyzing complex situations of interaction, in which, in common terms, “the whole is more than the sum of the parts” (p.24)

As noted in the previous chapters and the data of the study, FASDs fit within the notion of ‘complex situations of interactions’ with social systems seeking to respond to FASDs. By incorporating a systems theory within strategies of addressing FASDs, will likely greatly assist in addressing the grounded theory of the study, in that ‘Advocating against the Tide’ can be radically reduced if ‘different disciplines’ come together to address the complexity of FASDs. Systems theory is routinely taught at undergraduate level of social work education. Its core objective is for the social worker must assess and offer an analysis of all the systems that are with the environment that may be impacting and contributing to the individual’s behavior and

welfare. Currently, the situating of the individual living with an FASDs would not be routinely translated within undergraduate social work education.

Blending family systems theory to individuals and caregivers living with FASDs, will incorporate and acknowledge the need for maintaining service interventions to meet the long-term needs of individuals with an FASD (Petrenko, 2015). As an integrated theory, a systems approach will also facilitate the individual with an FASD to acknowledge within their environment. At the core of systems theory is the basic principle that interventions seek to reduce risk and increase protective factors, two major objectives of working with a child or adolescent living with an FASD. As noted in the literature that the majority of children diagnosed with an FASD will come from “family systems where addiction, mental health, abuse and trauma lie within the family story” (p.26). It is therefore suggested, that systems theory is seen as a foundation level theoretical approach of any cultural strategy in responding to FASDs, giving the identified needs of collaborative professionals and agencies in supporting CWSW’s in their statutory duty.

Operating Within Culture of Denial

Understanding the complexity of FASDs remains a difficult task to be addressed within Irish culture. The neuro-disability of FASD still suffers from a degree of arrogance within society leaving many to accept their ‘blind spot’ professionally (Mukherjee et. al., 2015). A philosophy that "no man is an island" needs to be incorporated within an all agency and interdisciplinary approach to addressing FASDs within a specific cultural lens (Jonsson, Salmon and Warren, 2014)

The Irish culture does have a significant level of child welfare case deaths as profiled by *The National Review Panel* (2017) which reviewed 22 deaths of children who died in child welfare service over 18 months. Although none of the cases examined in this 2017 review were

attributed to FASDs, it must be considered that mortality linked to FASDs "may be underreported" Thanh and Jonsson, (2018, p. 52), which is highly possible within the specific culture of the enquiry. A 2018 review panel of child welfare child deaths in Alberta, Canada, which reviewed nine premature deaths linked prenatal alcohol exposure to four of the cases under review of the Office of the Child and Youth Advocate, (2019). One of those reviewed was Darian (16). Darian had had a significant level of interventions from child welfare services throughout his short life starting at his birth. At the time of his premature death at 16, Darian was subject to a Guardianship Order. Darian was diagnosed with an FASD at the age of nine. It was noted by Thompson, Hackman and Burd (2014) that mortality is an underappreciated aspect of FASD for individuals who are undiagnosed. It may also be considered given the number of children suffering premature death living with a diagnosis is underappreciated and not being acknowledged appropriately in society.

Children are more likely seen by a professional and perhaps diagnosed with ADHD, conduct disorder or reactive attachment disorder and medicated accordingly, but it's likely such medication does not help, and if interventions are planned on a wrong diagnosis, then both diagnosis and medications will fail to address the needs of the child. This is a core issue to child welfare service in preventing the tragedy's highlighted in this study and empowering CWSWs to carry out their statutory duty and achieve the best interest of the child. The development of policy, protocol and practice standards across state systems of care and social services is essential in upholding their statutory obligation of the state on the welfare of these children. Calls have been made for the development of practice standards to guide CWSWs within the challenge of intervening in cases of FASDs (Badry, 2009, Badry and Choate, 2015) researchers have argued that policy and guidance documents act as powerful discursive resources which define 'good' and 'professional' (Nicoll and Harrison, 2003, p. 33). CWSWs deserve, given the

mandated requirements of their role, to have the opportunity to be 'good' and 'professional' in their interventions on cases of FASDs.

Knowledge Translation

One of the most challenging aspects of understanding the neuro-disability of FASDs is having a comprehensive professional education concerning the full etiology of the disability. Currently, for many CWSWs, the primary focus of concern for a child in utero will be illicit drug use. Although children may be born with outcomes associated with illicit drug use, such as Neonatal Abstinence Syndrome (NAS) their difficulties will not be as severe as those born of prenatal alcohol exposure (Kreitinger et. al., 2016). Unfortunately, while society, in general, focuses their concern on illicit drug use, the damage and lifelong consequences of PAE go unchecked. It is shown that it is alcohol that offers the most significant and only diagnosis (Thanh and Jonsson, 2016).

Here again we see the critical need for CWSWs to be equipped with the skills of prevention, assessment and care planning for a child with an FASD. Therefore, one may predict that child welfare service and CWSWs are going to see an increase in this disability within the services and specific casework. Currently, FASDs are said to impact 1 in 20 children (May et. al., 2018) The absence of Knowledge Translation on the vast body of empirical research conducted over the past 50 years or so, maybe be the primary cause of why the FASD disability is poorly acknowledged in society today. Knowledge Translation is defined by the World Health Organisation as: "The synthesis, exchange, and application of knowledge by relevant stakeholders to accelerate the benefits of global and local innovation in strengthening health systems and improving people's health." (Organisation, 2005). Evidence continues to emerge in society that there is a major failure on the knowledge translation of empirical findings on

FASDs. The last words of the WHO definition “improving people’s health’ is central in efforts to meet the needs of those living with an FASD.

The complexity and potential variance in the presentations of FASDs offers a daunting task to the CWSW seeking to understand the needs and plan safe care for the child. As noted the secondary disabilities of FASDs as portrayed by Streissguth's et. al. (1996) longitudinal study offers the professional a mammoth task in understanding the individual characteristics of each of the secondary disabilities. How to differentiate between the traditional ideology of any given condition and those conditions stemming from PAE as demonstrated is challenging. As discussed throughout this study, those impacted by Prenatal Alcohol Exposure may suffer long-lasting neurological and behavioral effects, effects which are highly likely to draw them into the attention of CWSWs.

The findings of this study suggest a lack of knowledge transfer through professional education on FASDs within CWSW and the allied health service structures. CWSWs interventions are professionally acknowledged as interventions that require collaborative, interdisciplinary and multidisciplinary collaboration. The vast majority of Child welfare and protection protocols in western culture require some form of collaboration service provision in statutory duties to keep children safe (Darlington and Feeney, 2008). Such mandated processes will have established protocols to ensure the collaborative actions within allied health services.

A repeated phrase throughout this data on FASDs was the phrase "pathway". Respondents talked of wanting and needing a pathway when responding to cases of FASDs. A selection of these sayings is "I suppose there is no clear pathway". This was a recurring sub-category offered within the data. This is a core challenge facing social work policy and protocol. The data offer a clear and compelling picture to Child Welfare Service, Schools of Social Work and allied health personnel of the critical need for collaboration in working to ensure, education

and protocols development. The need for skill enhancement and clearer focus by CWSWs is well documented (Badry and Choate, 2015; Badry and Felske, 2011; Gibbs, Bagley, Badry, and Gollner, 2018; Pomeroy and Parrish, 2011; Wilson, 2013).

As data articulates, CWSWs knowledge suffer from an Intellectual Haze around FASDs. In 2019 we still have poor acceptance on the truth and reality of FASDs and the acknowledgement of their prevalence within Child Welfare Service. Practising in an “intellectual haze” and “muddling through” poses a significant risk both for the CWSWs themselves but also for the child in need of state services and protection. Suffering an intellectual haze in any clinical health setting should be viewed as a severe weakness for any organization offering state services to vulnerable members of society. It also has the potential to create vulnerability within the helping professional of CWSWs. A vulnerability in the professional serving a vulnerable child is likely to have negative consequences for all concerned. Clearing the ‘haze’ through the delivery of competency-based education (competency-based education) to improve intellectual understanding of FASDs, is the most effective approach to reduce the vulnerability of the state child welfare service and empowering CWSWs to be effective in meeting the statutory requirements of their role in responding to FASDs.

Such failures in both education and care pathways concerning both the prevention and management of FASDs is leading to tragic outcomes for some children. Pringle (2014) stated:

"Principles of good social work practice were either not known to agency staff due to deficiencies in hiring or training, or they were not practiced. There was a lack of proper supervisory oversight and poor communication between staff and supervisors" (p. 25).

Pringle (2014) noted ‘principles of good social work practice not being’ known ‘as a factor which contributed to the fatality of six-year-old Sam, at the hands of ten-year-old Derek, who was living with a diagnosis from with FASDs. Both children received services from Child

Welfare Service, and at the time of the incident were cared for by foster parents. Badry and Choate (2015) stated the need for CWSWs to be professionally trained to accommodate the needs of children living with an FASD. However, lack of undergraduate and graduate education on FASDs leaves frontline CWSWs bereft of essential skills and knowledge to respond to these children. Badry and Choate (2015) go further when they suggest the education of CWSWs can be a "critical tool for change" (p. 29).

This would facilitate the finding of this study, where CWSWs talk of the intellectual haze, the professional positioning, advocating against the Tide and not having the knowledge base to have difficult conversations. Being a "critical tool of change" within the current dialogue on FASDs will require increasing the skill level of CWSWs through competency-based education modules to address the four conceptual categories documented in this study. Such Competency Based Education is likely to further greatly assist in addressing the grounded theory of this study. Operating within a culture where they have to advocate against the Tide when delivering a statutory role of developing a Plan of Safe Care, can only be achieved through the delivery of Competency Based Education, preferable within graduate and undergraduate schools of social work.

Part of the difficulty facing both child welfare service policy development and undergraduate and postgraduate education understands the components of Competency Based Education. This difficulty is primarily caused by what I described in part the literature review, as the plethora of research publications combined with a social media discourse on FASDs that fails to acknowledge both the individual cultural and child welfare service needs in addressing FASDs. The Center for Disease Control and Prevention (CDC) (2015) provides a succinct Competency Based Education framework of seven modules of education. It will need cultural adaptation in its translation within any cultural site outside of the USA.

Any protocol development that does not incorporate Competency Based Education within its development and rollout is likely to fail. CWSWs cannot be successful in interventions if not supported within a multidisciplinary framework and knowledge mobilisation. Within the site of the inquiry, the HSE partner agency is key to such collaboration owing to the location of Child and Adolescent Mental Health service 0-18 being situated within this partner agency. Also, the National Foster Care Association, Adoption Authority, Juvenile justice services are all key to the collaborative role of supporting and enabling the CWSW to be effective in delivering a Plan of Safe Care and facilitating a social model of disability in response the children with an FASD.

Such a framework of competency level education may be an ideal starting point for both Undergraduate and postgraduate education to ensure CWSW can become FASD-Informed in their interventions. Although the study is focusing on the needs of CWSWs and their response to FASDs, it has been noted that the philosophy that *no man is an island* needs to be incorporated at an all agency and interdisciplinary approach to addressing FASDs with a specific cultural lens. It is imperative to consider that evidence which points to the need for a specific cultural lens to be applied when addressing FASDs: “Implicit cultural understandings challenge those working to increase public awareness and support for programs to prevent and address fetal alcohol spectrum disorder” (Kendall-Taylor & Fond, 2017 p. 105). Collectively the upskilling of CWSWs can deliver what Badry & Choate (2015) call for in allowing “social work should position itself to provide leadership” (p.30) within the multidisciplinary approach to FASDs within child welfare structures. Incorporating multidisciplinary, culturally specific approaches and competency-based education are three vital components for success in addressing FASD and easing the burden on CWSWs. This is best achieved by state agencies engaging with their own indigenous home-based professional researchers, as such researchers and research will embody the components of a cultural approach.

The following is a brief synopsis of each of the seven modules offered by the Centre Disease CDC). The modules are slightly adapted to account for the cultural setting and CWSWs education. It is fundamental to remember that in addressing the needs of child welfare service and CWSWs that it is imperative to be addressed within an interdisciplinary lens. Working collectively and developing a service led dialogue that is driven by a social model will likely produce the best outcome for both children living with the disability and their caregivers. Crucially, what also may be beneficial in any systems approach, is the education of child welfare service management and policy level advisors to become FASD-informed, to facilitate the correct rollout of any policy and protocol to front-line child welfare service professional.

Competency I

Foundations. Competency I serve as a foundation for the entire curriculum and can be used as an introduction to training based on this Curriculum Development Guide. Upon completion of Competency I, the health care student or provider will be able to demonstrate knowledge of the historical background of disorders related to prenatal exposure to alcohol, known collectively as fetal alcohol spectrum disorders (FASDs).

Competency II

Alcohol use disorders.

This module offers skill development centered on how to communicate with women of childbearing age about issues related to FASDs: In this module, delegates can learn how to avoid language which may impart stigma within interventions to meet the child's welfare needs

Competency III

Alcohol screening and brief interventions.

Create opportunities for learning to models of addiction and their relevance

In the prevention of FASDs and risk screening. Addressing what services currently operate with a specific culture and how brief interventions can be delivered within the cultural lens. The optimization of current services and the integration of FASDs prevention strategies are discussed.

Competency IV

Biological effects of alcohol on fetus.

Delegates will be able to describe the effects of alcohol on the developing embryo and fetus. Assure that providers understand the long-term impact and behavioral or functional manifestations of the biomedical issues involved in FASDs. Learning how to impart the no alcohol no-risk message within the context of culture and maternal needs.

Competency V

Screening, diagnosis, and assessment for treatment planning.

This module offers different case example-based exercises to demonstrate the core need for interdisciplinary and culturally competent screening and assessment to arrive at a Plan of Safe Care that ensures the best interest of the child is achieved. Delegates will be able to screen and assess infants, children, adolescents, related disorders and plan accordingly.

Competency VI

Treatment across the life span for persons with fetal alcohol spectrum disorders.

The health care student or provider will be able to provide long-term case management for persons with FASDs. Provide case examples and schemas for knowledge application related to an FASD tailored intervention approaches: to exemplify person-based and adaptive and executive functioning-focused strategies of intervention that emphasizes individually tailored treatment for individuals with an FASD and their families

Competency VII

Ethical, legal and policy issues.

The health care student or provider will be able to recognize ethical, legal and policy issues related to FASDs and alcohol use during pregnancy. Within the cultural site of this inquiry, significant ethical, legal and policy issues will need to be addressed when seeking to address the more global point of FASDs and their impact on Child Welfare Service.

Implications for Child Welfare Practice

Screening for FASDs in 2019 is problematic owing to the multiple etiological factors assigned to developmental and behavioral presentations in children (Lennon and Czochara, 2019), a factor that becomes even more challenging for the CWSWs when trying to devise plans of safe care within the child welfare service. It is an essential component of planning safe care for a child, that a CWSW would understand and incorporate the underlying factors and etiology for behaviors considered within assessment work. It will also be necessary for foster parents to be up-skilled and FASD-Informed, in order to work collaboratively with CWSWs in devising plans of safe care for a child impacted by prenatal alcohol exposure.

As Chapter 2 demonstrated, a significant number of children living with an FASD will reside within the foster-care services following admission to child welfare service structures. Currently, under Section 16 of the national standards for foster care (2003), it requires that foster parents are trained to carry out safe care objectives. Section 16 states, "Foster carers participate in the training necessary to equip them with the skills and knowledge required to provide high-quality care" (p. 37). A key strategy of devising a policy framework and practice standards to facilitate the provision of safe care planning will be the Competency Based Education of both CWSWs and state-approved foster parents leading to both becoming FASD-informed. Working collectively and collaboratively these two critical functions of a child welfare service can make a significant impact on securing a Plan of Safe Care for a child living with an FASD.

Three critical areas for CWSWs of overlapping symptoms with FASDs, which are routine issues for CWSWs in interventions are neglect, maltreatment and attachment disorders. Disentangling the specifics of understanding the etiology of FASDs versus the multitude of environmental forces will need substantive professional skill-based education to achieve the task. According to a body of research as many as 75% of adults living with an FASD will have experienced physical, sexual or emotional abuse in childhood (Conry, Fast and Loock, 1997; Streissguth et. al., 1996; Thiel et. al., 2011). Also, the disentanglement of the neurodisability of FASDs and its vast array of presentations, from more socially acceptable and understood neurodisabilities (Autism, Attention Deficit Hyperactive Disorder, Asperger's Syndrome,) will further need specific knowledge implementation within the CWSW education modules.

Neglect and FASD

As already noted, it was eight children suffering 'failure to thrive' from the Washington area of child welfare service that offered the data to the now-famous Jones and Smith paper of 1973. As in many Child Welfare Service, 'failure to thrive' rests under the more defined label of neglect. The overlapping neurobehavioral and neurodevelopment presentations of both FASDs and Neglect is difficult to define. It is not uncommon that a child with an unseen FASD will enter the child welfare service and have the following as the first entry on their case files "was removed from the home for neglect and failure to thrive" (Hammond, 2012, p. 48). Although failure to thrive will be a widespread practice occurrence for a CWSW intervention, it is not to suggest that all cases with failure to thrive label and neglect are automatically cases of FASD.

Mukherjee et. al. (2018) urges caution when viewing neglect as a possible indication of PAE and FASD, as their research found that the neurodevelopmental outcomes of Neglect and PAE coexist in many presentations. Again, this is bread and butter for the statutory CWSWs, and as such, the role needs support in helping the CWSWs teasing apart the different etiology of

Neglect, failure to thrive and FASDs. Professionally teasing apart the different etiologies of presenting factors in child welfare service interventions is a crucial task, to not mislabel the child with an FASD and send them down a diagnostic pathway. This task of separating the different presentations which ‘coexist’ is possible within Competency Based Education and CWSWs becoming FASD-informed in their interventions.

Attachment and FASD

On the other hand, attachment behaviors have been shown as a likely stemming from PAE stating, “ Children with FASD may be more likely to have a disorganized attachment compared to those without FASD (O’Connor, Sigman and Brill, 1987, p. 834). It is also becoming more evident with child welfare services that perhaps hanging everything on the attachment label is potentially not the correct approach. “Attachment disorders are also likely to be a significant factor. Previously, many challenging behaviors disrupted placements have been put down to attachment alone, it is now becoming apparent that children may well have undiagnosed FASD” (Gregory, Reddy, and Young, 2015, p. 232). Attachment is one of the most cited issues revolving in foster care and placement stability, but sadly as noted by Gregory, et. al. (2015), a significant number of children with attachment failings may be children with an undiagnosed brain impairment coming from PAE. The need for integrating FASDs education with attachment is evident. Again, the need exists to upskill caregivers to become FASD-informed, a fundamental aspect of ensuring placement stability and preventing repeated moves of children with an FASD.

Trauma and FASD

A further study by Price, Cook, Norgate and Mukherjee (2017) highlighted “traumatic childhood experiences (trauma) such as maltreatment can lead to markedly similar neurological,

cognitive and behavioral deficits" (p. 90), deficits similar to those outlined in the research literature of FASDs. Consideration of all children living with an FASD, "but particularly children with a history of removal from the biological parents e.g., children in the child welfare system, or children who are adopted, one should consider the possibility of co-occurring trauma." (Shah, Shapiro, Milgrom, and Hoyme, 2018b, p. 114)

The complexity offered to the CWSWs of teasing out the unique presentations derived from trauma versus those derived from PAE is immense and needs systemwide support in such interventions. Children living with an FASD will do so with a level of deficits in functioning. These deficits can exacerbate difficulties in peer relationships and poor judgment and can predispose an individual to an increased risk for placement disruption within child welfare service provision. Integration of FASDs Competency Based Education and current Trauma education models would greatly assist the CWSWs. Although CWSWs may have received education on trauma and its impact on the individual child, revisiting such education and introducing the neurodevelopment profile of FASDs is essential. Again, the system-wide support would be policy, protocol and Competency Based Education to upskill, empower and protect CWSWs in their statutory duty.

Collectively, all three areas are interwoven on CWSWs caseloads today. Given the concern of missed and misdiagnosis, it is further likely that CWSWs may be providing interventions that are potentially not going to be effective, and therefore compromising principles of safe care and best interest of the child. It is this understanding of the neurological and behavioral presentations and the broader secondary disabilities and how they manifest within Child Welfare Service, that is likely the biggest challenge of current knowledge translation efforts, and the absence of such, is likely yet another potential *tide* of suppression impacting the role of CWSWs in carrying out their statutory duty to ensure the welfare of a child.

Defining the statutory role of CWSWs in different countries is complicated, but primarily, all CWSWs within each society, operate under mandated law and are obligated to uphold that state's legislative directives on keeping children safe. As shown by (Coveney, 2018) within the cultural site of this inquiry, children born of an alcohol exposed pregnancy are entitled to full protection under the Convention on the Rights of the child. Therefore, offering a statutory responsibility to children within child welfare services both to the national legalization and that of the Convention. As discussed in the context chapter, the site under inquiry has one of the highest alcohol rates in pregnancy and therefore likely incurring a heavy burden of FASDs in the Irish child welfare services and the CWSWs, a burden that is challenging to accommodate within a statutory duty of the state. How CWSWs engage this disability, what knowledge is required, and what policy or practice standard they can follow are all key challenges facing child welfare services.

With CWSWs data in this study describing a *'lonely road'* an **'absolute nightmare'** a **merry-go-round of assessments**, *'not going there'* and one where they *are fearful* in carrying out their interventions. The CWSWs contributing to this study reflected a status *that they were damned if they do and damned if they do not respond* in such cases. The reason is primarily due to an absence of education and practice and policy standards and is highlighting a significant weakness within statutory accountability of the corporate parent. A corporate parent is defined in Scotland as "An organization's performance of actions necessary to uphold the rights and safeguard the well-being of the looked-after child or care leaver, and through which physical, emotional, spiritual, social and educational development is promoted." (Scottish Government, 2015). Given the documented prevalence rates of FASDs in child welfare services shown in both context and literature chapters of this inquiry, points to a considerable corporate parent need to

ensure their welfare, safety and overall development. By not doing so, the potential for tragic circumstances will continue to impact state child welfare services globally.

This was highlighted directly by Badry and Choate (2015) in their assessment of the *Two Tragedies Report*, a report which looks specifically at two children in foster care, one with an FASD the other not, but how a poor system response to the child with a diagnosis, led to this tragedy. They stated clearly that the case rested on a ‘systemic failure’ contributing to a child’s death’ (Badry and Choate, 2015, p. 21). In such findings from children suffering a fatality as a result of their disability, a disability that was not of their own making is a focus for child welfare service personnel at a senior level to address. Child welfare service needs to engage and step up its professional response to ensure its system response to this vulnerable cohort of children is meeting the statutory and corporate response expected of state services. What must be remembered is that the issue of mortality for individuals living with an FASD, is that it is not the condition that causes death but the secondary disabilities and the failure of society to accept and respond. As both Vignettes 1 and 2 were children directly in the care of state services (Foster Care). This issue of preventing premature deaths associated with an FASD is of paramount importance to all sections of society. It also needs to be firmly included within the paramountcy principle that drives many western child welfare laws.

Prevention of FASDs

It may be argued that the prevention of FASDs is not a core responsibility of child welfare service and indeed CWSWs. However, given the evidence from (Petrenko and Alto, 2017) that FASDs is ‘predicted to rise’ it may be of great benefit to child welfare service to actively engage and advocate for more significant prevention strategies to combat the impact of admissions of FASDs to child welfare service structures. In a recent coroner's report by (Fogliani, 2019) (Western Australia) which detailed the tragic circumstances of 13 young people

who had taken their own lives by suicide, found "there was potential, a missed opportunity to help the child" (p. 232). A further and intriguing aspect to this coroner's report is that none of the 13 children had a diagnosis of an FASD at the time of their death, but the coroner and her team stated:

"I have not found that any of the children and young persons had FASD, but a number of them were vulnerable to the development of this disorder. Further, while none had been diagnosed with an FASD, the circumstantial evidence would suggest that a number of them were likely to have been on the spectrum for FASD" (P. 256)

The high level of missed and misdiagnosis has been indicated in the literature multiple times over recent years (Brown et. al., 2017; Chasnoff, Wells et. al., 2015). The culture under inquiry is likely to have a high level of misdiagnosis owing to the inadequate acknowledgement of the FASD disability. Children displaying cognitive and behavioral profiles may more easily be screened more traditional conditions such as Attention Deficit Hyperactivity Disorder (ADHD) and Oppositional Defiant/Conduct Disorder, learning disabilities, or communication disorders (Nash, Koren, and Rovet, 2009). This may be one of the most significant issues facing Child Welfare Service, as children get misdiagnosed, miss-medicated and sent down the wrong service stream leading to a more destructive trajectory for the child. Even when a child has a diagnosis they are failing to have their disability acknowledged, which is mainly due to the lack of education and protocols to guide within allied health systems of care - especially within child welfare service and CWSWs.

In total, however, this documentation offered little in seeking to conceptualize the role of CWSWs within this complex phenomenon lurking on their caseloads (Badry and Choate, 2015). Within site under inquiry, a picture of child welfare service and CWSWs operating under a *Cinderella Syndrome* (pre-fairy godmother) where a medical superiority view of FASDs was

dominant. A *Cinderella Syndrome* like the original fairy-tale is offered to describe where I see child welfare services and CWSWs operating like Cinderella. CWSWs are expected to manage and plan safe care of a substantial number of children, but to do this out of sight and not have a voice. Child welfare services at the macro level are engineering this *Cinderella Syndrome* by remaining subservient to a medical dialogue on FASDs.

It may be a prudent and productive strategy for child welfare service officials and CWSWs to become vocal and prolific agents of change by advocating for the prevention of FASDs, thereby reducing the impact on child welfare service and CWSWs. Shaking off the Cinderella syndrome will be the first step for CWS in supporting CWSWs responses to FASDs. This will require courage and conviction on the part of senior child welfare officials to lead on the development of policy, protocol and education to support front-line CWSWs responding to FASDs. This will further require child welfare senior officers to become proactive leaders with partner agencies, encouraging partner agencies to adapt strategies to benefit child welfare services and CWSWs.

Leadership from child welfare may be to advocate with the department of education to follow-up on the recommendation offered by Fogliani, (2019) who recommended the education of prevention on FASDs should begin in secondary schools:

Recommendation 6:

That education campaigns are conducted in all secondary schools in Western Australia to alert students to (i) the dangers of consuming alcohol during pregnancy and (ii) the prevalence of FASD (with a culturally relevant education campaign for Aboriginal children).

This recommendation was further noted by Burd and Popova (2019) who further stated that boys and girls be educated on the risks of alcohol use during pregnancy.

It is widely accepted within the dialogue on FASDs prevention, that prevention is a collective shared responsibility that requires many different approaches. It is therefore articulated that prevention is focused on broad awareness building health promotion which includes prevention campaigns, pamphlets, warning signs and labels, and other forms of public education campaigns which would be deemed as a level one approach (Poole, 2008). It is therefore very much within a level one approach that partner agencies could agree to a collaborative, cooperative and offer a consensus model in developing and administering recommendation six as recommended by Fogliani (2019) with a specific cultural lens on maternal-child health prevention needs. Young people are shown to absorb information quicker and to retain this information lifelong (Davidow, Forde, Galván, and Shohamy, 2016). Given the problematic alcohol culture of the study site and its documented high rates of alcohol consumption during pregnancy, an approach to instilling the prevention message within second-level education could offer a major cultural shift in favor of enhancing maternal-child health needs of the future.

An approach of implementing recommendation 6 by Fogliani (2019) has the potential of creating a non-stigmatizing education program with young people (both male and female) with a dialogue that is helpful to the prevention need, rather than having a conversation that could hurt when trying to instill prevention messages when a woman is already pregnant. What is agreed is that women want clear accountable information on the risks of alcohol in pregnancy (Holland et. al., 2015). The process by which young people, while in their young adolescent stage of life could be empowered on the dangers of alcohol in pregnancy is likely to offer significant societal benefits from a universal base within second-level education. By adopting Fognini's (2019) recommendation and developing it within Freire's Empowerment Education model as described by Wallerstein and Bernstein, (1988), has the ability to address the complex and emotive topic within the pre-pregnancy stage, a factor which is likely to significantly reduce the current

concerns around stigma and misinformation concerning alcohol in pregnancy and FASDs (Aspler et. al., 2019; Bell, Andrew, et. al., 2015).

A core objective of Freire's Education Empowerment is "health and prevention model for personal and social change" (Wallerstein and Bernstein, 1988, p. 381). Giving the site of this inquiry, where alcohol in pregnancy levels is cited as high as 82% (O'Keeffe et. al., 2015), and sees Ireland placed in the top 5 countries of the world for rates of FASDs Popova et. al., (2017), an approach to education on the prevention of FASDs could yield significant social change within a short timeframe within the cultural site of this inquiry. Government of Ireland (1998) in the education act of that year emphasizes that schools should promote the social and personal development of students and provide them with health education. The promotion of maternal-child health is a natural fit for social and personal development of future generations.

As discussed, Prevention of FASDs is the remit of an all-agency approach and one which child welfare service needs to engage with, and even advocate for establishing in societies where prevention is not robust enough. Seeking cross-governmental departmental responsibility on the prevention of FASDs is crucially to ensure that prevention messages are evidenced-based and are approved public health messages with the best scientific evidence on alcohol use and risk fetal development. Although currently, single agency efforts do happen – such as public health agency Canada (PHAC) (Public Health Agency of Canada, Canada and Health Canada, 2012) and within site the Health Service Executive (HSE) issuing an all-Ireland Pocket guide on alcohol in pregnancy in 2013. The difficulty with single agency promotion is that it lacks the universal clout that a cross-departmental approach can yield, while at the same time bringing the personnel of all cross-departmental services on board with such procedures.

A vital issue in prevention that gets little attention is the scientific fact that siblings of an older child born with PAE have a heightened risk of also being born with an FASD (Abel, 1988).

It, therefore, follows that a prevention intervention on a single pregnancy may reap benefits in future pregnancy in reducing FASD births. Also, a consideration in prevention strategies is that alcohol consumption is showing to increase with age during childbearing years. This may provide increased vulnerability to FASD births as the age of the mother increases (Jacobson, Jacobson, Sokol, Chiodo and Corobana, 2004; Jacobson et. al., 2008). It is, therefore, possible through effective public health strategies delivered across government departments, to educate on prevention strategies as such strategies may see significant improvement in lowering the birth rate of FASDs and subsequent cost burden in any cultural setting.

Again, the model currently underway in New Zealand (Group, 2016), which was adopted a cross-departmental approach may help with the concern around social media representation of this public health need. Preventing FASDs from occurring in the first place has an enormous benefit to the child, birth mother, society, and as highlighted here that such prevention will ultimately aid child welfare service and CWSWs in reducing the burden of the complex disability with the services. The socioeconomic costs associated with Prenatal Alcohol Exposure are well documented in research (Svetlana Popova, Stade, Bekmuradov, Lange and Rehm, 2011; Thanh and Jonsson, 2018) with individuals who are impacted needing services across all governmental services of Education, Justice, Child Welfare, Mental Health Services (Badry and Choate, 2015). As adults affected will also struggle to live independently and struggle to hold down employment (Streissguth et. al., 1996). Giving the international body of evidence on failing to prevent the disability and its costly implication of the public finances, it is in a cross-departmental best interest to robustly engage in prevention messages.

FASD prevention and service delivery work is complex on several levels. There are many different ideologies of how to approach 'prevention' of FASD with the many publications to date on the topic. Anne Streissguth (1997) developed one of the most acknowledged strategies of a

prevention model in her book *Fetal Alcohol Syndrome - a guide for families and communities*. In this text, she talks of the five Ps of prevention:

1. Public education
2. Professional training
3. Public Policy
4. Programs and Services
5. Parent and Citizen activism (p. 250).

This model has similarities to the strategy currently worked at the cross-governmental approach in New Zealand; the 5 Ps outlined are crucial to addressing this public health challenge and is still relevant today, and one which needs to be utilized within a cross-departmental strategy in addressing prevention of FASD. As the study has noted, it is imperative that the prevention and management of FASDs are addressed through a cultural lens giving the unique challenges some cultures present. As discussed by Petrenko, et. al., "Different cultural practices and degrees of development concerning primary, secondary, and tertiary medical and psychological intervention have led to a varied response to alcohol use during pregnancy as well as attitudes about prenatal alcohol exposure" (Petrenko and Alto, 2017). The site of this inquiry has unique challenges given the long associated history with alcohol Mongan, Hope and Nelson, (2009), and significant cultural issues with regards to abortion (Kennedy, 2018). Over recent years, discussions and legislative changes to the question of abortion within the cultural site have seen the issue of the unborn become divisive and heated. Coupled with these two dominant forces at play in Ireland, Irish women for years have had poor medical advice on prevention of alcohol exposed pregnancy, as most Irish physicians did not have an understanding of FASDS (Gill and Sharif, 2017).

Assessment

FASDs present challenges in screening and identifying those at risk and in need of services (Fogliani, 2019). A development over recent years within the FASD research has seen the emergence of what might be called 'express screening' to detect children and young people living with an FASD. Two such developments have been eye-movement tracker Zhang et. al., (2019) and genetic DNA screening Portales-Casamar et. al., (2016) both of which can screen and offer a positive or negative finding within a short period. In the Eye movement screening, it is anticipated that a child could be screened within 30 min. As all research has positive merits, the concern with such expressed screening is that child welfare service and CWSWs will get increased and possibly significant demands, as both these screening methods purely give a positive/ negative outcome for FASD. They do not offer anything substantive in terms of care needs or planning of a treatment need. Families want supportive and helpful interventions to aid their caring role (Chamberlain et. al., 2017; Raja Mukherjee et. al., 2013). Again, these developments are a brief screening mechanism and do not offer a full diagnostic of FASDs.

Within the particular culture of inquiry, participants spoke of not having faith in the unapproved diagnostic service operating within the site. Again, this aligns with international evidence that current diagnostic guidelines have limited and disputed agreement globally (Burd and Wilson, 2004) and consideration on the advantages and the disadvantages is needed before labelling a child with a lifelong disability (Domeij, Hultcrantz et. al., 2018). Respondents also spoke of believing the nothing comes from diagnosis and had a more considerable investment in seeking psychosocial assessments where possible. Within the data PATRICK, and SHARON, all spoke repeatedly of seeking more of psychosocial assessments and policies to guide. They did, however, also speak of confusion and the lack of joined-up thinking around the assessment process with the concept of no clear pathway to guide such assessment work. Such views put

forward within the data follows within general FASD dialogue that the accurate identification of FASDs is very challenging due to its overlapping symptoms of occurring disorders that might be impacting the individual (Popova et. al., 2016). Therefore, the need to take a measured approach to a diagnosis is warranted by the application of psychological and neurological screening to build a comprehensive profile of the child before diagnosing. Such a screening approach also aids in seeking to prevent misdiagnosis or incorrect diagnosis.

The prevailing medical model and dialogue around diagnosis is primarily responsible for the creation of isolation and the social-relational oppression of those living with and diagnosed with an FASD. As Dej (2011) describes:

“Psy-experts identify the FASD child as an innocent victim with the potential to be a productive citizen, given professional and timely interventions. The FASD child identity is medicalized so that the scientific community, psy-disciplines, and community programmers can have virtually uninhibited access to the individual and his/her environment.” (P.142).

It is likely that over-focusing on a diagnostic lens, is feeding the ‘over-the cliff-edge’ status of individuals living with the disability. What is clear from qualitative research with caregivers is the view that service provision and accessibility are the most significant need within service structures, and that CWSWs should be equipped with the knowledge of such services to provide the correct responses. (Fuchs et. al. 2010, p. 241). A pertinent need within child welfare services is to facilitate the more significant investment of CWSWs in the delivery of services is the need to shift the FASD lens from a medical model to a lens of a social model of disability as coined by Oliver in 1983. A current look at the disability from a medical lens may look somewhat like what Cologon and Thomas (2014) describe - at its most fundamental, a medical model view of disability considers disability to be something 'broken' inside a person. From this

perspective, the required response is, therefore, to 'fix' the person, to try to change the person in ways that make it easier to 'fit in' with society, or to seek to eliminate the 'disability'... The medical model is also viewed as a 'tragedy model' or a 'charity model,' due to the underlying medical model view of people who experience disability as tragic and in need of charity and pity (p. 29).

Based on the evidence emerging in the data of this inquiry, the literature and the coroner's reports featured, the study offers this 5-step intervention model as a possible approach to the site of this inquiry given the lack of approved diagnostic framework and the lack of specific services to meet needs of a child with a label of having an FASD. This 5-Step approach fits with what the data is saying in that participants talked of *searching for a path* and **finding a way** when intervening in Cases of FASDs. As noted in the recommendations of the investigation into the death of HLS, the application of screening tools and educating staff are a priority of child welfare service in addressing FASDs. This was reaffirmed by Popova et. al., (2013) who offered that:

Routine screening protocols should be established to identify people with FASD in child welfare, special education, the justice system and other settings to provide appropriate support and early interventions. Service staff should be trained in FASD awareness, identification, and interventions to provide better care. (p. 18).

A development over recent years within the FASD research has seen the emergence of what might be called 'express screening' to detect children and young people living with an FASD. Two such developments have been eye-movement tracker (Zhang et. al., 2019) and genetic DNA screening (Portales-Casamar et. al., 2016) both of which can screen and offer a positive or negative finding within a short period. In the Eye movement screening, it is anticipated that a child could be screened within 30 min. As all research has positive merits, the concern with such expressed

screening is that child welfare service and CWSWs will get increased and possibly significant demands, as both these screening methods purely give a positive/ negative outcome for FASD. They do not offer anything substantive in terms of care needs or planning of a treatment need. Families want supportive and helpful interventions to aid their caring role (Chamberlain et. al., 2017; Mukherjee et. al., 2013) Again, these developments are a brief screening mechanism and do not offer a full diagnostic of FASDs.

Within the particular culture of inquiry, participants spoke of not having faith in the unapproved diagnostic service operating within the site. Again, this aligns with international evidence that current diagnostic guidelines have limited and disputed agreement globally (Burd and Wilson, 2004) and consideration on the advantages and the disadvantages is needed before labelling a child with a lifelong disability (Domeij, Hultcrantz et. al., 2018). Respondents also spoke of believing the nothing comes from diagnosis and had a more considerable investment in seeking psychosocial assessments where possible. Within the data PATRICK, 10, 7, 14 5 and SHARON, all spoke of seeking more of psychosocial assessments. They did, however, also speak of confusion and the lack of joined-up thinking around the assessment process with the concept of no clear pathway to guide such assessment work. Such views put forward within the data follows within general FASD dialogue that the accurate identification of FASDs is very challenging due to its overlapping symptoms of occurring disorders that might be impacting the individual (Popova et. al., 2016). Therefore, the need to take a measured approach to a diagnosis is warranted by the application of psychological and neurological screening to build a comprehensive profile of the child before diagnosing. Such a screening approach also aids in seeking to prevent misdiagnosis or incorrect diagnosis.

Through listening to the needs and wants of participants and how confusion reigns when responding to the child with an FASD, the following 5 -Step Neurodevelopment practice model

is likely a positive resource if offered within a policy framework to help guide a path of intervention. Ultimately, such a policy formation will significantly enhance the ability of the CWSW to carry out their statutory role, and one that will give greater clarity in establishing a plan of safe care.

5-Step neurodevelopmental screening

As the cost burden of FASDs is increasingly documented in empirical research studies, the likelihood is that such publications are having detrimental impact on state systems to act due to fear associated with FASDs costs. In 2013, Popova and colleagues noted that the cost of a diagnosis in Canada to be between \$3,110 to \$4,570 per person. Such costs may be prohibitive for child welfare services given the estimated prevalence's rates documented in this study. This fear of diagnostic costs was noted recently by Burd and Popova (2019) who offered the following response to the issue of diagnostic services:

Even the wealthiest countries cannot provide this service. The good news is, it is not needed. Most individuals with FASD are in systems of care that with a few modest modifications can greatly improve care for people with FASD and their families. (p.1)

This acknowledgment by Burd and Popova that even the “wealthiest countries” cannot fulfill its obligation to meet the needs of those living with an FASD, will possibly come as some relief to policy practitioners grappling with the reality of FASDs. It is also worth noting that this is somewhat of a flipping-of-the-script within the research world of FASDs, as both of these researchers have historically promoted the diagnostic mantra needs in previous research Popova et al, (2017) where it was argued that “a diagnosis of FASD has several potentially important benefits for affected children and youth, namely, early access to developmental interventions” (p. 4). Clearly, we are seeing a shift in FASDs research, a shift that ultimately acknowledging that costs are even challenging wealthy countries in addressing FASDs. It is within this frame of

costs, that the study offers a protocol for child welfare services that minimises costs while maximising benefits to children and families living with this pervasive disability.

The 5-step Screening Protocol approach does not label and suggests that the label of diagnosis should only happen after careful consideration with interdisciplinary care planning. Within a sequential approach, an approach that can collect and integrate data to directly influence the caring needs of a child or young person living with an FASD. The 5-step screening protocol offers one screening tool each for both executive function and adaptive function. There are numerous screening tools available across cultures and within professionals that offer an assessment of both cognitive and adaptive domains; therefore, a D-REF and a VABS are not fixed or rigid components of the framework. Again, the positive aspect of this framework is that it does not affix labels, a factor that can ensure a child does not suffer stigma as a result of their needs assessment being met.

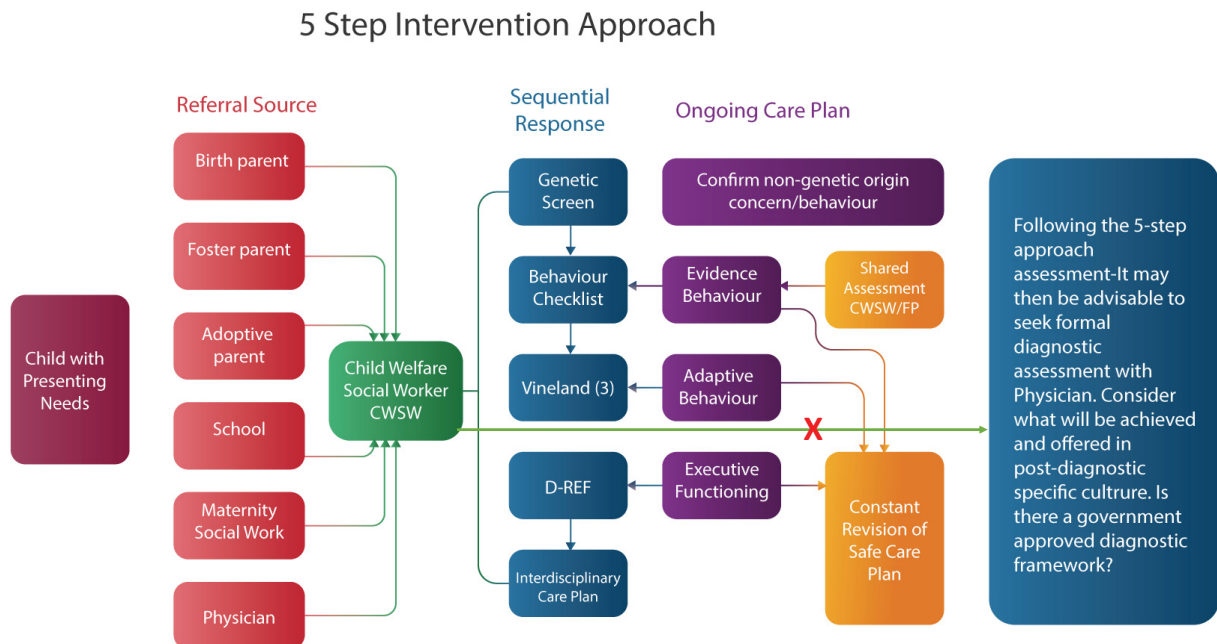


Figure 5. 5 Step Intervention Approach to guide CWSWs in responding to FASDs

The process described here is a sequential approach when first engaging with a child who may be suffering a neurodisability and where such concern is emanating from prenatal alcohol exposure.

The **X** is an advisory that CWSWs should not go from initial identification to diagnostic procedure when responding to a child's need.

Genetic screen.

Virtually all congenital disabilities or clinical impairments have more than one cause, “it was appreciated in the early part of the twentieth century that clusters of malformations might be related to a specific etiology – either genetic or environmental in origin” (Clarren, 2018). In children and newborns, genetic screening targeting different diseases have been being applied effectively for the past 50 years (Pasquier et. al., 2019). Several neurodisabilities, although having similar presentations to that of an FASD, can present on a CWSW caseload. It is essential to understand the different etiology's associated neurodevelopment disorders.

A genetic screen can help to exclude a genetic etiology for a child's cognitive or behavior needs. It is crucial from an ethical practice standpoint that both parent and child is properly counselled before a genetic screen on the potential of a positive screen. A genetic disorder that could have broader family implications “parents and guardians be informed about the potential benefits and potential harms of testing, and their permission should be obtained (Ross, Saal, David, and Anderson, 2013, p. 235). A negative screen becomes the first piece of information to direct care planning and indicates that the neurodevelopment or neurobehavioral presentation is not organic to the child's presentation. This is not a conformation of prenatal alcohol exposure, as there are multiple non-organic factors which can alter fetal brain development. A negative screen simply rules out organic causation – many causations remain.

Currently, the lead UK assessment centre for FASD always requires a genetic screen before embarking on the full FASD assessment/diagnosis. In “All cases had a microarray analysis (a genetic test to assess the genetic profile of the individual and detect common abnormalities) before acceptance in order to rule out other known common genetic causes of developmental delay (Mukherjee, Cook, Norgate, and Price, 2018, p. 24). This is an excellent example of good ethical standards and practice, and a process that can minimize the risk of misdiagnosis as discussed by Chasnoff, Wells and King, 2015. Equally, Hoyme, Kalberg, & May, (2019) note that other syndromes which offer a similar profile to FASD must be confirmed before seeking an FASD diagnosis. A genetic screen therefore is essential component of any approach to understanding the correct etiology of FASDs.

Child behavior checklist.

The CBCL assess childhood behavior with three main areas (total problems, externalizing problems, and internalizing problems) and eight sub-areas of (withdrawn, somatic complaints, anxious/depressed, social problems, thought problems, attention problems, delinquent behavior, and aggressive behavior) (Achenbach and Edelbrock, 1980). The CBCL consists of 113 questions on specific problem behaviors scored on a 3-point Likert scale where 0 indicates that behavior is absent; 1 indicates that it occurs sometimes, and 2, that it occurs often. The application of a CBCL by CWSWs working in partnership with caregivers has enormous potential of evidencing behavior without the need for a diagnostic label.

Furthermore, as children entering child welfare service will come from a range of toxic environments which are likely to create behaviors and developmental problems, such presentations may look like an FASD but are not linked to PNE. Hence, this non-stigmatizing approach can benefit a broader range of children residing in the system. Using the data supplied from a CBCL, CWSWs can be empowered in their overall care plan as they seek to plan safe

care. The only criteria for delivering a CBLC assessment is to be qualified at with a master's level of education. See Warnick, Bracken and Kasl (2008) for an evaluation of the CBCL.

Vineland-2 and Vineland-3.

Adaptive functioning is an individual's ability to successfully negotiate the tasks and problems of everyday living (Edwards and Greenspan, 2010; Jirikowic, Kartin and Olson, 2008).

Vineland Adaptive Behavior Scales (VABS). The Vineland covers four adaptive behavior domains: communication, daily living skills, socialization, and motor skills (the latter being optional for individuals over age 6). It also provides an Adaptive Behavior Composite Score. Three subscales – internalizing, externalizing, and other – comprise the optional Maladaptive Behavior Index that provides a measure of undesirable behaviors that may interfere with an individual's adaptive behavior. The optional Maladaptive Critical Items do not contribute to a subscale or composite but provide a brief measure of more severe maladaptive behaviors that examiners may want to consider in the overall assessment of adaptive behavior. (Sparrow, 2011).

D-REF.

Executive functioning deficits are considered to be one of the most negative outcomes of FASDs (Green et. al., 2009). The Delis Rating of Executive Function (D-REF; Delis, 2012) is designed to measure executive function problems in children and adolescents ages 5 to 18 years. The D-REF consists of 36 items (available for online or paper administration) scored on a 4-point Likert scale: Seldom/Never, Monthly, Weekly, or Daily. The measure yields three core indexes—behavioral functioning, emotional functioning, and cognitive functioning—as well as four second-level index scores—attention/working memory, activity level/impulse control, abstract thinking/problem solving, and compliance/anger management—The D-REF consists of three measurement components one for parent, one for teacher and self-rating forms. The D-REF

forms can be administered digitally using a computer or tablet or in the standard pencil-paper format. A validation study of D-REF can be sourced here (Warnick, Drake and Vidrine, 2015).

A pathway forward within Child Welfare Service, therefore, may be better travelled if the lens of a social model was more routinely engaged within child welfare and protection work of the CWSWs. The application of an incremental approach that places a diagnosis at the end of the process may, therefore, enhance the role of the CWSW and remove some of the barriers that currently constitute "Advocating against the Tide". Research has offered in considerable quantity that the most challenging aspects of living with an FASD is both executive function (Diamond, 2013; Doyle et. al., undefined/ed; Green et. al., 2009; Kelly Nash et. al., 2015) and adaptive functioning (Edwards and Greenspan, 2010; Jirikowic et. al., 2008). Seeing these two primary impairments through a social lens may offer significant results to caregivers and facilitate the CWSW to operate within the framework of a social model of disability. Oliver, as the creator of the model, did not see it a theory but more a practice model that could help alleviate the needs of those living with a disability (Levitt, 2017).

This approach of addressing needs in a pre-diagnostic holistic assessment was recently promoted in the finding of the coroner's report of HLS, the young man who died tragically in Australia and featured in Vignette1 of the study. Contributing to the inquiry, Dr. James Fitzpatrick recommended in 209 and 210 of the investigation the following:

"For children coming into care, Dr. Fitzpatrick suggested there should be a screening process on entry into care irrespective of any screening done previously, as it is an opportunity to examine the child at the moment they are coming into care, so any developmental or behavioral problems that might compromise care placement can be immediately identified and resourced appropriately." (209)

It further suggested how this might be achieved with the following:

“such screening could be done within DCP by a psychologist or social worker who would implement child development screening tools. Only the following screening would there potentially be a need to get specialist agencies involved, preferably when a group of children, had been identified so that diagnosis can be achieved cost-effectively and efficiently.” (210)

This suggestion would require some limited additional training for existing DCP staff, but Dr. Fitzpatrick suggested for professional staff it would likely only require a few days training period for behavioral scales, although more might be required for development scales, once trained it would enable the Department to have a standardized way of approaching the issue.” (Linton, 2018 p. 38).

It is worth noting at this stage in this look at a social model response that the application of screening tools is currently applied within more developed cultures where FASD is more accepted and recognized. In such advanced cultures – multidisciplinary assessment services centres offer a range of screening tools (Coons-Harding, Flannigan, Burns, Rajani, and Symes, 2019), leading to a diagnostic if appropriate. As noted here by Coons et. al., in 2019, currently significant approaches on the screening for neurodevelopment deficits takes place in Alberta, Canada. It is also worth noting that it was collaborative actions of Foster Parents and CWSWs in Alberta in the early 1990s, that is considered as the origins of this developed systems approach in Alberta, Canada that now has over 20 multidisciplinary teams for FASD assessments (Shankar, 2015).

Intervention

Evidence indicates that with the right supports and early intervention, children living with an FASD can have positive outcomes and lead productive lives contributing to society. Without such interventions and supports, it is more likely that individuals living with an FASD will

develop severe secondary disabilities and become a burden on public health services and costs. The complex nature of FASDs requires an individualized and collaborative approach to service delivery that supports an individual both with the child welfare service and across their lifespan. Developing a pathway upon which a CWSW can walk, is an urgent requirement of child welfare services in ensuring that a Plan of Safe Care can be instigated and acted upon in the best interest of a child living with an FASD.

A child living with impaired executive functioning will have difficulties with remembering multi-step instructions, impulsivity and day to day problem solving. Standard intervention strategies delivered by CWSWs with children in public care will not work with children with an FASD and suffering executive functioning impairment. As noted, children living with an FASD provide significant challenges to the task of planning safe care and to upholding the best interests of the child. The task of achieving both safe planning and best interests will need a collaborative working model that spans across-governmental departments and services. The term Interdisciplinary is used as opposed to multidisciplinary to denote the practice of all professionals within the care planning having separate, distinct professional roles but collectively working in partnership to pool the collective expertise to meet a broad range of needs presenting in a child with an FASD.

Achieving this collaborative shared responsibility will need to have a policy framework adapted to incorporate the 5-step Screening Protocol. Placing the framework within a policy and practice standards will likely significantly reduce the professional positioning currently experienced by CWSWs and support their efforts to advocate with the tide in securing a child's welfare. As noted in Figure 5-Step-Step programme -care planning needs to be continuously reviewed with protocol directing CWSWs in a case manager role of establishing safe care planning and ensuring the 'Best interest' outcome.

Policy Implications

A major concept emerging within this data and broader inquiry offer what I called Controlling Hierarchies which are maintaining a status quo, a status quo which ultimately is resulting in *professional positioning* and leaving CWSWs *Advocating against the Tide*.

Ultimately, hierarchies operating within child welfare service who are not familiar with or educating on FASDs are going to significantly impede the ability of CWSWs to conduct early interventions to enhance the development of FASDs progression to secondary disabilities and costly burden on society. Although the literature on FASDs is heavily narrated on the provision of early interventions, there is poor articulation on what, precisely early interventions are. Harvey writing for The Prevention and Early Intervention Network (PEIN), a 24-agency collaboration advancing for better early intervention services with the site of this inquiry Harvey (2014) defines early intervention as follows

“Prevention is defined as ‘providing a protective layer of supports to stop problems from arising in the first place or from arising in the first place or from getting worse.’”

and

Early Intervention noted as ‘Providing supports at the earliest possible stages when problems occur’ (p.2).

It is important to note that the challenge facing child welfare service officials, be it policy officers or staff development managers responsible for advancing safe care, is immense and one that may lack a clear pathway. A study by Lloyd et. al. (2019) offers perhaps the clearest evidence of this. Their study which looked at the US Child Welfare Service, and specifically the CAPTA (2010) Reauthorization legislation in The USA child welfare system of that year. In this reauthorization of the primary child protection and welfare legislation, it introduced a clear mandate concerning FASDs. In this mandate, the law requires:

Policies and procedures (including appropriate referrals to child protection service systems or other appropriate services) to address the needs of infants born with and identified as being affected by illegal substance abuse [sic] or withdrawal symptoms resulting from prenatal drug exposure, or a Fetal Alcohol Spectrum Disorder [FASD], including a requirement that health care providers involved in the delivery of care of such infants notify the child protective services system of that occurrence of such condition of such infants. (P.L. 111-320, 106(b)(2)(B)(ii))

As a mandated law, this offers two significant challenges to the child welfare service. Firstly, it institutes in law the need to provide, "policies and procedures" to meet the needs of all children suffering from illegal substances and those born with an FASD. This directive is a clear mandated requirement to have these children seen, to have their needs met and for CWSWs to devise a Plan of Safe Care.

The second major challenge offered is the directive to "health care providers" to refer to such cases of illicit drugs and FASDs concerns to state child welfare and protection services. This follows on the research and recommendation of Williams et. al. (2015) when it calls upon that all pediatric doctors to make appropriate referrals to child welfare service of children suffering from an alcohol exposed pregnancy. Such directives are placing a significant burden on child welfare service and CWSW and stipulate the need for both policy and practice standards to accommodate such instructions. An important caveat in the legislation is the wording used. Health care providers are to 'notify' rather than make a report of child abuse. The wording of 'notify' signifies that the CWSW will be the person to determine if the referral constitutes risk of child abuse and neglect or that the parent needs services around their substance use/misuse (Sect. 106(b)(2)(B)(ii)). This signifies again that legislative approaches to FASDs need to be operated

with great care and professionalism by all allied health personnel and having the skills and competency to do so is paramount.

Lloyd et. al. (2019) found that only two of fifty states reviewed were fully compliant with the 2010 mandate to ensure safe care planning for this vulnerable cohort. The two states found to be fully compliant were Delaware and North Carolina (p.16). This failure to fully grasp the legislative mandate of CAPTA in ensuring safe care planning is a potentially significant factor in children slipping through the net within child welfare service and suffering significant destructive secondary disabilities leading to fatalities. It was noted by chasnoff (2011) that this legalisation passed easily within the US senate, but “no funds were made available to institute training for hospitals and health care personnel on how to recognize a substance-exposed child” (p.212). This is a pivotal point for corporate officials to consider in that knowledge mobilisation/translation is a fundamental component to be incorporated alongside legislative and policy strategies to meet the needs of this cohort of vulnerable children within service structures.

A further policy brief by the Guttmacher Institute (2019) notes that 23 US states now consider substance use during pregnancy to be grounds for formal child protection response “abuse under civil Child welfare statutes and 3 consider it grounds for civil commitment” (p. 1). Outside of legal, legislative mandates, children with an FASD are still reported to be entering Child Welfare services in significant numbers. Although a majority of FASD contemporary research will more often than not have ‘early diagnosis’ recommendation in the first or second paragraph of a research paper. Such research proclamations can lead to confusion when the culture has poor recognition and a lack of therapeutic services to meet the needs of a child with an FASD an especially those presenting in child welfare populations.

A 2018 study found that the level of children with a diagnosis related to prenatal substance abuse entering foster care was 11 times greater than those without a diagnosis from the

same demographic (Prindle, Hammond and Putnam-Hornstein, 2018). However, as noted in the literature, this evidence on the impact of FASDs on child welfare is not new news as documented by Astley et al back in 2002 finding that the rate was 10 to 15 times greater than those not impacted by prenatal alcohol exposure. With such high rates of prenatally exposed children entering child welfare service and evidence of poor policy, procedure and practice standards to accommodate, it further highlights a critical need for CWSWs to be educated in brain sciences as noted by (Rutledge, 2014). Such education is likely to support social workers in understanding FASDs within their statutory interventions within the site of the study. The national agency for the protection and welfare of children, Tusla, receives a referral a child in need every 10 minutes (Tusla, 2018). Given the high proven rate of alcohol use during pregnancy as discussed in Chapter 2, it is therefore increasingly likely that many children living with or suspected of FASD will form a significant percentage of the total referral numbers each year. In 2017 the total number of referrals for a child in need was placed at 53,755 (Tusla, 2018).

Pathways Forward

Utilizing a Social Model of Disability to Meet Needs

As discussed throughout the study, FASDs are firmly classed within the field of neurodisabilities and is cited sufficiently as the leading cause of intellectual disability globally (Greenspan and Woods, 2018). It may be considered that following half a century of research dedicated to the disability, has had the negative effect where its unseen by most within society. Again, this leaves child welfare service and CWSWs perched on the cliff edge, trying to provide services to fulfil the best interest principles of statutory law. As a leading cause of intellectual disability, it, therefore, follows that a natural fit to accommodate individuals living with an FASD would be within the Social Model of Disability (Oliver, 1983).

The social model of disability emerged out of activism by physically disabled people in the 1970s. The social model specifically draws attention to the 'economic, environmental and cultural barriers' faced by people with differing levels of disability (Featherstone, Gupta, Morris and Warner, 2018). The term was coined by Oliver (1983), and it captured the idea that disabled people were not disadvantaged by physical impairments but by the barriers to well-being that result from social inequalities and the negative attitudes of other people. Over time, the idea of a social model has been incorporated and utilized within the field of learning disability (Barnes, 2012), mental health (Beresford 2002) and most recently incorporated into dementia care principles (Thomas and Milligan, 2015). Thomas and Milligan (2015) were looking at the needs of dementia patients. How the needs of dementia patients were met offers a clear signpost to meeting the needs of children living with an FASD. Thomas and Milligan state "they ask why social oppression of people with disabilities occurs in society, linking it to the social-relational character as the tool of oppression (p. 8). Cultures which seeks to deny and dismiss the neurodisability of FASDs is a culture that is offering a tool of oppression on children and families who are in need due to prenatal alcohol exposure impairments.

Social Consequences

As noted in both literature and vignettes, individuals living with the disability are viewed within a tragic lens of society. Their isolation and difficult life journey into the recognized secondary disabilities due to society's failure to engage early, ensures that the medical model hold over this cohort of vulnerable children and young people is potentially destructive to individuals, caregivers and society. As Helgesson (2018) states:

"A diagnosis can also be a burden that reduces the concerned individuals' confidence in the possibilities of shaping their own lives, for instance, by leading to resignation regarding their ability to reach personal goals. If the diagnosis leads to "stigmatization

beyond what is caused by how others perceive the disabilities, this can also restrict the individuals' space to manoeuvre, because of the practical social effects of stigmatization."

(p. 4)

Adopting a social model of disability which 'flips the script' away from a diagnostic mantra in addressing the significant prevalence rates of FASDs impacting Child Welfare Service, is potentially a game-changer and one that could mitigate the development of secondary disabilities, empower CWSWs and caregivers while easing the financial burden on society. Although Oliver's development of the Social Model of Disability in 1983 was primarily focused on physical disabilities, its maturity over the past 35 years has seen it expand to encompass neurodisabilities fully (Levitt, 2017). If services are to reach out to this cohort of vulnerable children and young people, then clearly a need exists to see the disability within a social lens, a view that can assist in the development of service to meet requirements.

Services and resources (including trained, responsive personnel) should be based on need, evidence and be constructed on a continuum to meet the changing nature of the FASD disability as it progresses through different stages of development. Oliver social model states, "we were not disabled by our impairments but by the disabling barriers we faced in society" (Oliver, 2013, p. 1024). This statement is considered a cornerstone of Oliver's Social Model of disability. As the study documents and the literature shows, individuals with or suspected of having a disability are profoundly isolated and discriminated against with society due to stigma and denial of the disability. Coupled with the isolation and seeking help from child welfare service and CWSWs, the data from CWSWs suggest that their advocacy for this vulnerable cohort is routinely dismissed within hierarchical structures and professional positioning by those with no understating of the disability.

This recommendation is almost identical to that which was recommended by Dr. Fitzpatrick in the HLS report, demonstrating a ramping up of pressure on the child welfare service to proactively engage in meeting the needs of children within the Child Welfare Service. Children residing in child welfare service are highlighted continuously as one of the most high-risk groups to carry FASDs, as shown repeatably and recently by (Popova et. al., 2019; Popova et. al., 2014) and to have their disability missed or misdiagnosed (Chasnoff, Wells et. al., 2015). It is interesting to note that the USA has seen a fairly significant ramping up concerning the child welfare service of reporting of all substances (including alcohol) to be grounds for child abuse proceedings. According to the Guttmacher Institute (2019), the following is the current state of child welfare service responsibilities in the US:

- Twenty-three states and the District of Columbia consider substance use during pregnancy to be child abuse under civil child-welfare statutes, and three find it grounds for civil commitment.
- Twenty-five states and the District of Columbia require health care professionals to report suspected prenatal drug use, and eight states require them to test for prenatal drug exposure if they suspect drug use.
- Nineteen states have either created or funded drug treatment programs specifically targeted to pregnant women, and 17 states and the District of Columbia provide pregnant women with priority access to state-funded drug treatment programs.
- Ten states prohibit publicly funded drug treatment programs from discriminating against pregnant women. (p.1)

A further 43 states, as of 2013, have specific policies for addressing Alcohol in Pregnancy. Concern abounds that such policy mandates may be counterproductive, as many have a punitive approach, thus causing women to fear seeking help for fear their child will be removed by child

protection services (Roberts, Thomas, Treffers and Drabble, 2017; Subbaraman and Roberts, 2019).

It is well documented that women report not feeling safe discuss their alcohol use for fear they will be seen negatively by child welfare service professionals. The ‘fear of judgement’ is a significant factor is women seeking help and support around their alcohol use in pregnancy. (Muggli, Cook, O’Leary, Forster, and Halliday, 2015, Poole, 2008). Coupled with this, as discussed earlier in Williams et. al. directive of 2015 to the American pediatrics, that all cases of FASDs are to be notified to child welfare service. This further demonstrates that both child welfare services and CWSWs are poorly considered in the current dialogue on FASDs as legislative directives and mandates increase. If CWSWs are not educated, it likely increases the probability that women will also not seek to engage with the service to promote the best interest of the child, thus losing out on both preventive and early intervention opportunities. This was recently demonstrated Rutman and Hubberstey (2019) who found the fear of having their children removed was a major barrier to women seeking assistance and support for the alcohol and addiction issues.

What is poorly articulated or not even discussed in the legislative ramping-up, is the role of CWSWs in responding to such legislative demands placed upon their statutory duty. Rarely do we see acknowledgement on the need for new skill sets to address the requirements of engaging child welfare concerns. Neither do we see the development of policy or protocols to guide CWSWs in the complex and emotive area of practice. Outside of (Badry and Choate, 2015; Pomeroy and Parrish, 2011; Wilson, 2013) the implications of initial assessment and screening in child welfare service for FASDs has received little attention. Coupled with this, is the lack of training and education concerning FASDs are likely significant contributors to the confusion and misunderstanding on what is FASD as found by Brown and Singh, 2017 when looking reviewing

professionals in criminal justice settings. And in the environment of the inquiry Gill and Sharif, (2017) found a worrying lack of knowledge and awareness within the crucial profession of pediatric doctors. Although the statutory duty to offer a Plan of Safe Care to a child with an FASD falls directly on the CWSWs, such a policy would require the collaborative actions from allied health colleagues.

As shown by Durkin (2016), CWSWs without education offered reduced self-efficacy levels due to a lack of knowledge and protocols to guide their interventions. Uneducated interventions may result in punitive actions that reinforce the belief in pregnant women that CWSWs will remove their child, thus preventing them from seeking support. Fear of the child protection system is discussed in several studies. In the most recent survey by Rutman and Hubberstey (2019) review services provided to pregnant women they found women " liked best about their program were: staff and their non-judgmental approach; peer support and sense of community; and having multiple services in one location, including help with mandated child protection" (p. 1).

Punitive approaches do not work and cannot be considered in the best interests of the child or motherhood. Such strategies will likely create fear and drive stigma against women who maybe want some support with their addiction. Research has shown that pregnancy is a pivotal time for women, who will genuinely look to address addictions issues (Gopman, 2014). Again, this supports a cross-governmental strategy where programmes and services can be designed and announced with sensitivity to maternal-child needs. It is unlikely that any culture can achieve total prevention of FASDs. Although the USA and Canada have been very active in the prevention and management of FASDs since the publication by Jones and Smith (1973), their respective cultures still experience FASD birth outcomes. It is, therefore, necessary for all cultures to address the service response and needs on the disability of FASDs through both effective prevention strategies

that do not stigmatize and psychosocial service responses to those impacted and meeting the needs of those in need.

Through listening to the needs and wants of participants and how the confusion in responding to the child with an FASD, following the 5 -Step Neurodevelopment practice model is likely a positive resource if offered within a policy framework to help guide a path of intervention. Ultimately, such a policy formation will significantly enhance the ability of the CWSW to carry out their statutory role, and one that will give greater clarity in establishing a plan of safe care. A study by Davidson et. al., (2012) in Northern Ireland looking at the interface of mental illness and child protection, found a pervasive desire for collaboration from the participants to their study:

Respondents offered many suggestions for improving interagency relationships, collaborative processes and outcomes for children and parents. These suggestions encompassed three major content areas: improving communication; enhancing the knowledge base of professionals in both sectors; and providing adequate resources and appropriate service models (p. 187)

Findings speak the same need of the CWSWs and allied health professionals within this inquiry. Collaboration and cooperation are the primary desire of CWSWs in their interventions on FASDs. The 5-step Neurodevelopment screening process outlined here requires collaborative working to be effective. Collaborative work will require policy, protocol and practice standards similar to those implemented in child welfare service for child protection (Child Neglect, Physical, Sexual and Emotional welfare and abuse) working together with standards as outlined within the site of the inquiry in the Children First Legislation, 2015, implemented in 2017.

A vital requirement of this legislation is the requirement to establish an interdepartmental working group to ensure working together to keep children safe, equally, under the Act. Sect 7 defines the Best interests of the child as a paramount consideration in the delivery of services to

children and young people. Upholding the Best Interest principle and supporting CWSWs in their statutory duties can be significantly enhanced by the establishment of policy and the incorporation of the 5-step screening protocol. Again, (Svetlana Popova et. al., 2019) States that given the overwhelming body of evidence concerning FASDs "As such, public policy and clinical care for people with FASD needs to change to respond to such predictable outcomes" (p. 18). Such outcomes that are extensively covered within this study and CWSWs want to respond. Perhaps the most significant outcome, as discussed in this study, is that of child premature deaths associated with an FASD. Such incidences of children with an FASD dying in public care will have significant implications for child welfare service moving forward, as the potential of litigation from birth families is developing. Removing a child from parental care to a place of safety that then fails in the provision of that safety provides for such litigation evidence. Again, here we can see the value of introducing policy as it protects both children, CWSWs and the agency in its provision of public services.

Facilitating CWSWs at Corporate Level

Understanding organizational expectations, professional roles, responsibilities were identified as of fundamental importance to participants within this inquiry. Clear organizational expectations in the form of management structures, procedural guidelines and specific professional roles and responsibilities for teams and individual practitioners are necessary when seeking to respond to the needs of the child with an FASD. However, participants equally offered that such understanding and clarity were absent in their Advocating against the Tide to carry out their statutory duty. This would appear to be a relatively global problem when addressing the impact of FASDs on child welfare services. A significant impediment at the management level of child welfare service is potentially driven by cost fears of formally

recognizing the disability. This is further exacerbated by the contradictory nature of how FASDs are now portrayed with social media.

If as Greenmyer et. al., (2018) states: the individual cost of caring for a child with an FASD far exceeds that of a child with a similar neurodisability, this may place fear in the management of child welfare service of opening addressing the disability. This was discussed by Chasnoff (2011) in his text *The Mystery of Risk*, notes the following from a former director of Child and Family Services " If we know what it costs to raise a child like this. Then we'll have to pay foster parents enough to take the children in. We can't afford it" (p. 222). This small excerpt maybe a major catalyst in understanding the system failure of child welfare service to adequately address the burden of FASDs known to be residing in the system, since the early 1970s. It was then that CWSWs took eight children from the Washington child welfare service to the Jones and Smith Clinic. (Jones et. al., 1973). While the child welfare service may fear the cost, it could be equally argued that CWSW role has been airbrushed out of the FASD dialogue since their pivotal role in Washington in 1972. If child welfare service at the macro level are fearful of costs and CWSWs continue to be isolated in their statutory role, it does not bode well for ensuring safe plans of care or ensuring that the best interest of the child living with prenatal alcohol exposure is upheld.

What is recommended here in the 5-Step-step protocol and recommended into a policy/ practice standard is directly addressing this fear of cost burden while also addressing the fear of stigmatizing children with an FASD label long before they need to have such a label applied. As a model, it is also helping to empower CWSWs in addressing the tide currently holding them back, by having clear steps and procedures to navigate when conducting their interventions with children who have an FASD.

The application of this model, in line with the recommendation, offered in the HLS coroner's report by Fitzpatrick, to up-skill both social work and psychology with knowledge of screening internally to child welfare service will dramatically reduce socioeconomic costs, while offering rich hands-on data to develop care plans and ensure the best interest of the child. It will also empower CWSWs, to uphold their statutory duty and make them less vulnerable in this complex area of practice.

Conclusion

Lemione, et al, (1968) first documented the scientific evidence outcome of an alcohol-exposed pregnancy. Clear evidence indicates that child welfare services are failing in acknowledging the significant burden of children suffering from prenatal alcohol exposure entering their service structures. Indeed, the evidence in literature, coroners' reports, and data of the study all indicate FASD is a major problem for child welfare services to address this burden. Addressing this 'problem' requires leadership within child welfare services, leadership that is FASD-informed and looking through a social lens in their response.

The study poses a number of serious questions for policy, practice and practitioners in child welfare system which can only be addressed by taking FASD seriously and working collaboratively across all agencies of state systems of care. A systems approach to address prevention, screening and assessment, provision of services all of which need to be driven from an evidence base. The data in this inquiry clearly indicates that CWSWs want to deliver safe care, but they are prevented by a number of forces that do not consider the statutory obligation the CWSW carries when seeking to establish safe care. The need of management level within child welfare service to engage is clearly evidenced as a corporate parent. It needs to ensure that it CWSWs can carry out their statutory duty and empower CWSWs in upholding the best interest of the child at all stages of assessment for PAE.

The data in this study suggests the CWSWs are in a position of high complexity in responding to and intervening in cases of FASDs. Children and young adults living with an FASD will have multiple complex needs requiring continuous care requiring services from a range of different professionals. In order to effectively address the statutory legal duty of a CWSW in cases of FASDs, there needs to be a fresh conceptual approach that empowers CWSWs within an all discipline, all agencies collaborative approach. It is only through leadership at the top of child welfare service that CWSW can be empowered to carry out their statutory role effectively in meeting the needs and ensuring the best interest of the child is upheld.

Ireland is at a very formative stage in addressing FASDs and, as such, is in a position to learn from the previous half a century of research, avoiding the failing factors associated with the prevention and management of FASDs. Adding to the already over-researched bank of fetal alcohol publications, will not offer anything substantive to the children and families living with the disability. It will, however, potential if not managed carefully, add to the stigmatizing of Irish motherhood and continue to deliver contradictory advice to prevention strategies. Sensitive strategies which seek to empower women to make safe choices through a non-judgemental dialogue that is spoken with appropriate cultural care. CWSWs and allied health personnel need to establish professional dialogue, rapport and empower women to make informed choices. A dialogue which needs to have the prevention of stigma against birth mothers and those living with the disability as core criteria in such strategies of education prevention.

As Badry and Choate (2015) noted “Given its complexity, FASD acts as a highly powerful issue to focus social work education around” (p.29), which signifies a highly challenging task facing social work educators. By investing in CWSWs, whether at undergraduate level or in employment settings, the prevention and management of FASDs can be

greatly enhanced within the culture under inquiry. As noted, the ringfencing of FASD funds to directly educate CWSWs and their allied health colleagues can have significant rewards and benefits for society. CWSWs are agents of social justice and can ensure the prevention of stigma in front line work of state agencies, while upholding the basic rights of the child living with an FASD.

References

- Abel, E. L. (1988). Fetal alcohol syndrome in families. *Neurotoxicology and Teratology*, 10(1), 1–2.
- Achenbach, T., & Edelbrock, C. (1980). *Child Behavior Checklist: CBCL*. T. Achenbach, University of Vermont.
- Albert, V. (2017). *From Child Abuse to Permanency Planning: Child Welfare Services Pathways and Placements*. Routledge.
- Alexander, M., Dang, E., Floyd, L. R., Sharpe, T. T., Weber, M. K., Szetela, C., ... Rudeen, K. P. (2007). Educating Health Professionals about Fetal Alcohol Spectrum Disorders. *American Journal of Health Education*, 38(6), 364–373.
<https://doi.org/10.1080/19325037.2007.10598996>
- American Psychiatric Association (2013) *Diagnostic and Statistical Manual (5th Edn)*. American Psychiatric Press, Washington, D.C.
- Anderson, T., Harding, K. D., Reid, D., & Peia, J. (2018). *FASD and Inappropriate Sexual Behavior*.
- Anderson, T., Mela, M., & Stewart, M. (2018). The Implementation of the 2012 Mental Health Strategy for Canada Through the Lens of FASD. *Canadian Journal of Community Mental Health*, 36(Special Issue), 69–81.
- Archer, T., Beninger, R. J., Palomo, T., & Kostrzewa, R. M. (2010). Epigenetics and biomarkers in the staging of neuropsychiatric disorders. *Neurotoxicity Research*, 18(3–4), 347–366.
- Aronson, J. E. (2000). Alcohol-related disorders and children adopted from abroad. *Adoption and Prenatal Alcohol and Drug Exposure*, 147–169.

- Assembly, U. G. (1989). Convention on the Rights of the Child. *United Nations, Treaty Series*, 1577(3).
- Association, (2013)Association, DSM. -5 A. P. (2013). Diagnostic and statistical manual of mental disorders. *Arlington: American Psychiatric Publishing*.
- Aspler, J., Zizzo, N., Bell, E., Di Pietro, N., & Racine, E. (2019). Stigmatization, Exaggeration, and Contradiction: An Analysis of Scientific and Clinical Content in Canadian Print Media Discourse About Fetal Alcohol Spectrum Disorder. *Canadian Journal of Bioethics*, 2(2), 23–35.
- Assembly, U. G. (1989). Convention on the Rights of the Child. *United Nations, Treaty Series*, 1577(3).
- Astley, S. J. (2004). *Diagnostic guide for fetal alcohol spectrum disorders: The 4-digit diagnostic code*. University of Washington.
- Astley SJ. (2010) Profile of the first 1400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network. *Can J Clin Pharmacol*. 2010;17: e132–64
- Astley, S. J., Stachowiak, J., Clarren, S. K., & Clausen, C. (2002). Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population. *The Journal of Pediatrics*, 141(5), 712–717.
- Astley, S. J. (2011). Diagnosing fetal alcohol spectrum disorders (FASD). *Prenatal Alcohol Use and Fetal Alcohol Spectrum Disorders: Diagnosis, Assessment and New Directions in Research and Multimodal Treatment*, 3, 29.

- Astley, S. J., & Clarren, S. K. (2000). Diagnosing the full spectrum of fetal alcohol-exposed individuals: Introducing the 4-digit diagnostic code. *Alcohol and Alcoholism*, 35(4), 400–410.
- Autti-Rämö, I. (2018). Have we done enough for people with fetal alcohol spectrum disorders? *Developmental Medicine & Child Neurology*.
- Badry, D. (2009). Fetal Alcohol Spectrum Disorder Standards: Supporting children in the care of children's services. *First Peoples Child & Family Review*, 4(1), 47–56.
- Badry, D., & Choate, P. (2015). Fetal Alcohol Spectrum Disorder: A disability in need of social work education, knowledge and practice. *Social Work and Social Sciences Review*, 17(3), 20–32.
- Badry, D., & Felske, A. W. (2011). Policy Development in FASD for Individuals and Families Across the Lifespan. *Fetal Alcohol Spectrum Disorder: Management Ofpolicy Perspectives and FASD, Edmonton, AB: Institute OfHealth Economics*.
- Bagley, K., & Badry, D. (2019). How Personal Perspectives Shape Health Professionals' Perceptions of Fetal Alcohol Spectrum Disorder and Risk. *International Journal of Environmental Research and Public Health*, 16(11), 1936.
- Bakhireva, L. N., Garrison, L., Shrestha, S., Sharkis, J., Miranda, R., & Rogers, K. (2017). Challenges of Diagnosing Fetal Alcohol Spectrum Disorders in Foster and Adopted Children. *Alcohol*.
- Barnes, C. (2012). The social model of disability: Valuable or irrelevant. *The Routledge Handbook of Disability Studies*, 12–29.
- Barry, S., Kearney, A., Lawlor, E., McNamee, E., & Barry, J. (2007). The Coombe Women's Hospital study of alcohol, smoking and illicit drug use, 1988-2005. *Dublin: Coombe Women's Hospital*.

- Baskin, J., Delja, J. R., Mogil, C., Gorospe, C. M., & Paley, B. (2016). *FETAL ALCOHOL SPECTRUM DISORDERS AND CHALLENGES FACED BY CAREGIVERS: CLINICIANS' PERSPECTIVES*. 23, 17.
- Bastons-Compta, A., Astals, M., & Garcia-Algar, O. (2016). Fetal alcohol spectrum disorder (FASD) diagnostic guidelines: A neuropsychological diagnostic criteria review proposal. *J Neuropsychopharmacol Ment Health*, 1(2), e104.
- Behnke, M., Smith, V. C., & Abuse, C. on S. (2013). Prenatal substance abuse: Short-and long-term effects on the exposed fetus. *Pediatrics*, 131(3), e1009–e1024.
- Bell, E., Andrew, G., Di Pietro, N., Chudley, A. E., N. Reynolds, J., & Racine, E. (2015). It's a shame! Stigma against fetal alcohol spectrum disorder: Examining the ethical implications for public health practices and policies. *Public Health Ethics*, 9(1), 65–77.
- Bell, E., Zizzo, N., & Racine, E. (2015). Caution! Warning labels about alcohol and pregnancy: Unintended consequences and questionable effectiveness. *The American Journal of Bioethics*, 15(3), 18–20.
- Beresford, P. (2002). Thinking about 'mental health': Towards a social model. *Journal of Mental Health*, 11(6), 581–584.
- Bertrand, J., & Consortium, I. for C. with F. A. S. D. R. (2009). Interventions for children with fetal alcohol spectrum disorders (FASDs): Overview of findings for five innovative research projects. *Research in Developmental Disabilities*, 30(5), 986–1006.
- Bertrand, J., Floyd, R. L., Weber, M. K., O'Connor, M., Riley, E. P., Johnson, K. A., & Cohen, D. E. (2004). National Task force on FAS/FAE. *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis*. Atlanta, GA: Centers for Disease Control and Prevention, 4.

- Bertrand, J., Floyd, R. L., & Weber, M. K. (2005). Guidelines for identifying and referring persons with fetal alcohol syndrome. *Morbidity and Mortality Weekly Report: Recommendations and Reports*, 54(11), 1–CE.
- Birks, M., & Mills, J. (2011). Essentials of grounded theory. *Grounded Theory: A Practical Guide*, 11–26.
- Birks, Melanie, & Mills, J. (2015). *Grounded theory: A practical guide*. Sage.
- Blackburn, C. (2017). *Developing Inclusive Practice for Young Children with Fetal Alcohol Spectrum Disorders: A Framework of Knowledge and Understanding for the Early Childhood Workforce*. Routledge.
- Blackstock, C. (2011). Wanted: Moral Courage in Canadian Child Welfare. *First Peoples Child & Family Review*, 6(2).
- Blair, G., & Meadows, S. (1996). *A Real-life Guide to Organizational Change*. Gower Publishing, Ltd.
- Bloomberg, L. D., & Volpe, M. (2012). *Completing your qualitative dissertation: A road map from beginning to end*. Sage Publications.
- Blumer, H. (1969). *Symbolic interactionism*. Berkley. University of California Press.
- Blumer, H. (1954). What is Wrong with Social Theory? *American Sociological Review*, 19(1), 3–10. JSTOR. <https://doi.org/10.2307/2088165>
- Braganza, M., Akesson, B., & Rothwell, D. (2017). An Empirical Appraisal of Canadian Doctoral Dissertations Using Grounded Theory: Implications for Social Work Research

- and Teaching. *Journal of Teaching in Social Work*, 37(5), 528–548.
<https://doi.org/10.1080/08841233.2017.1386259>
- Brown, J. D., Sigvaldason, N., & Bednar, L. M. (2005). Foster parent perceptions of placement needs for children with a fetal alcohol spectrum disorder. *Children and Youth Services Review*, 27(3), 309–327.
- Brown, J. D., & Rodger, S. (2009). Children with disabilities: Problems faced by foster parents. *Children and Youth Services Review*, 31(1), 40–46.
- Brown, J. M., Haun, J., Zapf, P. A., & Brown, N. N. (2017). Fetal Alcohol Spectrum Disorders (FASD) and competency to stand trial (CST): Suggestions for a ‘best practices’ approach to forensic evaluation. *International Journal of Law and Psychiatry*, 52, 19–27.
- Brown, J., Harr, D., Morgan, S., Varga, S., & Fenrich, A. (2017). Fetal Alcohol Spectrum Disorder (FASD): A call on mental health treatment professionals to become informed. *J Psychol*, 1(1), 1–3.
- Bryant, A., & Charmaz, K. (2007). *The Sage handbook of grounded theory*. Sage.
- Buckley, H., Carr, N., & Whelan, S. (2011). ‘Like walking on eggshells’: Service user views and expectations of the child protection system. *Child & Family Social Work*, 16(1), 101–110.
- Burd, L., & Popova, S. (2019). Fetal Alcohol Spectrum Disorders: Fixing Our Aim to Aim for the Fix. *International Journal of Environmental Research and Public Health*, 16(20), 3978. <https://doi.org/10.3390/ijerph16203978>
- Burd, L., & Wilson, H. (2004). Fetal, infant, and child mortality in a context of alcohol use. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, 127, 51–58.

- Burns, K., O'mahony, C., Shore, C., & Parkes, A. (2018). What social workers talk about when they talk about child care proceedings in the District Court in Ireland. *Child & Family Social Work, 23*(1), 113–121.
- Burns, L., Breen, C., Bower, C., O'Leary, C., & Elliott, E. J. (2013). Counting Fetal Alcohol Spectrum Disorder in Australia: The evidence and the challenges. *Drug and Alcohol Review, 32*(5), 461–467.
- Butler, S. (2009). Obstacles to the implementation of an integrated National Alcohol Policy in Ireland: Nannies, neo-liberals and joined-up government. *Journal of Social Policy, 38*(2), 343–359.
- Butler, S. (2015). Ireland's Public Health (Alcohol) Bill: Policy Window or Political Sop? *Contemporary Drug Problems, 42*(2), 106–117.
- Caley, L., Syms, C., Robinson, L., Cederbaum, J., Henry, M., & Shipkey, N. (2008). What human service professionals know and want to know about fetal alcohol syndrome. *Canadian Journal of Clinical Pharmacology, 15*(1), e117–e123.
- CAPTA, (2010) US Department of Health and Human Services, Administration for Children and Families. The Child Abuse Prevention and Treatment Act, as amended by Public Law No. 111-320, the CAPTA. Reauthorization Act of 2010. Retrieved From: <https://www.acf.hhs.gov/cb/resource/pi1003>
- Carpenter, B., Blackburn, C., & Egerton, J. (2014). A brief introduction to fetal alcohol spectrum disorders. *Fetal Alcohol Spectrum Disorders: Interdisciplinary Perspectives, 3*–13.

- Carpenter, B., Schloesser, J., & Egerton, J. (2009). European developments in early childhood intervention. Available on the [Http://Www. Eurlyaid. Net/DOWNLOAD%20OBJECTS/Gesamt_ECI. Pdf Website](http://www.Eurlyaid.Net/DOWNLOAD%20OBJECTS/Gesamt_ECI.Pdf), (Retrieved 20.7. 2010).
- Carter, M. J., & Fuller, C. (2015). Symbolic interactionism. *Sociopedia. Isa, 1*, 1–17.
- Catterick, M., & Curran, L. (2014). *Understanding Fetal Alcohol Spectrum Disorder: A Guide to FASD for Parents, Carers and Professionals*. Jessica Kingsley Publishers.
- Center for Disease Control and Prevention (CDC) (2015). FASD Regional Training Centers Curriculum Development Team. Fetal alcohol spectrum disorders competency-based curriculum development guide for medical and allied health education and practice. Atlanta, GA:
- Chamberlain, K., Reid, N., Warner, J., Shelton, D., & Dawe, S. (2017). A qualitative evaluation of caregivers' experiences, understanding and outcomes following diagnosis of FASD. *Research in Developmental Disabilities, 63*, 99–106.
- Chang, G., Wilkins-Haug, L., Berman, S., Goetz, M. A., Behr, H., & Hiley, A. (1998). Alcohol use and pregnancy: Improving identification. *Obstetrics & Gynecology, 91*(6), 892–898.
- Charach, A., Bélanger, S. A., McLennan, J. D., & Nixon, M. K. (2017). Screening for disruptive behavior problems in preschool children in primary health care settings. *Paediatrics & Child Health, 22*(8), 478–484. <https://doi.org/10.1093/pch/pxx128>
- Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. SAGE.
- Charmaz, K. (2008). Views from the Margins: Voices, Silences, and Suffering. *Qualitative Research in Psychology, 5*(1), 7–18. <https://doi.org/10.1080/14780880701863518>
- Charmaz, K. (2014). *Constructing Grounded Theory*. SAGE.

- Charmaz, K. (2017). The power of constructivist grounded theory for critical inquiry. *Qualitative Inquiry*, 23(1), 34–45.
- Charmaz, K., & Belgrave, L. L. (2012). Qualitative Interviewing and Grounded Theory Analysis. In *The SAGE Handbook of Interview Research: The Complexity of the Craft* (2nd ed., pp. 347–366). <https://doi.org/10.4135/9781452218403>
- Chasnoff, I. J. (2011). *The mystery of risk: Drugs, alcohol, pregnancy, and the vulnerable child*. NTI Upstream Chicago, Ill, USA.
- Chasnoff, I. J., Telford, E., Wells, A. M., & King, L. (2015). Mental health disorders among children within child welfare who have prenatal substance exposure: Rural vs. urban populations. *Child Welfare*, 94(4), 53.
- Chasnoff, I. J., Wells, A. M., & King, L. (2015). Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics*, 135(2), 264–270.
- Chevalier, A., Finn, C., Harmon, C., & Heckman, J. (2006). The microeconomics of early child investment. *Journal of Children's Services*, 1(2), 18–30.
- Choate, P., & Badry, D. (2018). Stigma as a dominant discourse in fetal alcohol spectrum disorder. *Advances in Dual Diagnosis*.
- Chokroborty-Hoque, A., Alberry, B., & Singh, S. M. (2014). Exploring the complexity of intellectual disability in fetal alcohol spectrum disorders. *Frontiers in Pediatrics*, 2, 90.
- Christie, A. (2005). Social work education in Ireland: Histories and challenges. *Portularia*, 1, 111–128.
- Chudley, A. E. (2017). Diagnosis of fetal alcohol spectrum disorder: Current practices and future considerations. *Biochemistry and Cell Biology*, 1–6. <https://doi.org/10.1139/bcb-2017-0106>

- Chudley, A. E., Conry, J., Cook, J. L., Loock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal*, *172*(5 suppl), S1–S21.
- Clarke, A. E., Friese, C., & Washburn, R. S. (2017). *Situational analysis: Grounded theory after the interpretive turn*. Sage Publications.
- Clarke, A. E. (2005). *Situational analysis: Grounded theory after the postmodern turn*. Sage. Thousand Oaks, CA.
- Coggins, T. E. (2011). Toward understanding and treating children with prenatal alcohol exposure and Fetal Alcohol Syndrome Disorders. *Perspectives on Language Learning and Education*, *18*(3), 78–86.
- Coles, C. D. (2003). Individuals affected by fetal alcohol spectrum disorder (FASD) and their families: Prevention, intervention and support. Tremblay RE, Barr RG, Peters RdeV, Eds. *Encyclopedia on Early Childhood Development*, 1–6.
- Collins, R. L., & McNair, L. D. (2002). Minority women and alcohol use. *Alcohol Research and Health*, *26*(4), 251–256.
- Cologon, K., & Thomas, C. (2014). *Ableism, disablism and the early years*.
- Conry, J., Fast, D. K., & Loock, C. A. (1997). *Youth in the criminal justice system: Identifying FAS and other alcohol-related neurodevelopmental disabilities*. Province of British Columbia, Ministry of the Attorney General.
- Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S. M., Baldwin, M. E., Chudley, A. E., ... Lutke, J. (2016). Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. *Canadian Medical Association Journal*, *188*(3), 191–197.

- Coons-Harding, K. D., Flannigan, K., Burns, C., Rajani, H., & Symes, B. (2019). Assessing for Fetal Alcohol Spectrum Disorder. *Journal of Population Therapeutics and Clinical Pharmacology*, 26(1), e39–e55.
- Corbin, J. M., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology*, 13(1), 3–21.
- Coveney, F. B. (2018). Does Ireland Measure Up?: Prenatal Alcohol Exposure and the Application of Protection Rights under the United Nations Convention on the Rights of the Child. *The International Journal of Children's Rights*, 26(4), 626–663.
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five tradition*. Thousand Oaks, CA: Sage.
- Creswell, J. W. (2007). *Qualitative Inquiry And Research Design: Choosing Among Five Approaches (2nd ed)*. London: Sage.
- Creswell JW. 2013. *Qualitative inquiry and research design: Choosing among five approaches*. (3rd ed.). Thousand Oaks, CA: Sage.
- Cromarty, H., (2018) 'safe with intervention'. The Report of the expert panel on the deaths of children and youth in residential placements. Toronto, ON, Canada. Retrieved From: <http://www.mcscs.jus.gov.on.ca/english/Deathinvestigations/OfficeChiefCoroner/Publicationsandreports/SafeIntervention.html>
- Cunningham, J., & Cunningham, S. (2014). *Sociology and social work*. Learning Matters.
- Curran, L. (2007). *Illicit drug and alcohol use during pregnancy as a child protection issue: Multi-disciplinary views: a thesis submitted in partial fulfillment of the M. Sc. in Child Protection and Welfare* (PhD Thesis).

- Currie, B. A., Hoy, J., Legge, L., Temple, V. K., & Tahir, M. (2016). *ADULTS WITH FETAL ALCOHOL SPECTRUM DISORDER: FACTORS ASSOCIATED WITH POSITIVE OUTCOMES AND CONTACT WITH THE CRIMINAL JUSTICE SYSTEM*. 23, 16.
- Dally, A. (1982). *Inventing motherhood: The consequences of an ideal*. New York, NY: Shocken Books.
- Daly, S. F., Kiely, J., Corke, T. A., & Matthews, T. G. (1992). Alcohol and cigarette use in a pregnant Irish population. *Irish Medical Journal*, 85(4), 157.
- Darlington, Y., & Feeney, J. A. (2008). Collaboration between mental health and child protection services: Professionals' perceptions of best practice. *Children and Youth Services Review*, 30(2), 187–198. <https://doi.org/10.1016/j.childyouth.2007.09.005>
- Davidow, J. Y., Foerde, K., Galván, A., & Shohamy, D. (2016). An upside to reward sensitivity: The hippocampus supports enhanced reinforcement learning in adolescence. *Neuron*, 92(1), 93–99.
- Davidson, G., Duffy, J., Barry, L., Curry, P., Darragh, E., & Lees, J. (2012). Championing the interface between mental health and child protection: Evaluation of a service initiative to improve joint working in northern Ireland. *Child Abuse Review*, 21(3), 157–172. <https://doi.org/10.1002/car.1164>
- Day, N. L., Helsel, A., Sonon, K., & Goldschmidt, L. (2013). The Association Between Prenatal Alcohol Exposure and Behavior at 22 Years of Age. *Alcoholism: Clinical and Experimental Research*, 37(7), 1171–1178.
- Deegan G, Byrne L (2019) Tusla Protects 350 children deemed to be at risk of harm before their birth. Health supplement. Irish Times Newspaper. Retrieved from: <https://www.independent.ie/irish-news/tusla-protects-350-children-deemed-to-be-at-risk-of-harm-before-their-birth-37750986.html>

Dej, E. (2011). WHAT ONCE WAS SICK IS NOW BAD: THE SHIFT FROM VICTIM TO DEVIANT IDENTITY. *Canadian Journal of Sociology/Cahiers Canadiens de Sociologie*, 36(2), 137.

Dempsey, L., Dowling, M., Larkin, P., & Murphy, K. (2016). Sensitive interviewing in qualitative research. *Research in Nursing & Health*, 39(6), 480–490.

Denny, C. H., Acero, C. S., Naimi, T. S., & Kim, S. Y. (2019). Consumption of Alcohol Beverages and Binge Drinking Among Pregnant Women Aged 18–44 Years—United States, 2015–2017. *Morbidity and Mortality Weekly Report*, 68(16), 365.

Department of Health, (2007). Minister Gallagher renews advice to women not to drink alcohol in pregnancy, Dublin, Ireland. retrieved from: <http://health.gov.ie/blog/press-release/minister-gallagher-renews-advice-to-women-not-to-drink-alcohol-in-pregnancy/>

Department of Health. (2018). Public Health (Alcohol) Act 2018.

Dublin: Department of Health. Retrieved from:

<http://www.irishstatutebook.ie/eli/2018/act/24/enacted/en/pdf>

Devaney, C., & Gregor, C. M. (2017). Child protection and family support practice in Ireland: A contribution to present debates from a historical perspective. *Child & Family Social Work*, 22(3), 1255–1263.

Diamond, A. (2013). Executive Functions. *Annual Review of Psychology*, 64, 135–168.

Dick, B. (2014). Grounded theory: A thumbnail sketch, retrieved on 9 December 2016;

<http://www.aral.com.au/resources/grounded.html> -

Directive, E. U. (1995). 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data. *Official Journal of the EC*, 23(6).

Doak, J., Katsikitis, M., Webster, H., & Wood, A. (2019). A fetal alcohol spectrum disorder diagnostic service and beyond: Outcomes for families. *Research in Developmental Disabilities*, 93, 103428.

Dobson, C. C., Holman, P. J., Comeau, W., Bodnar, T., Lam, V., Brien, J. F., ... Weinberg, J. (2016). The Effects of Alcohol Exposure on Fetal Development. In *Fetal Development* (pp. 331–364). Springer.

Domeij, H., Hulcrantz, M., Nehlin Gordh, C., Fahlström, G., Rangmar, J., Helgesson, G., ... Heintz, E. (2018). Ethical aspects of diagnosis and interventions for children with Fetal Alcohol Spectrum Disorder (FASD) and their families. *BMC Medical Ethics*, 19(1), 1–7.

Don-Solomon, A., & Eke, G. J. (2018). ONTOLOGICAL & EPISTEMOLOGICAL PHILOSOPHIES UNDERLYING THEORY BUILDING: A SCHOLARLY DILEMMA OR AXIOMATIC ILLUMINATION-THE BUSINESS RESEARCH PERSPECTIVE. *European Journal of Business and Innovation Research*, 6(2), 1–7.

Dorris, M. (1989). *The broken cord*. New York: Harper & Row.

Doyle, L. R., Moore, E. M., Coles, C. D., Kable, J. A., Sowell, E. R., Wozniak, J. R., ... Cifas, T. (undefined/ed). Executive Functioning Correlates With Communication Ability in Youth With Histories of Heavy Prenatal Alcohol Exposure. *Journal of the International Neuropsychological Society*, 1–12. <https://doi.org/10.1017/S1355617718000772>

- Drabble, L. A., Poole, N., Magri, R., Tumwesigye, N. M., Li, Q., & Plant, M. (2011).
Conceiving risk, divergent responses: Perspectives on the construction of risk of FASD in
six countries. *Substance Use & Misuse, 46*(8), 943–958.
- Dubowitz, H., Kim, J., Black, M. M., Weisbart, C., Semiatin, J., & Magder, L. S. (2011).
Identifying children at high risk for a child maltreatment report. *Child Abuse & Neglect, 35*(2), 96–104.
- Dubovsky, D. (2009). Co-morbidities with mental health for an individual with FASD. *Fetal
Alcohol Spectrum Disorder (FASD): Across the Lifespan: Proceedings from an IHE
Consensus Development Conference, 67–71.*
- Durkin, K. M. (2016). *The role of self-efficacy on child welfare workers' fetal alcohol spectrum
disorder (FASD) training and practice.* The University of Alabama.
- Edwards, W. J., & Greenspan, S. (2010). Adaptive behavior alcohol spectrum and fetal
disorders. *The Journal of Psychiatry & Law, 38*(4), 419–447.
- Fast, D. K., Conry, J., & Looock, C. A. (1999). Identifying fetal alcohol syndrome among youth
in the criminal justice system. *Journal of Developmental and Behavioral Pediatrics, 20*(5), 370–372.
- Featherstone, B., Gupta, A., Morris, K., & Warner, J. (2018, March). Let's stop feeding the risk
monster: Towards a social model of “child protection” [Text].
<https://doi.org/info:doi/10.1332/204674316X14552878034622>
- Field, M. S., & Stover, P. J. (2018). Safety of folic acid. *Annals of the New York Academy of
Sciences, 1414*(1), 59–71. <https://doi.org/10.1111/nyas.13499>

- Flannigan, K., Pei, J., Stewart, M., & Johnson, A. (2018). Fetal Alcohol Spectrum Disorder and the criminal justice system: A systematic literature review. *International Journal of Law and Psychiatry*, 57, 42–52. <https://doi.org/10.1016/j.ijlp.2017.12.008>
- Fleisher, S. (2010). Fetal alcohol syndrome: Raising awareness about alcohol in pregnancy. *British Journal of Midwifery*, 18(5), 316–317.
- Fogliani, R.V.C (2019). *Record of Investigation into the Death*. (Report No.25/2017). Retrieved from https://www.coronerscourt.wa.gov.au/_files/inquest-2019/13-Children-and-Young-Persons-in-the-Kimberley-Region-Finding.
- Fraser, M. W., Lombardi, B. M., Wu, S., de Saxe Zerden, L., Richman, E. L., & Fraher, E. P. (2018). Integrated primary care and social work: A systematic review. *Journal of the Society for Social Work and Research*, 9(2), 175–215.
- Forder, A. (1976). Social work and system theory. *The British Journal of Social Work*, 6(1), 23–42.
- Fuchs, D., Burnside, L., Marchenski, S., & Mudry, A. (2007). Children with FASD involved with the Manitoba child welfare system. Retrieved January, 11, 2007.
- Fuchs, Don, Burnside, L., Marchenski, S., & Mudry, A. (2010). Children with FASD-related disabilities receiving services from child welfare agencies in Manitoba. *International Journal of Mental Health and Addiction*, 8(2), 232–244.
- Furey, E, and Canavan, J. (2019) A review on the availability and comparability of statistics on child protection and welfare, including children in care, collated by Tusla: Child and Family Agency with statistics published in other jurisdictions. Retrieved from: https://www.tusla.ie/uploads/content/COMPWELFINALREPORTMARCH29_-_Final.pdf

- Gannon-Leary, P. (2006). Glut of information, dearth of knowledge? A consideration of the information needs of practitioners identified during the FAME project. *Library Review*, 55(2), 120–131.
- Gentles, S. J., & Vilches, S. L. (2017). Calling for a Shared Understanding of Sampling Terminology in Qualitative Research: Proposed Clarifications Derived From Critical Analysis of a Methods Overview by McCrae and Pursell. *International Journal of Qualitative Methods*, 16(1), 1609406917725678.
<https://doi.org/10.1177/1609406917725678>
- George Mason University (2015). Phase 1 report on Fetal Alcohol Spectrum Disorders. prepared for The Arc. Department of Social Work
- Gibbs, A. (2018). An evidence-based training and support course for caregivers of children with fetal alcohol spectrum disorder (FASD) in New Zealand. *Advances in Dual Diagnosis*.
- Gibbs, A., Bagley, K., Badry, D., & Gollner, V. (2018). Fetal alcohol spectrum disorder: Effective helping responses from social workers. *International Social Work*, 0020872818804032.
- Gibson, K., Samuels, G., & Pryce, J. (2018). Authors of accountability: Paperwork and social work in contemporary child welfare practice. *Children and Youth Services Review*, 85, 43–52.
<https://doi.org/10.1016/j.chilyouth.2017.12.010>
- Gilgun, J. F. (1994c). Hand into glove: Grounded theory and social work practice research. In E. Sherman and W.J. Reid (Eds.), *Qualitative research in social work*. pp. 115-125. New York: Columbia University Press.
- Gilgun, J. F. (2015). Beyond description to interpretation and theory in qualitative social work research. *Qualitative Social Work*, 14(6), 741–752.

- Gilgun, J., & Sands, R. G. (2010). Call for papers: Special issue on the contributions of qualitative methods to social work intervention research. *Qualitative Social Work*, 9(4), 569–571.
- Gilgun, J. F., & Sands, R. G. (2012). *The contribution of qualitative approaches to developmental intervention research*. Sage Publications Sage UK: London, England.
- Gill, I., & Sharif, F. (2017). Out of sight, out of mind? A national survey of paediatricians in Ireland regarding fetal alcohol spectrum disorders. *Department of Paediatrics Articles*. Retrieved from <https://epubs.rcsi.ie/paedart/8>
- Giustini, D., Ali, S. M., Fraser, M., & Boulos, M. N. K. (2018). Effective uses of social media in public health and medicine: A systematic review of systematic reviews. *Online Journal of Public Health Informatics*, 10(2).
- Glazer, B., & Strauss, A. (1967a). The discovery of grounded theory Chicago. *Adeline, USA*.
- Glazer, B., & Strauss, A. (1967b). The discovery of grounded theory. *London: Weidenfeld and Nicholson*, 24(25), 288–304.
- Glazer, B. G. (1992). *Emergence vs forcing: Basics of grounded theory analysis*. Sociology Press.
- Gopman, S. (2014). Prenatal and Postpartum Care of Women with Substance Use Disorders. *Obstetrics and Gynecology Clinics of North America*, 41(2), 213–228.
<https://doi.org/10.1016/j.ogc.2014.02.004>
- Gough, P., & Fuchs, D. (2008). *Children with FASD-related Disabilities Receiving Services from Child Welfare Agencies in Manitoba*. Centre of Excellence for Child Welfare web 2006.
- Government of Ireland. (2015). *Children first act*. Dublin: The Stationary Office.

- Government of Ireland (1998) The Education Act 1998. Dublin: The Stationery Office.
- Government of Ireland (2018) Public Health Alcohol Act. 2018. Dublin: The Stationary office
- Green, C. r., Mihic, A. m., Nikkel, S. m., Stade, B. c., Rasmussen, C., Munoz, D. p., & Reynolds, J. n. (2009). Executive function deficits in children with fetal alcohol spectrum disorders (FASD) measured using the Cambridge Neuropsychological Tests Automated Battery (CANTAB). *Journal of Child Psychology and Psychiatry*, 50(6), 688–697.
<https://doi.org/10.1111/j.1469-7610.2008.01990.x>
- Greenspan, S., & Woods, G. (2018). Social incompetence of FASD offenders: Risk-awareness as a factor in criminal culpability. In *Ethical and Legal Perspectives in Fetal Alcohol Spectrum Disorders (FASD)* (pp. 127–143). Springer.
- Greenspan, S., Brown, N. N., & Edwards, W. (2016). FASD and the concept of “intellectual disability equivalence.” In *Fetal Alcohol Spectrum Disorders in Adults: Ethical and Legal Perspectives* (pp. 241–266). Springer.
- Gregory, G., Reddy, V., & Young, C. (2015). Identifying children who are at risk of FASD in Peterborough: Working in a community clinic without access to gold standard diagnosis. *Adoption & Fostering*, 39(3), 225–234.
- Group, F. W. (2016). Taking Action on Fetal Alcohol Spectrum Disorder: 2016–2019: An action plan. *Wellington, New Zealand: Ministry of Health*.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. *Handbook of Qualitative Research*, 2(163–194), 105.
- Guttmacher Institute (2019). State policies in brief as of May 1, 2019: Substance Use During Pregnancy. Retrieved from: <https://www.guttmacher.org>
- Hammond, D. (2011). Health warning messages on tobacco products: A review. *Tobacco Control*, 20(5), 327–337. <https://doi.org/10.1136/tc.2010.037630>

- Hammond, D. C. (2012). Lens neurofeedback treatment with fetal alcohol spectrum disorder and neglect. *Journal of Neurotherapy*, 16(1), 47–52.
- Harvey, B. (2014). The Case for prevention and early intervention. *Promoting Positive Outcomes for Children, Families and Communities*. Dublin: Prevention and Early Intervention Network.
- Hedwig, T. H. (2013). *The Cultural Politics of Fetal Alcohol Spectrum Disorders and the Diagnosis of Difference*.
- Health Canada (2013) Canadian perinatal health record. Retrieved From:
<http://publications.gc.ca/site/eng/411563/publication.html>
- Health and Social Care Professions Council (CORU). (2011). *Code of professional conduct and ethics for social workers*. Retrieved
from <http://www.coru.ie/uploads/typeset%20SW%20code%20Feb%202010.pdf>
- Hellemans, K. G., Sliwowska, J. H., Verma, P., & Weinberg, J. (2010). Prenatal alcohol exposure: Fetal programming and later life vulnerability to stress, depression and anxiety disorders. *Neuroscience & Biobehavioral Reviews*, 34(6), 791–807.
- Hemingway, S. J. A., Bledsoe, J. M., Davies, J. K., Brooks, A., Jirikowic, T., & Olson, E. M. (2018). Twin study confirms virtually identical prenatal alcohol exposures can lead to markedly different fetal alcohol spectrum disorder outcomes-fetal genetics influences fetal vulnerability. *Adv Pediatr Res*, 5, 23.
- Hibbard, R. A., Desch, L. W., Abuse, C. on C., & Neglect. (2007). Maltreatment of children with disabilities. *Pediatrics*, 119(5), 1018–1025.
- Hill, K. (2012). Permanency and placement planning for older youth with disabilities in out-of-home placement. *Children and Youth Services Review*, 34(8), 1418–1424.

- Holland, K., McCallum, K., & Blood, R. W. (2015). Conversations about alcohol and pregnancy. *Canberra: Foundation for Alcohol Research and Education.*
- Holleran Steiker, L. K. (2009). A Dialogue on Fetal Alcohol Spectrum Disorder (FASD) and the Prenatal Impact of Substances on Children: An Interview With Elizabeth C. Pomeroy. *Journal of Social Work Practice in the Addictions, 9(4)*, 417–422.
- Hoyme, H. E., Kalberg, W. O., Elliott, A. J., Blankenship, J., Buckley, D., Marais, A.-S., ... Abdul-Rahman, O. (2016). Updated clinical guidelines for diagnosing fetal alcohol spectrum disorders. *Pediatrics, 138(2)*, e20154256.
- Hoyme, H. E., Kalberg, W. O., & May, P. A. (2019). *Re: Non-specific FASD diagnostic criteria lead to over-diagnosis.*
- Huitson, N. R. (2014). *Decoding the FASD Enigma: Application of a New Multidisciplinary Policy Paradigm* [PhD Thesis]. Arts and Social Sciences: School of Criminology.
- HSE and Tusla (2019). Hidden Harm strategic statement: seeing through hidden harm to brighter futures. Dublin: HSE and Tusla. Retrieved from :
<https://www.drugsandalcohol.ie/30190/2/StrategicGuide.pdf>
- Irish Association of Social Workers (2006) *The code of ethics*, Retrieved from:
<https://www.iasw.ie/attachments/8b37e75a-26f6-4d94-9313-f61a86785414.PDF>,
- Jacobson, S. W., Jacobson, J. L., Sokol, R. J., Chiodo, L. M., & Corobana, R. (2004). Maternal age, alcohol abuse history, and quality of parenting as moderators of the effects of prenatal alcohol exposure on 7.5-year intellectual function. *Alcoholism: Clinical and Experimental Research, 28(11)*, 1732–1745.

- Jacobson, S. W., Stanton, M. E., Molteno, C. D., Burden, M. J., Fuller, D. S., Hoyme, H. E., ...
Jacobson, J. L. (2008). Impaired eyeblink conditioning in children with fetal alcohol syndrome. *Alcoholism: Clinical and Experimental Research*, 32(2), 365–372.
- Jampolsky, F. (2018). Introduction; FASD and the Revolving Door of Criminal Justice. In *Ethical and Legal Perspectives in Fetal Alcohol Spectrum Disorders (FASD)* (pp. 187–200). Springer.
- Jirikowic, T., Kartin, D., & Olson, H. C. (2008). Children with fetal alcohol spectrum disorders: A descriptive profile of adaptive function. *Canadian Journal of Occupational Therapy*, 75(4), 238–248.
- Jones, K., & Smith, D. (1973). Recognition of the fetal alcohol syndrome in early infancy. *The Lancet*, 302(7836), 999–1001.
- Jonsson, E. (2019). *Fetal Alcohol Spectrum Disorders (FASD): A Policy Perspective*. SAGE Publications Sage CA: Los Angeles, CA.
- Jonsson, E., Salmon, A., & Warren, K. R. (2014). The international charter on prevention of fetal alcohol spectrum disorder. *The Lancet Global Health*, 2(3), e135–e137.
[https://doi.org/10.1016/S2214-109X\(13\)70173-6](https://doi.org/10.1016/S2214-109X(13)70173-6)
- Kable, J. A., & Mukherjee, R. A. (2017). Neurodevelopmental disorder associated with prenatal exposure to alcohol (ND-PAE): A proposed diagnostic method of capturing the neurocognitive phenotype of FASD. *European Journal of Medical Genetics*, 60(1), 49–54.
- Kambeitz, C., Klug, M. G., Greenmyer, J., Popova, S., & Burd, L. (2019). Association of adverse childhood experiences and neurodevelopmental disorders in people with fetal alcohol spectrum disorders (FASD) and non-FASD controls. *BMC Pediatrics*, 19(1), 1–9.

- Kegler, M. C., Raskind, I. G., Comeau, D. L., Griffith, D. M., Cooper, H. L. F., & Shelton, R. C. (n.d.). Study Design and Use of Inquiry Frameworks in Qualitative Research Published in Health Education & Behavior. *Health Education*, 8.
- Kendall-Taylor, N., & Fond, M. (2017). Reframing Fetal Alcohol Spectrum Disorder: Studying Culture to Identify Communication Challenges and Opportunities. *Studies in Media and Communication*, 5(2), 105–117. <https://doi.org/10.11114/smc.v5i2.2687>
- Kennedy, S. (2018). Irish women and the Celtic Tiger economy. In *The end of Irish history?* Manchester University Press.
- Kenny, M., & Fourie, R. (2015). Contrasting classic, Straussian, and constructivist Grounded Theory: Methodological and philosophical conflicts. *The Qualitative Report*, 20(8), 1270.
- Kilkelly, U. (2008). Children's Rights and the Family: Myth and Reality. *Studies: An Irish Quarterly Review*, 97(385), 7–18. Retrieved from JSTOR.
- King, C. A., Horwitz, A., Czyz, E., & Lindsay, R. (2017). Suicide risk screening in healthcare settings: Identifying males and females at risk. *Journal of Clinical Psychology in Medical Settings*, 24(1), 8–20.
- Kislov, R., Waterman, H., Harvey, G., & Boaden, R. (2014). Rethinking capacity building for knowledge mobilization: Developing multilevel capabilities in healthcare organisations. *Implementation Science*, 9(1), 166.
- Knuiman, S., Rijk, C. H., Hoksbergen, R. A., & Baar, A. L. (2015). Children adopted from Poland display a high risk of fetal alcohol spectrum disorders and some may go undiagnosed. *Acta Paediatrica*, 104(2), 206–211.
- Kreitinger, C., Gutierrez, H., Hamidovic, A., Schmitt, C., Sarangarm, P., Rayburn, W. F., ... Bakhireva, L. N. (2016). The Effect of Prenatal Alcohol Co-Exposure on Neonatal

- Abstinence Syndrome in Infants Born to Mothers in Opioid Maintenance Treatment. *The Journal of Maternal-Fetal & Neonatal Medicine : The Official Journal of the European Association of Perinatal Medicine, the Federation of Asia and Oceania Perinatal Societies, the International Society of Perinatal Obstetricians*, 29(5), 783–788.
<https://doi.org/10.3109/14767058.2015.1018168>
- Landgraf, M. N., Albers, L., Rahmsdorf, B., Vill, K., Gerstl, L., Lippert, M., & Heinen, F. (n.d.). Fetal alcohol spectrum disorders (FASD) – what we know and what we should know— The knowledge of German health professionals and parents. *European Journal of Paediatric Neurology*. <https://doi.org/10.1016/j.ejpn.2018.02.010>
- Lang, S. E. (2015). *Report of the Motherisk Hair Analysis Independent Review*. Ministry of the Attorney General. Retrieved From: <https://www.attorneygeneral.jus.gov.on.ca/english/about/pubs/lang/>
- Lange, S., Probst, C., Gmel, G., Rehm, J., Burd, L., & Popova, S. (2017). Global prevalence of fetal alcohol spectrum disorder among children and youth: A systematic review and meta-analysis. *JAMA Pediatrics*, 171(10), 948–956.
- Lange, S., Rehm, J., & Popova, S. (2018). Implications of Higher Than Expected Prevalence of Fetal Alcohol Spectrum Disorders. *JAMA*, 319(5), 448.
<https://doi.org/10.1001/jama.2017.21895>
- Lange, S., Shield, K., Rehm, J., & Popova, S. (2013). Prevalence of fetal alcohol spectrum disorders in child care settings: A meta-analysis. *Pediatrics*, 132(4), e980–e995.
- LaRossa, R. (2005). Grounded Theory Methods and Qualitative Family Research. *Journal of Marriage and Family*, 67(4), 837–857.
- Lee, E., Macvarish, J., & Bristow, J. (2010). *Risk, health and parenting culture*. Taylor & Francis.

- Lemione, P., Harasseau, H., Borteryu, J. P., & Menuet, J. C. (1968). Les enfants de parents alcooliques: Anomalies observées à propos de 127 cas [The children of alcoholic parents: anomalies observed in 127 cases]. *Quest Medicale*, 21.
- Lennon, J. C., & Czochara, B. (2019). Questioning Fetal Alcohol Syndrome: A Case Report of Multiple Etiological Factors. *Journal of Pediatric Neuropsychology*.
<https://doi.org/10.1007/s40817-019-00065-3>
- Leslie, L. K., Gordon, J. N., Meneken, L. E. E., Premji, K., Michelmore, K. L., & Ganger, W. (2005). The physical, developmental, and mental health needs of young children in child welfare by initial placement type. *Journal of Developmental and Behavioral Pediatrics: JDBP*, 26(3), 177.
- Levitt, J. M. (2017). Exploring how the social model of disability can be re-invigorated: In response to Mike Oliver. *Disability & Society*, 32(4)
- Lim, A. W. Y., Van Schalkwyk, M. C. I., Hessari, N. M., & Petticrew, M. P. (2019). Pregnancy, Fertility, Breastfeeding, and Alcohol Consumption: An Analysis of Framing and Completeness of Information Disseminated by Alcohol Industry–Funded Organizations. *Journal of Studies on Alcohol and Drugs*, 80(5), 524–533.
<https://doi.org/10.15288/jsad.2019.80.524>
- Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited. *The Sage Handbook of Qualitative Research*, 4, 97–128.
- Lindsay, J., Royle, C., & Johnston, M. (2008). 3. Rate of Maternal Alcohol Consumption during Pregnancy. *Canadian Perinatal Health Report*.
- Linton, S. H. (2018). *Record of Investigation into the Death*. Report No.006/2013). Western Australia. Retrieved from:

https://www.coronerscourt.wa.gov.au/1/inquest_into_the_death_of_hls_subject_to_suppression_order.aspx

Lloyd, M. H., Luczak, S., & Lew, S. (2019). Planning for safe care or widening the net?: A review and analysis of 51 states' CAPTA policies addressing substance-exposed infants. *Children and Youth Services Review*.

Long, J. & Mongan, D., 2013. Alcohol consumption in Ireland 2013. Dublin: Health Research Board. Retrieved from: <http://www.drugsandalcohol.ie/22138/>

Louw, K.-A. (2018). Substance use in pregnancy: The medical challenge. *Obstetric Medicine*, 1753495X17750299.

Manning, M. A., & Hoyme, H. E. (2007). Fetal alcohol spectrum disorders: A practical clinical approach to diagnosis. *Neuroscience & Biobehavioral Reviews*, 31(2), 230–238.

Martin, J., Barry, J., Goggin, D., Morgan, K., Ward, M., & O'Suilleabhain, T. (2010). Alcohol-attributable mortality in Ireland. *Alcohol & Alcoholism*, 45(4), 379–386.

Mattson, S. N., & Riley, E. P. (1998). A review of the neurobehavioral deficits in children with fetal alcohol syndrome or prenatal exposure to alcohol. *Alcoholism: Clinical and Experimental Research*, 22(2), 279–294.

Mattson, S. N., Roesch, S. C., Glass, L., Dewese, B. N., Coles, C. D., Kable, J. A., May, P. A., Kalberg, W. O., Sowell, E. R., & Adnams, C. M. (2013). Further development of a neurobehavioral profile of fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research*, 37(3), 517–528.

Mattson, S. N., Crocker, N., & Nguyen, T. T. (2011). Fetal alcohol spectrum disorders: Neuropsychological and behavioral features. *Neuropsychology Review*, 21(2), 81–101.

- Maxwell, J. A. (2012). *A Realist Approach for Qualitative Research*. SAGE.
- Malbin, D. (2002). *Trying differently rather than harder: Fetal alcohol spectrum disorders*.
Office of Child Abuse and Neglect.
- Manthey, J., Shield, K. D., Rylett, M., Hasan, O. S. M., Probst, C., & Rehm, J. (2019). Global alcohol exposure between 1990 and 2017 and forecasts until 2030: A modelling study. *The Lancet*, 0(0). [https://doi.org/10.1016/S0140-6736\(18\)32744-2](https://doi.org/10.1016/S0140-6736(18)32744-2)
- May, P. A., Baete, A., Russo, J., Elliott, A. J., Blankenship, J., Kalberg, W. O., ... Abdul-Rahman, O. (2014). Prevalence and characteristics of fetal alcohol spectrum disorders. *Pediatrics*, 134(5), 855–866.
- May, P. A., Chambers, C. D., Kalberg, W. O., Zellner, J., Feldman, H., Buckley, D., ... Hoyme, H. E. (2018). Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. *JAMA*, 319(5), 474–482. <https://doi.org/10.1001/jama.2017.21896>
- McLennan, J. D., & Braunberger, P. (2017). A Critique of the New Canadian Fetal Alcohol Spectrum Disorder Guideline. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 26(3), 179.
- McLellan (2018) Report to the Minister of Justice and Solicitor General Public Fatality Inquiry (Report No. 2014/5) Government of Alberta. Retrieved from:
<https://open.alberta.ca/dataset/86a1f9d9-f118-49aa-a051->
- McCormick, A. (2016). Social Care and Fetal Alcohol Spectrum Disorders in the UK. In *Fetal Alcohol Spectrum Disorders in Adults: Ethical and Legal Perspectives* (pp. 209–221). Springer.

- McQuire, C., Daniel, R., Hurt, L., Kemp, A., & Paranjothy, S. (2019). The causal web of fetal alcohol spectrum disorders: A review and causal diagram. *European Child & Adolescent Psychiatry*. <https://doi.org/10.1007/s00787-018-1264-3>
- Meekosha, H., & Dowse, L. (2007). Integrating critical disability studies into social work education and practice: An Australian perspective. *Practice*, *19*(3), 169–183.
- Mertens, D. M. (2005). *Research and evaluation in education and psychology: Integrating diversity with quantitative, qualitative, and mixed methods*. Thousand Oaks, Calif.: Sage Publications.
- Monaco, G. L., Bonetto, E., Codaccioni, C., Araujo, M. V., & Piermattéo, A. (2019). Alcohol “use” and “abuse”: When culture, social context and identity matter. *Current Opinion in Food Science*.
- Mongan, D., Hope, A., & Nelson, M. (2009). *Social consequences of harmful use of alcohol in Ireland*.
- Moore, E. M., & Riley, E. P. (2015). What happens when children with fetal alcohol spectrum disorders become adults? *Current Developmental Disorders Reports*, *2*(3), 219–227.
- Morse, J. M. (2002). Qualitative health research: Challenges for the 21st century. *Qualitative Health Research*, *12*(1), 116–129.
- Morse, J. M., Stern, P. N., Corbin, J., Bowers, B., Charmaz, K., & Clarke, A. E. (2016). *Developing Grounded Theory: The Second Generation*. Routledge.
- Muggli, E., Cook, B., O’Leary, C., Forster, D., & Halliday, J. (2015). Increasing accurate self-report in surveys of pregnancy alcohol use. *Midwifery*, *31*(3), e23–e28.
- Mukherjee, R. A. S., Cook, P. A., Norgate, S. H., & Price, A. D. (2018). Neurodevelopmental outcomes in individuals with fetal alcohol spectrum disorder (FASD) with and without

- exposure to neglect: Clinical cohort data from a national FASD diagnostic clinic. *ALC Alcohol*.
- Mukherjee, R., Wray, E., Hollins, S., & Curfs, L. (2015). What does the general public in the UK know about the risk to a developing foetus if exposed to alcohol in pregnancy? Findings from a UK mixed methodology study. *Child: Care, Health and Development*, *41*(3), 467–474.
- Mukherjee, Raja, Cook, P. A., Fleming, K. M., & Norgate, S. H. (2016). What can be done to lessen morbidity associated with fetal alcohol spectrum disorders? *Archives of Disease in Childhood*, archdischild–2016.
- Mukherjee, Raja, Wray, E., Commers, M., Hollins, S., & Curfs, L. (2013). The impact of raising a child with FASD upon carers: Findings from a mixed methodology study in the UK. *Adoption & Fostering*, *37*(1), 43–56.
- Mukherjee, Raja, Wray, E., Curfs, L., & Hollins, S. (2015). Knowledge and opinions of professional groups concerning FASD in the UK. *Adoption & Fostering*, *39*(3), 212–224.
- Mullally, A., Cleary, B. J., Barry, J., Fahey, T. P., & Murphy, D. J. (2011). Prevalence, predictors and perinatal outcomes of peri-conceptual alcohol exposure-retrospective cohort study in an urban obstetric population in Ireland. *BMC Pregnancy and Childbirth*, *11*(1), 27.
- Murray, L., Tarren-Sweeney, M., & France, K. (2011). Foster carer perceptions of support and training in the context of high burden of care. *Child & Family Social Work*, *16*(2), 149–158.
- Nagel, D. A., Burns, V. F., Tilley, C., & Aubin, D. (2015). When Novice Researchers Adopt Constructivist Grounded Theory: Navigating Less Travelled Paradigmatic and

- Methodological Paths in PhD Dissertation Work. *International Journal of Doctoral Studies*, 10, 365–383.
- National Review Panel (NRP) (2017) *National Review Panel Annual Report (2017)* retrieved from: https://www.tusla.ie/uploads/content/Annual_Report_2017.pdf
- Nash, K., Koren, G., & Rovet, J. (2009). *Neurobehavioral screening tool (NST): Guidelines and scoring*. Toronto, ON: The Hospital for Sick Children.
- Nash, Kelly, Stevens, S., Greenbaum, R., Weiner, J., Koren, G., & Rovet, J. (2015). Improving executive functioning in children with fetal alcohol spectrum disorders. *Child Neuropsychology*, 21(2), 191–209.
- Nicoll, K., & Harrison, R. (2003). Constructing the good teacher in higher education: The discursive work of standards. *Studies in Continuing Education*, 25(1), 23–35.
- Nicolls GA. Fetal Alcohol Syndrome: Implications for Psychologists. *Clinical Psychology Review* 1994;14(2):91-111.
- Office of the Child and Youth Advocate Alberta. *Investigate review*. 2019; Retrieved from: <https://www.ocya.alberta.ca/adult/publications/investigative-review/>.
- O'Connor, M. J., Portnoff, L. C., Lebsack-Coleman, M., & Dipple, K. M. (2019). Suicide risk in adolescents with fetal alcohol spectrum disorders. *Birth Defects Research*.
- O'Connor, M. J., Sigman, M., & Brill, N. (1987). Disorganization of attachment in relation to maternal alcohol consumption. *Journal of Consulting and Clinical Psychology*, 55(6), 831.
- O'Dwyer, C., & Mongan, D. (2019). Public awareness of alcohol-related health conditions in Ireland: Findings from the Healthy Ireland Survey. *Drugnet Ireland*, 19–21.

- Oireachtas, H. of the. (2015, December 10). Public Health (Alcohol) Act 2018 – No. 24 of 2018 – Houses of the Oireachtas [Text]. Retrieved March 6, 2019, from <https://www.oireachtas.ie/en/bills/bill/2015/120>
- O’Keeffe, L. M., Kearney, P. M., McCarthy, F. P., Khashan, A. S., Greene, R. A., North, R. A., ... Dekker, G. A. (2015). Prevalence and predictors of alcohol use during pregnancy: Findings from international multicenter cohort studies. *BMJ Open*, *5*(7), e006323.
- Oktaf, J. S. (2012). *Grounded Theory*. Oxford University Press, USA.
- Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society*, *28*(7), 1024–1026. <https://doi.org/10.1080/09687599.2013.818773>
- Olney, J. (2004). Fetal alcohol syndrome at the cellular level. *Addiction Biology*, *9*(2), 137–149.
- Olson, H. C., Oti, R., Gelo, J., & Beck, S. (2009). “Family matters:” fetal alcohol spectrum disorders and the family. *Developmental Disabilities Research Reviews*, *15*(3), 235–249.
- Organization, W. H. (2014). Guidelines for the identification and management of substance use and substance use disorders in pregnancy. *Guidelines for the Identification and Management of Substance Use and Substance Use Disorders in Pregnancy*.
- O’Donnell, A., Abidi, L., Brown, J., Karlsson, N., Nilsen, P., Roback, K., Skagerström, J., & Thomas, K. (2018). Beliefs and attitudes about addressing alcohol consumption in health care: A population survey in England. *BMC Public Health*, *18*(1), 391.
- Oram, S. (2019). Child maltreatment and mental health. *Lancet Psychiatry*.
- Organization, W. H. (2005). Bridging the “know–do” gap meeting on knowledge translation in global health.

- Organization, W. H. (2007). International Statistical Classification of Diseases and Related Health Problems: Tenth revision-Version for 2007. Retrieved From: *Http://Apps. Who. Int/Classifications/Apps/Icd/Icd10online/*.
- PHAC, 2019. Government of Canada supports projects to address and prevent Fetal Alcohol Spectrum Disorder in Canada; Retrieved From: <https://www.canada.ca/en/public-health/news/2019/07/government-of-canada-supports-projects-to-address-and-prevent-fetal-alcohol-spectrum-disorder-in-canada.html>
- Padgett, D. K. (2009). Guest editorial: Qualitative and mixed methods in social work knowledge development. *Social Work, 54*(2), 101–105.
- Parton, N. (1981). Child abuse, social anxiety and welfare. *The British Journal of Social Work, 11*(1), 391–414.
- Pasquier, L., Isidor, B., Rial-Sebbag, E., Odent, S., Minguet, G., & Moutel, G. (2019). Population genetic screening: Current issues in a European country. *European Journal of Human Genetics, 1*.
- Patel, M., Agnihotri, S., Hawkins, C., Levin, L., Goodman, D., & Simpson, A. (2019). Identifying Fetal Alcohol Spectrum Disorder and psychiatric comorbidity for Children and Youth in Care: A community approach to diagnosis and treatment. *Children and Youth Services Review, 104*606.
- Payne, J., France, K., Henley, N., D'antoine, H., Bartu, A., O'leary, C., Elliott, E., & Bower, C. (2011). Changes in health professionals' knowledge, attitudes and practice following provision of educational resources about prevention of prenatal alcohol exposure and fetal alcohol spectrum disorder. *Paediatric and Perinatal Epidemiology, 25*(4), 316–327.

- Peadon, E., Rhys-Jones, B., Bower, C., & Elliott, E. J. (2009). Systematic review of interventions for children with fetal alcohol spectrum disorders. *BMC Pediatrics*, *9*(1), 35.
- Pelech, W., Badry, D., & Daoust, G. (2013). It takes a team: Improving placement stability among children and youth with Fetal Alcohol Spectrum Disorder in care in Canada. *Children and Youth Services Review*, *35*(1), 120–127.
- Petrenko, C. L. (2015). Positive behavioral interventions and family support for fetal alcohol spectrum disorders. *Current Developmental Disorders Reports*, *2*(3), 199–209.
- Petrenko, C. L., & Alto, M. E. (2017). Interventions in fetal alcohol spectrum disorders: An international perspective. *European Journal of Medical Genetics*, *60*(1), 79–91.
- Petrenko, C. L., Demeusy, E. M., & Alto, M. E. (2019). 6-month Follow up of the Families on Track Intervention Pilot Trial for Children with Fetal Alcohol Spectrum Disorders and Their Families. *Alcoholism: Clinical and Experimental Research*.
- Petrenko, C. L., Tahir, N., Mahoney, E. C., & Chin, N. P. (2014). Prevention of secondary conditions in fetal alcohol spectrum disorders: Identification of systems-level barriers. *Maternal and Child Health Journal*, *18*(6), 1496–1505.
- Petryk, S., Siddiqui, M. A., Ekeh, J., & Pandey, M. (2019). Prenatal alcohol history—setting a threshold for diagnosis requires a level of detail and accuracy that does not exist. *BMC Pediatrics*, *19*(1), 372.
- Pomeroy, E. C., & Parrish, D. E. (2011). Prenatal impact of alcohol and drugs on young children: Implications for interventions with children and parents. *SL A. Straussner & CH Fewell (Eds.), Children of Substance Abusing Parents: Dynamics and Treatment*, 77–99.

- Poole, N. (2008). *Fetal alcohol spectrum disorder (FASD) prevention: Canadian perspectives*. Agence de la santé publique du Canada.
- Popova, S., Lange, S., Shield, K., Burd, L., & Rehm, J. (2019). Prevalence of Fetal Alcohol Spectrum Disorder among Special Sub-populations: A Systematic Review and Meta-analysis. *Addiction (Abingdon, England)*.
- Popova, Svetlana, Lange, S., Burd, L., & Rehm, J. (2012). Health care burden and cost associated with fetal alcohol syndrome: Based on official Canadian data. *PloS One*, 7(8), e43024.
- Popova, Svetlana, Lange, S., Burd, L., & Rehm, J. (2014). Canadian children and youth in care: The cost of fetal alcohol spectrum disorder. *Child & Youth Care Forum*, 43, 83–96. Springer.
- Popova, Svetlana, Lange, S., Probst, C., Gmel, G., & Rehm, J. (2017). Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: A systematic review and meta-analysis. *The Lancet Global Health*, 5(3), e290–e299. [https://doi.org/10.1016/S2214-109X\(17\)30021-9](https://doi.org/10.1016/S2214-109X(17)30021-9)
- Popova, Svetlana, Lange, S., Shield, K., Burd, L., & Rehm, J. (n.d.). Prevalence of fetal alcohol spectrum disorder among special subpopulations: A systematic review and meta-analysis. *Addiction*, 0(0). <https://doi.org/10.1111/add.14598>
- Popova, Svetlana, Stade, B., Bekmuradov, D., Lange, S., & Rehm, J. (2011). What do we know about the economic impact of fetal alcohol spectrum disorder? A systematic literature review. *Alcohol and Alcoholism*, 46(4), 490–497.
- Portales-Casamar, E., Lussier, A. A., Jones, M. J., MacIsaac, J. L., Edgar, R. D., Mah, S. M., Barhdadi, A., Provost, S., Lemieux-Perreault, L.-P., & Cynader, M. S. (2016). DNA

- methylation signature of human fetal alcohol spectrum disorder. *Epigenetics & Chromatin*, 9(1), 25.
- Price, A., Cook, P. A., Norgate, S., & Mukherjee, R. (2017). Prenatal alcohol exposure and traumatic childhood experiences: A systematic review. *Neuroscience & Biobehavioral Reviews*, 80, 89–98.
- Price, K. J., & Miskelly, K. J. (2015). Why ask why? Logical fallacies in the diagnosis of fetal alcohol Spectrum disorder. *Ethics & Behavior*, 25(5), 418–426.
- Prindle, J. J., Hammond, I., & Putnam-Hornstein, E. (2018). Prenatal substance exposure diagnosed at birth and infant involvement with child protective services. *Child Abuse & Neglect*, 76, 75–83.
- Pringle, B. (2014) Two Tragedies: Holding Systems Accountable, Special Investigation Report. Saskatoon, SK: Saskatchewan Youth Advocate
- Public Health Agency of Canada, Canada, & Health Canada. (2012). *The sensible guide to a healthy pregnancy*. Retrieved from http://publications.gc.ca/collections/collection_2013/aspc-phac/HP5-33-2012-eng.pdf
- Ralph, N., Birks, M., & Chapman, Y. (2015). The methodological dynamism of grounded theory. *International Journal of Qualitative Methods*, 14(4), 1609406915611576.
- Rangmar J, Lilja M, Köhler M, & Reuter A. (2018). Children who face development risks due to maternal addiction during pregnancy require extra medical and psychosocial resources. *Acta Paediatrica (Oslo, Norway : 1992)*.
- Rasmussen, C., Benz, J., Pei, J., Andrew, G., Schuller, G., Abele-Webster, L., Alton, C., & Lord, L. (2010). The impact of an ADHD co-morbidity on the diagnosis of FASD. *Journal of Population Therapeutics and Clinical Pharmacology*, 17(1).

- Rasmussen, C., Kully-Martens, K., Denys, K., Badry, D., Henneveld, D., Wyper, K., & Grant, T. (2012). The effectiveness of a community-based intervention program for women at-risk for giving birth to a child with Fetal Alcohol Spectrum Disorder (FASD). *Community Mental Health Journal, 48*(1), 12–21.
- Reder, P. Duncan, S., & Grey, M. (1993a). *Beyond blame – child abuse tragedies revisited*. London: Routledge.
- Rehm, J., Mathers, C., Popova, S., Thavorncharoensap, M., Teerawattananon, Y., & Patra, J. (2009). Global burden of disease and injury and economic cost attributable to alcohol use and alcohol-use disorders. *The Lancet, 373*(9682), 2223–2233.
- Reynolds, C. M., Egan, B., O'Malley, E. G., McMahon, L., Sheehan, S. R., & Turner, M. J. (2019). Fetal growth and maternal alcohol consumption during early pregnancy. *European Journal of Obstetrics & Gynecology and Reproductive Biology, 236*, 148–153.
- Riley, E. P., Infante, M. A., & Warren, K. R. (2011). Fetal alcohol spectrum disorders: An overview. *Neuropsychology Review, 21*(2), 73.
- Riley, E. P., & McGee, C. L. (2005). Fetal alcohol spectrum disorders: An overview with emphasis on changes in brain and behavior. *Experimental Biology and Medicine, 230*(6), 357–365.
- Ritche, J., & Spencer, L. (1994). *Qualitative data analysis for applied policy research, Analyzing Qualitative Data Edited by: Bryman A, Burgess RG*. London: Routledge.
- Roberts, S. C. M., Thomas, S., Treffers, R., & Drabble, L. (2017). Forty Years of State Alcohol and Pregnancy Policies in the USA: Best Practices for Public Health or Efforts to Restrict

- Women's Reproductive Rights? *Alcohol and Alcoholism*, 52(6), 715–721.
<https://doi.org/10.1093/alcalc/agx047>
- Robson, C. (2011). *Real world research: A resource for users of social research methods in applied settings 3rd edition*. West Sussex: John Wiley & Sons.
- Ross, L. F., Saal, H. M., David, K. L., & Anderson, R. R. (2013). American College of Medical Genetics and Genomics. *Ethical and Policy Issues in Genetic Testing and Screening of Children*. *Genet Med*, 15(3), 234–245.
- Rutledge, N. (2014). Neuroscience and social work—Toward a brain-based practice. *Social Work Today*, 14(3), 22.
- Rutman, D., & Hubberstey, C. (2019). National Evaluation of Canadian Multi-Service FASD Prevention Programs: Interim Findings from the Co-Creating Evidence Study. *International Journal of Environmental Research and Public Health*, 16(10), 1767.
<https://doi.org/10.3390/ijerph16101767>
- Sacks, J. J., Gonzales, K. R., Bouchery, E. E., Tomedi, L. E., & Brewer, R. D. (2015). 2010 national and state costs of excessive alcohol consumption. *American Journal of Preventive Medicine*, 49(5), e73–e79.
- Salmon, J. (2008). Fetal alcohol spectrum disorder: New Zealand birth mothers' experiences. *Can J Clin Pharmacol*, 15(2), e191–e213.
- Sanders, J. L., & Buck, G. (2010). A long journey: Biological and non-biological parents' experiences raising children with FASD. *Journal of Population Therapeutics and Clinical Pharmacology*, 17(2), e308–e322.
- Saunders, M., Lewis, P., & Thornhill, A. (2007). Formulating the research design. *Research Methods for Business Students*, 130–161.

- Sbaraini, A., Carter, S. M., Evans, R. W., & Blinkhorn, A. (2011). How to do a grounded theory study: A worked example of a study of dental practices. *BMC Medical Research Methodology*, *11*(1). <https://doi.org/10.1186/1471-2288-11-128>
- Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. *Handbook of Qualitative Research*, *1*, 118–137.
- Seidel, J., & Kelle, U. (1995). Different functions of coding in the analysis of textual data. *Computer-Aided Qualitative Data Analysis: Theory, Methods and Practice*, 52–61.
- Selwyn, J., & Wijedesa, D. (2011). Pathways to adoption for minority ethnic children in England—reasons for entry to care. *Child & Family Social Work*, *16*(3), 276–286.
- Senturias, Y., & Burns, B. (2014). Managing Children and Adolescents With Fetal Alcohol Spectrum Disorders in the Medical Home. *Current Problems in Pediatric and Adolescent Health Care*, *44*(4), 96–101. <https://doi.org/10.1016/j.cppeds.2013.12.009>
- Shah, P. E., Shapiro, D., Milgrom, T., & Eugene Hoyme, H. (2018). Fetal Alcohol Spectrum Disorders: Diagnostic Considerations for Children with a History of Trauma. In J. M. Fogler & R. A. Phelps (Eds.), *Trauma, Autism, and Neurodevelopmental Disorders: Integrating Research, Practice, and Policy* (pp. 93–122). https://doi.org/10.1007/978-3-030-00503-0_6
- Shankar, I. (2015). The making of a medical disorder: Tracing the emergence of fetal alcohol spectrum disorder in Alberta. *Social Work in Public Health*, *30*(1), 38–50.
- Sharpe, T. T., Alexander, M., Hutcherson, J., Floyd, R. L., Brimacombe, M., Levine, R., ... Stuber, M. (2004). Report from the CDC. Physician and allied health professionals' training and fetal alcohol syndrome. *Journal of Women's Health*, *13*(2), 133–139.

- Sher, J., Frank, J. W., Doi, L., & de Caestecker, L. (2019). Failures in reproductive health policy: Overcoming the consequences and causes of inaction. *Journal of Public Health*.
<https://doi.org/10.1093/pubmed/fdy131>
- Shonkoff, J. P., & Fisher, P. A. (2013). Rethinking evidence-based practice and two-generation programs to create the future of early childhood policy. *Development and Psychopathology*, 25(4pt2), 1635–1653. <https://doi.org/10.1017/S0954579413000813>
- S.I. No. 143 (2011). Code of Professional Conduct and Ethics for Social Workers bye-law. Retrieved from:
<http://www.irishstatutebook.ie/eli/2011/si/143/made/en/print>
- Sisko, A., Truffer, C., Smith, S., Keehan, S., Cylus, J., Poisal, J. A., ... Lizonitz, J. (2009). Health spending projections through 2018: Recession effects add uncertainty to the outlook. *Health Affairs*, 28(2), w346–w357.
- Sparrow, S. S. (2011). Vineland adaptive behavior scales. *Encyclopedia of Clinical Neuropsychology*, 2618–2621.
- Stade, B., Ali, A., Bennett, D., Campbell, D., Johnston, M., Lens, C., ... Koren, G. (2009). The burden of prenatal exposure to alcohol: Revised measurement of cost. *Journal of Population Therapeutics and Clinical Pharmacology*, 16(1).
- Stahmer, A. C., Leslie, L. K., Hurlburt, M., Barth, R. P., Webb, M. B., Landsverk, J., & Zhang, J. (2005). Developmental and behavioral needs and service use for young children in child welfare. *Pediatrics*, 116(4), 891–900.
- Stewart, B., & Wild, C. P. (2017). World cancer report 2014. *Health*.
- Strauss, A., & Corbin, J. M. (1997). *Grounded theory in practice*. Sage.
- Strauss, A. L. (1987). *Qualitative Analysis for Social Scientists*. Cambridge University Press.

- Stratton, K., Howe, C., & Battaglia, F. C. (1996). *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, and treatment*. National Academies Press.
- Streissguth, A. P., Barr, H. M., Kogan, J., & Bookstein, F. L. (1996). Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). *Final Report to the Centers for Disease Control and Prevention (CDC)*, 96–06.
- Streissguth, Ann Pytkowicz. (1997). *Fetal alcohol syndrome: A guide for families and communities*. Paul H Brookes Publishing.
- Stuckler, D., & Basu, S. (2013). *The body economic: Why austerity kills*. Basic Books (AZ).
- Subbaraman, M. S., & Roberts, S. C. M. (2019). Costs associated with policies regarding alcohol use during pregnancy: Results from 1972-2015 Vital Statistics. *PLOS ONE*, 14(5), e0215670. <https://doi.org/10.1371/journal.pone.0215670>
- Taoiseach launches “Reducing Harm, Supporting Recovery – a health led response to drug and alcohol use in Ireland 2017-2025” | Department of Health. (n.d.). Retrieved August 26, 2018, from <https://health.gov.ie/blog/uncategorized/taoiseach-launches-reducing-harm-supporting-recovery-a-health-led-response-to-drug-and-alcohol-use-in-ireland-2017-2025/>
- Thanh, N. X., & Jonsson, E. (2016). *LIFE EXPECTANCY OF PEOPLE WITH FETAL ALCOHOL SYNDROME*. 23, 7.
- Thanh, N. X., & Jonsson, E. (2018). Total Cost of FASD Including the Economics of FASD Associated with Crimes. In *Ethical and Legal Perspectives in Fetal Alcohol Spectrum Disorders (FASD)* (pp. 49–66). Springer.
- Thiel, K. S., Baladerian, N. J., Boyce, K. R., Cantos, O. D., Davis, L. A., Kelly, K., ... Stream, J. (2011). Fetal alcohol spectrum disorders and victimization: Implications for families,

- educators, social services, law enforcement, and the judicial system. *The Journal of Psychiatry & Law*, 39(1), 121–157.
- Thompson, A., Hackman, D., and Burd, L. (2014). Mortality in fetal alcohol spectrum disorders. *Open Journal of Pediatrics*, 4(01), 21.
- Turchi, R. M., & Smith, V. C. (2018). *The Role of Integrated Care in a Medical Home for Patients With a Fetal Alcohol Spectrum Disorder*. 142(4), 19.
- Tusla, Child and Family Agency (2017c), *Quarterly Data Management Activity Report, Quarter 1 2017*. Dublin: Tusla, Child and Family Agency.
- U.S. Congress, Alcohol Beverage Labeling Act of 1988, Public Law 100-690, 27, 201, 1998.
- UN Committee on the Rights of the Child (2019). General comment no. 24(CRC/C/GC/24): children’s rights in juvenile justice. Retrieved From:
https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/
- Urquhart, C. (2016). Grounded Theory. *The International Encyclopedia of Communication Theory and Philosophy*, 1–13.
- Van Bijleveld, G. G., Dedding, C. W., & Bunders-Aelen, J. F. (2015). Children’s and young people’s participation within child welfare and child protection services: A state-of-the-art review. *Child & Family Social Work*, 20(2), 129–138.
- Version, D. 7.0. 23 (2016) *Web application for managing, analyzing, and presenting qualitative and mixed method research data*. Sociocultural Research Consultants, LLC, Los Angeles, CA.
- Wacquant, L. (2002). Scrutinizing the street: Poverty, morality, and the pitfalls of urban ethnography. *American Journal of Sociology*, 107(6), 1468–1532.

- Wahlquist, C. (2019) Aboriginal Women wins battle to keep her baby after six court appearances. Retrieved From: <https://www.theguardian.com/australia-news/2019/jul/18/aboriginal-woman-wins-battle-to-keep-baby-after-six-court-appearances>
- Walker, P. (2014). Reducing the harms of FASD in the Northern Territory through prevention and intervention. *Report to the Legislative Assembly of Northern Territory Government Select Committee on Action to Prevent FASD*.
- Wallerstein, N., & Bernstein, E. (1988). Empowerment Education: Freire's Ideas Adapted to Health Education. *Health Education Quarterly*, 15(4), 379–394.
<https://doi.org/10.1177/109019818801500402>
- Wang, A., Gerona, R. R., Schwartz, J. M., Lin, T., Sirota, M., Morello-Frosch, R., & Woodruff, T. J. (2018). A Suspect Screening Method for Characterizing Multiple Chemical Exposures among a Demographically Diverse Population of Pregnant Women in San Francisco. *Environmental Health Perspectives*, 126(7), 077009.
<https://doi.org/10.1289/EHP2920>
- Wang, L., & Pinkerton, K. E. (2007). Air pollutant effects on fetal and early postnatal development. *Birth Defects Research Part C: Embryo Today: Reviews*, 81(3), 144–154.
- Warnick, E. M., Bracken, M. B., & Kasl, S. (2008). Screening Efficiency of the Child Behavior Checklist and Strengths and Difficulties Questionnaire: A Systematic Review. *Child & Adolescent Mental Health*, 13(3), 140–147. <https://doi.org/10.1111/j.1475-3588.2007.00461>
- Warnick, B., Drake, M., & Vidrine, S. (2015). Test Review: Delis Rating of Executive Function (D-REF). *Journal of Psychoeducational Assessment*, 33(6), 597–601.
<https://doi.org/10.1177/0734282914564346>

- Warren, K. R. (2015). A review of the history of attitudes toward drinking in pregnancy. *Alcoholism: Clinical and Experimental Research*, 39(7), 1110–1117.
- Warren, K. R., & Chezem, L. L. (2018). FASD and Justice: An Historical Perspective. In *Ethical and Legal Perspectives in Fetal Alcohol Spectrum Disorders (FASD)* (pp. 3–21). Springer.
- Walker, D., & Myrick, F. (2006). Grounded Theory: An Exploration of Process and Procedure. *Qualitative Health Research*, 16(4), 547–559.
- Walsh, T., O’Broin, S., Cooley, S., Donnelly, J., Collins, C., McMillan, H., Harrison, R. F., McMahon, C., & Geary, M. (2007). Maternal folate status and neural tube defects in Ireland: The need for a national food fortification program. *Irish Medical Journal*, 100(5), 469–472.
- Warner, R. H., & Rosett, H. L. (1975). The effects of drinking on offspring: An historical survey of the American and British literature. *Journal of Studies on Alcohol*, 36(11), 1395–1420.
- Whelan, J. (2007). Values and Ethics Discourses in Irish Social Work: Which values do practitioners view as realistic and implementable in day to day practice. Retrieved from <https://www.academia.edu/29817267/>
- Whelan, S. (2018). *At the Front Door: Child Protection Reporting in a Changing Policy and Legislative Context* [PhD Thesis]. Trinity College Dublin.
- Weitzman, E. A. (2000). Software and qualitative research. *Handbook of Qualitative Research*, 2, 803–820.

- Williams, J. F., Smith, V. C., & Abuse, C. on S. (2015). Fetal alcohol spectrum disorders. *Pediatrics*, *136*(5), e1395–e1406.
- Williams, S. J., Dubovsky, D., & Merritt, J. (2011). Legal and psychological implications of nondisclosure in the adoption of a child with fetal alcohol spectrum disorder. *The Journal of Psychiatry & Law*, *39*(1), 193–214.
- Willig, C. (2008). A Phenomenological Investigation of the Experience of Taking Part in Extreme Sports'. *Journal of Health Psychology*, *13*(5), 690–702.
- Wilson, A. (2013). A Social Work student's developing understanding of Fetal Alcohol Spectrum disorder from medical. *First Peoples Child & Family Review*, *8*(1), 25–39.
- Wong, S., Ordean, A., & Kahan, M. (2011). Society of Obstetricians and Gynecologists of Canada. *SOGC Clinical Practice Guidelines: Substance Use in Pregnancy*, *256*, 190–202.
- Wyatt, K. A. M. for S. A. and A. C. M. for I. H. (n.d.). *\$7 million for Fetal Alcohol Spectrum Disorder*. Retrieved from <http://www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediarel-yr2018-wyatt165.htm>
- Zhang, C., Paolozza, A., Tseng, P.-H., Reynolds, J., Munoz, D. P., & Itti, L. (2019). Detection of Children/Youth with Fetal Alcohol Spectrum Disorder through Eye Movement, Psychometric and Neuroimaging Data. *Frontiers in Neurology*, *10*, 80.

APPENDICIES
Appendix A: Recruitment Flyer

SOCIAL WORK RESEARCH PARTICIPANTS NEEDED

**DO YOU WORK WITH A CHILD OR CARGIVER WHER FASDs
are present in your intervention?
Has FASDs impacted on your practice?**

Is the study a good fit for me?

You must be:

- Current employment in a state child welfare agency
- Registered with Coru
- Have a minimum of two years' experience as a child welfare social worker
- You **DO Not** need to be carrying a case of FASD on your caseload.

What will be required of you?

- Give written consent to take part in the study
- Complete an interview between 60 and 90 minutes (max)
- Be willing to have follow-up contact from the researcher.

NB. The researcher is particularly interested in hearing from Social workers who received FASD education from the researcher between 2011 – 2017.

Confidentiality

Your participation will be totally confidential within the study.

Contact Liam

Appendix B: Ethics approval Phase 1 (site)



Marian Brattman
Interim National Manager for Research
Policy and Strategy Directorate
Tusla Child and Family Agency
Brunel HQ
Military Road
Kilmainham
Dublin 8

1st February 2017.

Dear Mr. Curran,

You have received Tusla research ethical approval for the first phase of your study '*A grounded theory study of social work response to fetal alcohol spectrum disorder (FASD) in child welfare settings*'.

Further phases of the study will require submission to the Tusla Research Ethics Review group for consideration and approval.

Yours sincerely,

A handwritten signature in black ink, appearing to read "M. Brattman".

Marian Brattman
Interim National Manager for Research

Appendix C; Ethics Approval Phase 2 (site)



Marian Brattman
Interim National Manager for Research
Policy and Transformation Directorate
Tusla Child and Family Agency
Military Road
Kilmainham
Dublin 8

23rd August 2017

Dear Mr. Curran,

You have received Tusla research ethical approval for the addendum (submitted 1st August 2017) to your original proposal submitted on 'A grounded theory study of social work response to fetal alcohol spectrum disorder (FASD) in child welfare settings'.

You may circulate your recruitment flyer to IFCA on this basis, but evidence of research ethics approval for your addendum from Concordia University is required prior to engaging foster carers in interviews.

Yours sincerely,

Marian Brattman

Interim National Manager for Research

An Ghníomhaireacht um Leanaí agus an Teaghlach / Child and Family Agency
Oifig naimc in Irish (i.e. Oifig Átha Luain)
Office Address in Irish on one line (i.e. Corna Madadh, Áth Luain, Co na hIarmhí)
Office name in English in italics (i.e. Athlone Office)
Office address in English in italics on one line (i.e. Cornamaddy, Athlone, Co Westmeath)
t. +353 (0) 11 222 3333 f. +353 (0) 11 222 3333 / info@tusla.ie (Note: Please keep number format as shown)
www.tusla.ie

Appendix D; Ethics approval Phase 1 (University)



CERTIFICATION OF ETHICAL ACCEPTABILITY
FOR RESEARCH INVOLVING HUMAN SUBJECTS

Name of Applicant: William Curran
Department: Faculty of Arts and Science \ Psychology
Agency: N/A
Title of Project: How do child welfare social workers intervene with children who are living with or suspected of having an FASD? A constructivist grounded theory study
Certification Number: 30008098

Valid From: November 15, 2017 To: November 14, 2018

The members of the University Human Research Ethics Committee have examined the application for a grant to support the above-named project, and consider the experimental procedures, as outlined by the applicant, to be acceptable on ethical grounds for research involving human subjects.

A handwritten signature in black ink, appearing to be "J.P.", written in a cursive style.

Dr. James Pfaus, Chair, University Human Research Ethics Committee

Appendix E: Ethics approval Phase 2 (University)



CERTIFICATION OF ETHICAL ACCEPTABILITY
FOR RESEARCH INVOLVING HUMAN SUBJECTS

Name of Applicant: William Curran
Department: Faculty of Arts and Science \ Psychology
Agency: N/A
Title of Project: How do child welfare social workers intervene with children who are living with or suspected of having an FASD? A constructivist grounded theory study

Certification Number: 30008098

Valid From: June 08, 2017 to: June 07, 2018

The members of the University Human Research Ethics Committee have examined the application for a grant to support the above-named project, and consider the experimental procedures, as outlined by the applicant, to be acceptable on ethical grounds for research involving human subjects.

A handwritten signature in black ink, appearing to be "J. Pfau".

Dr. James Pfau, Chair, University Human Research Ethics Committee

Appendix F: Site Access Approval

From: "SD DNE [Service Director DNE]" <sd.dne@tusla.ie>
Date: Monday, December 5, 2016 at 11:00 AM
To: William Christopher Curran <william.curran@mail.mcgill.ca>, "SD DNE [Service Director DNE]" <sd.dne@tusla.ie>
Subject: RE: Research Access Request

Dear Liam,

Linda Creamer, Service Director, Dublin North East has granted permission for you to conduct the below research in the DNE area.

Regards

Julie Flood
Office of the Service Director

on behalf of
Linda Creamer, Service Director, DNE

—



An Ghníomhaireacht um Leanáí agus an Teaghlach
Child and Family Agency

2nd Floor, Units 4/5 Nexus Building, Blanchardstown Corporate Park, Ballycoolin, Dublin 15.
t. +353 (01) 897 6820

Email:

Appendix I: Information and Consent Form



INFORMATION AND CONSENT FORM

Study Title: A Grounded Theory Study of Social Work Responses to Fetal Alcohol Spectrum Disorder in Child Welfare Settings

Principal Investigator: William (Liam) Curran, Ph.D. student, Individualized (INDI) Program

Researcher's Contact Information: w_curran@live.concordia.ca; (lab) 514-848-2424 x2390

Faculty Supervisor: Dr. Roisin O' Connor, Department of Psychology, Concordia University; Roisin.OConnor@concordia.ca; (office) 514-848-2424 x2248

Faculty Co-Supervisors: Dr. Patti Ranahan, Applied Human Sciences, Concordia University; Dr. Tonino Esposito, University of Montreal/CRCF, McGill University

Source of funding for the study: Concordia University Fellowship

You are being invited to participate in the research study described above. This form provides information about what participating would mean. Please read it carefully before deciding if you want to participate or not. If there is anything you do not understand, or if you want more information, please email the PI.

A. PURPOSE

The purpose of the research is to document the responses of social workers when intervening and supporting children in the child welfare services who have or are suspected of having Fetal Alcohol Spectrum Disorders (FASDs).

B. PROCEDURES

If you participate, you will be asked to take part in an interview that will be audio recorded. During this interview, you will be asked to share your perspectives on FASDs within the context of your practice, and how your perspective influences your role as a child welfare social worker. You will not be asked to share identifying information of those who use your services. Within six months after the interview, you *may* be asked to take part in a brief follow-up. The researcher will use this as the opportunity to clarify information that you provided during the interview. This can be done face-to-face, via Skype, or telephone. In total, your participation in the interview will take 60 to 90 minutes. We anticipate that the follow-up will take <30 minutes. The follow-up aspect of the procedures is just to clarify any aspect of the data you offered in the study. This aspect of qualitative research is known as member checking. Member checking as a means of enhancing rigor in qualitative research, proposing that credibility and accurate descriptions or interpretations of data.

C. RISKS AND BENEFITS

You might face certain risks by participating in this research. However, we anticipate that the level of risk will be minimal. Possible risks include feeling some discomfort discussing practice

challenges you have encountered related to FASDs. You will not personally benefit from participating in this research. An information sheet concerning FASD/ or and, Alcohol and Pregnancy will be given to participants if they request information that is outside the scope of the interview. Participants are encouraged to discuss with the PI if any aspect of the process causes them any emotional distress. If a question troubles you in any way, you are free not to answer, and withdraw from the study.

D. CONFIDENTIALITY

We will not allow anyone to access the information, except people directly involved in conducting the research, and except as described in this form. We will only use the information for the purposes of the research described in this form. The information gathered will be identified by code only. You will be assigned a code before recording begins. Throughout the recording, you will be referred to by the assigned code. The PI will have a list that links the code to your name. This list will be used to contact you for follow-up and will be destroyed upon study completion. The audio recordings will be transcribed by a professional transcription service. The transcription service for this study will be based in Dublin, Ireland (AudioTrans). This third party will sign a *Confidentiality/ Non-Disclosure Transcriptionist Agreement*. The transcriptionist will only have access to the audio recordings, which are identified by a code. The audio recordings will be safeguarded on a password protected computer during transcription and then destroyed one year after study completion. The transcribed data will be safeguarded on a password protected computer and destroyed after five years. Named investigators as listed may have access to coded data including audio and transcripts. Only the PI (Liam Curran) will hold the master copy of names to codes while in Ireland. This data will then be stored in a sealed envelope and locked cabinet in the School of Social Work, Trinity College, Dublin Ireland.

The information you provide may be quoted during presentations and in publications. However, it will not be possible to identify you in any presentations or publications.

In certain situations, I might be legally required to disclose the information that you provide. This includes situations where there is a current risk to a child and/or child abuse. If this kind of situation arises, it is the duty of the researcher to inform the relevant authorities. The researcher will forward their concern to the Director of Services, DNE division of Tusla or the duty social work office of DNE.

E. CONDITIONS OF PARTICIPATION

You do not have to participate in this research. It is purely your decision. If you do participate, you can withdraw at any time. You can also ask that the information you provided not be used, and your choice will be respected. If you decide that you don't want us to use your information, you must tell the PI within six months of your interview date. There are no negative consequences for not participating, stopping in the middle, or asking us not to use your information.

F. PARTICIPANT'S DECLARATION

I have read and understood this form. I have had the chance to ask questions and any questions have been answered. I agree to participate in this research under the conditions described.

ii) I agree to be interviewed for this research study

Yes No

ii) I consent to the interview being audio-taped.

Yes No

iii) I agree to the use of anonymous quotations from this interview to be used in presentations, doctoral thesis or other publications that emerge from this research.

Yes No

IV) I agree to be contacted up to six months following interview date, should the PI require any clarification of my data.

Yes No

NAME (please print) _____

SIGNATURE _____

DATE _____

Additionally, if you have questions about the scientific or scholarly aspects of this research, please contact the PI. Their contact information is on page 1. You may also contact their faculty supervisor, whose information is also contained at the beginning of this form. If you have concerns about ethical issues in this research, please contact the Manager, Research Ethics, Concordia University, 514.848.2424 ex. 7481 or oor.ethics@concordia.ca.

Appendix K: Transcription Agreement

Confidentiality/Non-Disclosure Transcriptionist

Agreement

I, _____ transcriptionist, of Audiotrans, Dublin agree to maintain full confidentiality in regard to any and all audiotapes and documentations received from William (Liam) Curran related to his/her research study on the researcher study titled: ***How do child welfare social workers respond with children who are living with or suspected of having an FASD? A constructivist grounded theory study***

Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of audio-taped interviews, or in any associated documents.
2. To not make copies of any audiotapes or computerized titles of the transcribed interviews texts, unless specifically requested to do so by the researcher, William Curran
3. To store all study-related audiotapes and materials in a safe, secure location as long as they are in my possession.
4. To return all audiotapes and study-related materials to William Curran in a complete and timely manner.
5. To delete all electronic files containing study-related documents from my computer hard drive and any back-up device

I am aware that I can be held legally responsible for any breach of this confidentiality/non-disclosure agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audiotapes and/or files to which I will have access.

Transcriber's name (printed) _____

Transcriber's signature _____

Date _____

Researchers name (Printed) _____

Researchers signature _____

Date _____

Appendix J: Interview Guide

Interview Guide

Key Informants

Adult participants (Social Work Practitioner)

(The proposed guiding questions are provisional and will be continually adapted during the interviews, aiming to better understand and critique the professional context surrounding the practice experiences. All adaptations of interview questions will frequently be orientated by the primary research question of the study. This concept of adapting the interview guide as I go is an essential tenet of Constructivist Grounded Theory (ConGT)). Adaption of guide may require interviewing respondents aligned to social work and child welfare services.

Research Question: How do child welfare social workers respond with children who are living with an FASD or who are suspected of having an FASD?

(Fetal Alcohol Spectrum Disorders – FASDs)

Research aim: To better understand the presentation of FASDs within social work interventions and case management work in child welfare settings

Demographics

Years since SW Qualification:	Gender:
Service Area:	Current Role:

Preamble: Thank you for accepting the invite to take part in this research project. You were invited to take part because you operate as a child welfare and protection social work in the delivery of state services for vulnerable children. The purpose of today's interview is to understand better how social work responds to FASDs in their daily work duties. Some of the questions I will ask will be general to child welfare services, while others will be specific to the research of FASDs. Do you have any questions for me before we begin?

Thank you for reviewing, clarifying and signing the consent document related to this research and interview process.

A. Can you tell me a little bit about your experiences of intervening with families where there was a child welfare concern (general)?

Probes:

How would you describe a vulnerable child?

Have you encountered families of vulnerable children where alcohol is a contributing factor to vulnerability?

Can you tell me your understanding on FASDs?

B. Can you share your experiences you have had working with children living with a neurodevelopmental disability in your work?

Probes:

What diagnosed conditions have you encountered?

What services have you accessed?

Was there any collaborative work around such cases?

Did FASD figure with this cohort of neuro disabilities?

What if anything, do you know about FASDs?

Can you tell me about your thoughts and feelings when you learned about FASD?

How does FASD fit with your social work values?

How does FASD fit with your ethical practices?

Have you read any social work orientated literature on FASD?

Can you tell me about your undergraduate education on FASD?

C. Have you responded to a child or caregiver where FASDs is the presenting factor of your intervention?

Probes:

How did this case present to you? Family, medical

How did the case make you feel? – relationship with the caregiver

What supports did you offer? Medical model /social model, conflicts?

What did you feel like during the intervention?

D. Can you tell me what would help you in responding to FASDs?

Probes:

How did you find this resource? Availability, criteria of service access,

Did you encounter any difficulty in seeking supports or services? Screening tools?

E. Has your employer been helpful?

Probes: what sort of help did you receive? How was this helpful? Policy? Training?

F. How do experiences of responding to FASD impact on your professional interventions?

Probes:

Did you/would you discuss in supervision? Supervision helpful/encouraging

What would help you respond better? In relation to, multidisciplinary. Medical collaboration, professional development, peer support/rejection

G. Please tell me your overall experiences of FASDs with your practice?

Probes:

In relation to, for example, leadership, life skills, advocacy, social justice.

Can you describe how you would like to respond to Child? Adult

H. Is there something you might have thought about since the interview started that you would like to share with me?

Probes:

Emotions, values, ethics, personal care.

I. Is there anything else you would like to share with me?

Appendix H: List of resources give to participants

Resources to Assist Social Workers

- Alcohol in Pregnancy Guide – A Pocket Guide. HSE, Ireland
[http://www.hse.ie/eng/services/news/Alcohol and Pregnancy Guide.pdf](http://www.hse.ie/eng/services/news/Alcohol_and_Pregnancy_Guide.pdf)
 - Substance Abuse and Mental Health Services Administration: <http://www.samhsa.gov/fetal-alcohol-spectrum-disorders-fasd-center>
 - American Bar Association: <https://apps.americanbar.org/litigation/committees/childrights/content/articles/fall2012-0912-fasd-identification-advocacy.html>
 - Project CHOICES: <http://www.cdc.gov/ncbddd/fasd/previous-projects.html>
 - Toolkit from the American Academy of Pediatrics: <https://www.aap.org/enus/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrumdisorders-toolkit/Pages/default.aspx>
 - CDC’s FASD app: <https://itunes.apple.com/us/app/fetal-alcohol-spectrumdisorders/id517058288?mt=8&ls=1>
 - Documentary “Moment to Moment: Teens Growing Up with FASDs”: <http://www.ntiupstream.com/>
 - Book: Understanding Fetal Alcohol Spectrum Disorder: A guide for Parents, carers and professionals, Jessica Kinsley Publishers <http://www.jkp.com/uk/understanding-fetal-alcohol-spectrum-disorder.html>
- Fetal Alcohol Spectrum Disorder Promising Practices for Children in the Care of Alberta Children and Youth Services (2011). <http://fasd.alberta.ca/documents/FASD-COP-Final-Report-2011.pdf>

Appendix G: Access Approval to foster parents (Phase 2)



Unit 23
Village Green
Tallaght
Dublin 24
Tel: 01 459 9474
Email: info@ifca.ie
www.ifca.ie

Liam Curran, M.Sc.
INDI PhD Candidate,
Young Adult and Alcohol Research Lab,
Department of Psychology,
Concordia University,
7141 Sherbrooke St. West,
Montreal, QC H4B-1R6

30 June 2017

Dear Liam,

This is to confirm that the Irish Foster Care Association will support your study and will assist you in contacting foster carers to discuss the disability of FASD.

Please contact us when you are ready to carry out the interviews and we will put you in contact with relevant foster carers.

Wishing you the best with your research

Yours,



Breda O'Donovan,
Acting CEO.

Appendix M: A sample of personal reflection

20/8/2017 – Reflection

Watching the All Ireland football semi-final between Mayo and Kerry on the 20th of August 2017 produced an unlikely timing of an emergent category. I was watching the dying minutes of this match when the commentator made the reference to "searching for a winner" the teams were level. As I watched the play, I was struck by the way the players were moving the ball between themselves - then suddenly an interception and the ball was oscillating back and forth between that team. Yes, the word oscillating appeared in my data - children associating from assessment to assessment, from diagnosis to diagnosis and from professional to professional as if on a Ferris wheel with the CWSW looking for the holy grail that will address the child's need. The ball within the above football match came to represent the child with an FASD - passed from one professional to another - like the players these professionals did not have the knowledge or clear vision to score a point or a goal - in other words they did not have the ability to take the child to a goal winning moment of meeting their needs. As the players tossed the ball back and forth as they searched for a winner, the concept of child welfare social work searching for knowledge to help a child with an FASD emerged. Searching, searching back and forth like the ball on the pitch, going back and forth not knowing how or when to move forward. Just as a team must work together to deliver a score in a competitive match, so the need is evident that the CWSW cannot secure a child's welfare in isolation. The CWSW also needs a team if they are to secure a child's welfare and plan safe care.

Appendix N: A Sample of Memoing – “Not Once”


Memo June 16th, 2017

My data is thrown up some very difficult personal accounts both of dealing with the children living with an FASD but also there is a very strong feeling of concern for women’s health. As a male researcher I find myself constantly worrying about how this study will be interpreted by others and fearing to some extent that the study could be used like a 'sledge hammer to crack a nut' - meaning I worry that women could be blamed for the FASD disability while I am very aware that basic education information is not available to Irish women concerning alcohol use in pregnancy. The majority of my participants are women of child bearing age. Today in my interview with Marie she disclosed her personal life of discussing the birth of her first child. She discussed how not once had she been advised by the medical personnel that she should avoid alcohol. What is this saying about maternal-child health within Irish culture? Is stigma and the fear of stigma preventing knowledge translation which can empower women of child bearing age. Is fear controlling the dialogue and leaving women vulnerable? How do female CWSW balance the personal and the professional ethical issues concerning alcohol and pregnancy? Values and their relationship to practice are inherent an inherent aspect of undergraduate social work education. Is this education of values in social work sufficient to address the ethical, morale and personal values of alcohol use in pregnancy? Does prevention imply blame?

I am reminded of having read Dr Holland’s work at the University of Canberra, which clear stated that women want to know. It was found in that research that women were constantly bombarded with confusing message concerning alcohol in pregnancy. As Marie just note, not one professional had spoken to her about alcohol in pregnancy. This signifies a major gap in public health information on supporting women by empowering them with the correct

information. Also, if women are not getting the prevention education they need and want, this has implications for the CWSW as the potential for FASDs related referral to CWS are heightened. I am also wondering about how the majority of CWSW are female – does this mean that personal values will override the professional values of planning safe care for children – is gender in CWSW an underdeveloped area of the FASD dialogue on FASDs in CWSW??

Appendix O: Screen Shot dedoose software



dedoose
Great Research Made Easy

Merged Project 11/17/2017 + 7/17/2017 | Logout | Account | Home

Home

Codes

Media

Excerpts

Descriptors

Analyze

Memos

Training

Security

Data Set

Back

Projects

Project: Merged Project 11/17/2017 + 7/17/2017

Users: 1

Media: 18

Descriptors: 18

Excerpts: 1723

Codes: 10

Code Applications: 2216

Import Data

Export Data

Type	Title	Added	User	# Ex
Media	Liam Curran - SWIRL4 MP3.docx	07/26/2017	Liamcurran	123
Media	Liam Curran - SWIRL3 MP3.docx	07/27/2017	Liamcurran	177
Media	Liam Curran - SWIRL10 MP3.docx	07/27/2017	Liamcurran	169
Media	Liam Curran - SDSW1 MP3 .docx	08/18/2017	Liamcurran	105
Media	Liam Curran - SWIRL2.docx	08/21/2017	Liamcurran	114
Media	Liam Curran - SWIRL6.docx	08/24/2017	Liamcurran	157
Media	Liam Curran - SWIRL5	07/26/2017	Liamcurran	204
Media	Liam Curran - SWIRL7.docx	09/11/2017	Liamcurran	74
Media	Liam Curran - SWIRL8.docx	09/11/2017	Liamcurran	70
Media	Liam Curran - SWIRL14.docx	09/11/2017	Liamcurran	62
Media	Liam Curran - SWIRL11.docx	09/14/2017	Liamcurran	90
Media	Liam Curran - AHP4.doc	12/03/2017	Liamcurran	65

Codes

- 688 ADVOCATING AGAINST THE TIDE
- 265 CHALLENGING CULTURE NORMS
- 584 CHALLENGING PRACTICE INTERVENT...
- 151 CONTESTING MEDICAL PRIVILEGE
- 27 EMERGING KNOWLEDGE,SKILLS, C...
- 96 PROFESSIONAL POSITIONING
- 58 QUANTIFYING CHILDREN
- 112 RESPONDING TO NEEDS OF CHILDREN
- 80 SYSTEM SILOS LEADING TO COMPLEX ...
- 145 UNDERSTANDING NEEDS OF CHILD

Codes x Descriptor

Set: Full Project

Field: Gender

Frequency

Weight

Normalize

Hi/Miss

Sub-code Count

%

ADVOCATING AGAINST THE TIDE

Female	16.5%
Male	83.5%

CHALLENGING CULTURE NORMS

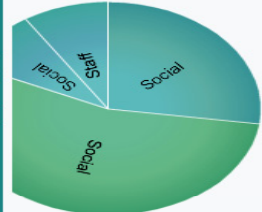
Female	33.7%
Male	66.3%

CHALLENGING PRACTICE INTERVENTIONS

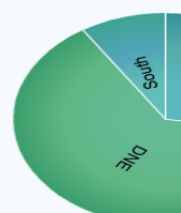
Female	26.8%
Male	73.2%

Descriptor Ratios Multi Chart

Set: Full Project, Field: Employer



Set: Full Project, Field: Location



Excerpts: 1723

Resource **Liam Curran - AHP4.doc** Added **12/19/2017** Username **Liamcurran** # Codes **1**

Yeah, and New Zealand are basically structuring it in to the whole thing of.....I suppose, what do you call it... They're cascading it down on four strands. I'm saying they're doing the prevention stra...

Resource **Liam Curran - AHP4.doc** Added **12/19/2017** Username **Liamcurran** # Codes **2**

Yeah, I mean, I mean okay, what do, okay, I mean like you can see exactly where I'm coming from, from, from a lot of the, from, in trying to manage, from your experience now working in Canada, what do you call it like, what would you think would be the best kind of situation for, you ...

Resource **Liam Curran - AHP4.doc** Added **12/19/2017** Username **Liamcurran** # Codes **1**

I mean like obviously we don't have, you know, we've very, very limited financial resources, but from we actually do have -- actually personally I actually feel that we actually do have the resources available to us, they just need a little bit of cooperation between the two serv...

Resource **Liam Curran - SWIRL15.doc** Added **12/19/2017** Username **Liamcurran** # Codes **2**

280