What Once Was Sick is Now Bad: The Shift from Pathologized Victim to Deviant Identity for
Those Diagnosed with Fetal Alcohol Spectrum Disorder

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Abstract

Fetal alcohol spectrum disorder (FASD) is constituted by different networks and institutions. In childhood, medicalized knowledges offer a pathologized understanding of those diagnosed with FASD. According to the literature, FASD children are victims of irresponsible mothers and poor parenting. With intensive programming provided by provincial governments and advocacy groups within a child's first six years, it is believed that FASD children can overcome the cognitive and behavioural symptoms and reach their optimum potential. As FASD children age however, the power afforded to medical discourses is substituted for knowledges produced by the criminal justice system. A shift takes place where FASD youth and adults are no longer constituted as victims, but are instead classified as deviant. Specific governing strategies reinforce the FASD adult as 'bad'. In this project, I problematize FASD as a psy-identity and use an individual's life course to demonstrate that while the symptoms associated with FASD do not change from childhood to adulthood, their conceptualization and use by different actors changes dramatically.

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Chapter 1: Introduction

The stories told about people with Fetal Alcohol Spectrum Disorder (FASD) are captivating. They are stories of addiction, despair, and loss; of hope, innocence, and perseverance; of violence, crime and impulsiveness. The juxtaposition between innocence and guilt, victim and perpetrator, sick and bad are little understood in the FASD population and beyond.

FASD is a complex, misunderstood and most important, socially constituted diagnosis. It is, above all, based on a certain social context – both in its creation in 1973 and its continued presence in certain populations and omission in others. Moreover, the perception of FASD makes a dramatic shift as the sympathy that marks society's response to a child gives way to responsabilization as an adult. Not only is the diagnosis of FASD itself socially constituted, but how it is perceived, managed and objectified is dependent upon how the various discourses make it up.

In this project I seek to understand the relationship between the criminal justice system and fetal alcohol spectrum disorder.¹ The FASD identity is used to constitute children as salvageable victims. In contrast, as adults the same classification works to make up people in conflict with the law as dangerous and beyond salvation. I will look at the brief history of this collection of symptoms as a diagnosable syndrome and how various discourses from the medical, political, grassroots and criminal justice disciplines create knowledges about FASD that responsabilizes the individual. This understanding of FASD is not inevitable or inherent to the illness. It has been constituted this way because

¹ The term FASD will be used throughout this project to refer to fetal alcohol syndrome, fetal alcohol effects, partial fetal alcohol syndrome, alcohol related birth defects and alcohol-related neurodevelopmental disorders.

of a series of complicated discourses concerning alcoholism, medicalization and demedicalization, cultural and socio-economic issues, politics and morality.²

Just as an FASD diagnosis varies significantly for each individual, so too do the primary and secondary disabilities associated with FASD. Primary disabilities are those problems resulting directly from neurological damage and range from mild to moderate mental retardation, poor memory and concentration skills,³ impulsivity, lying, inappropriate socialization, an inability to understand the consequences of their actions, and social withdrawal.⁴

According to the prevailing medical discourses, secondary disabilities are problems resulting from the primary disabilities but are not inherent to FASD, nor are they necessarily permanent, we are told. They can include mental health problems, disrupted school experience, involvement with the criminal justice system, inappropriate sexual behaviour, substance abuse problems, homelessness, dependent living and problems with steady employment.⁵

In this project I take a critical approach to understanding this grouping of syndromes known as FASD. It is important to recognize however, that while this research questions how and why this syndrome was constituted and continues to be understood as a pathology warranting the criminal justice system, this work is not intended to engage in

² Janet Golden, *Message in a Bottle: The Making of Fetal Alcohol Syndrome* (Cambridge: Harvard University Press, 2005) at 9-14.

³ Public Health Agency of Canada, *Fetal Alcohol Spectrum Disorder – Knowledge and Attitudes of Health Professionals about Fetal Alcohol Syndrome: Results of a National Survey* online: http://www.phac-aspc.gc.ca/publicat/fasd-surv-etcaf-enquete/pdf/fasd-surv-etcaf-enquete-2005_e.pdf, last accessed 12 August 2007 at 25.

⁴ *Ibid.*

⁵ Ann Streissguth (ed.) et al., “Primary and secondary disabilities in fetal alcohol syndrome” in Jonathan Kanter ed., *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (Seattle: University of Washington Press, 1997) 25 at 27, 33-34.

the question of whether or not FASD is real in the biological sense of the term. My point is that the deployment of the identity, real or not, has real effects.

Research on FASD as a constituted identity would not be complete without addressing its impact on First Nations, Métis and Inuit populations in Canada. Aboriginal communities have a unique association with issues involving FASD generally and adults in the criminal justice system more specifically. Correctional Service of Canada (CSC) claims that the incidence of FASD diagnosis amongst Aboriginal populations in Canada is more than ten times higher than Caucasians.⁶ In turn, the over-representation of incarcerated Aboriginals⁷ and individuals with FASD⁸ warrants further critical thought. One of the aims of this project is to understand how the discourses surrounding the FASD criminal identity incorporates Aboriginals as its population of choice. Understanding this discourse is pivotal to understanding the knowledges concerning adults with FASD in the criminal justice system.

Fetal Alcohol Spectrum Disorder as a Problem Worth Studying

Knowledges about FASD come from a multidisciplinary arrangement of disciplines that shift throughout the life course. Some of these areas include, but are not limited to: the health care system, the education system, the welfare system, the employment sector, the field of social work, the area of psychology and mental health,

⁶ Fred J. Boland et al., *Fetal Alcohol Syndrome: Implications for Correctional Service* (Correctional Service Canada, 1998) online: http://www.csc-scc.gc.ca/text/rsrch/reports/r71/r71e_e.shtml#6, last accessed 9 August 2006 at 14.

⁷ Law Commission of Canada, *What is a Crime? Challenges and Alternatives: Discussion Paper* (Her Majesty the Queen in Right of Canada, 2003) at 19.

⁸ Diane K. Fast & Julianne Conry, "The challenge of fetal alcohol syndrome in the criminal legal system" 9 *Addiction Biology* 161 at 161.

and the criminal justice system. These locales - most notably psy-sciences⁹ - create knowledges about FASD that constitute children as victims and adults as deviant. The relationship between individuals with FASD and the criminal justice system is complex. It requires an understanding of various networks of actors and knowledges, including: the medicalization of the criminal justice system; the criminal justice system's understanding of the biology of FASD; the (over)use of imprisonment; the challenge working with, rather than against, young offenders and adults with this syndrome; and advocates for people diagnosed with FASD who are often silenced in broader policy and political debates.

The aim of this project is to add to the little scholarship concerning FASD and to think critically about the diagnosis and its governing effects. This project is important because I want to change the way we think about mental health, especially in the criminal justice system. By showing the context in which diagnoses are made, the governing effects of pathologizing certain behaviours and people, and by following the use of these technologies in the criminal justice system, I hope to reconceptualise mental health as a problem to manage.

The research touches upon two main bodies of knowledge. First, it contributes to the literature concerning psy-identities and issues surrounding scientific explanations for social phenomena. Second, this work transitions clearly into the criminological literature and the debates concerning mental health, specifically for issues concerning FASD. Although there is little critical criminology connecting FASD research with the criminal justice system, I build upon the few works in the literature and further develop the literature by considering the life course of someone diagnosed with FASD.

⁹ By psy-sciences I am referring to psychology, psychiatry and other disciplines related to these areas.

As a psy-science identity FASD is constituted with the assumption that because it was ‘discovered’ by a science-based discipline, the diagnosis itself is objective and calculable. The creation of an identity appears to be an isolated incident, separated from space and time, only to exist unto itself rather than as part of a particular social context.¹⁰ Rosenberg finds this limit in scope problematic. He states that through scientific rhetoric, psy-identities are misleading as they appear to be completely rational and incontestable and ignore the true subjectivity to which all identities are constituted.¹¹

Similarly, given that psy-identities are presented as purely objective science it is not surprising that these identities are also portrayed as completely natural. Although in reality diagnoses are debated, negotiated, and even voted upon, (as is the case when each new version of the *Diagnostic and Statistical Manual* is set for publication)¹² once pathologized, psy-identities are presented as having been discovered. This means that a diagnosis has always existed but was hidden until now. If this is the case there is no place for change or a shift in thinking as society itself changes. A psy-identity is supposedly static.¹³ For FASD, the science behind the identity and the social connotations it supports (such as being ‘bad’ or untreatable) does not come under scrutiny because it appears impossible to critique. In reality, a greater awareness of the social circumstances surrounding its ‘discovery’ in 1973 and how social discourses continue to play a role in the perception of an FASD individual will add a richness to the literature that cannot be found in the scientific discourses.

¹⁰ Charles E. Rosenberg, “The tyranny of diagnosis: Specific entities and individual experience” (2002) 80 *The Milbank Quarterly* 237 at 246.

¹¹ *Ibid.* at 238.

¹² Herb Kutchins and Stuart A. Kirk, *Making us Crazy – DSM: The Psychiatric Bible and the Creation of Mental Disorders* (New York: The Free Press, 1997) at 239.

¹³ Nikolas Rose, “Calculable minds and manageable individuals” (1988) 1 *History of the Human Sciences* 179 at 180; and Ian Hacking, *Mad Travelers: Reflections on the Reality of Transient Mental Illness* (Charlottesville: University Press of Virginia, 1998).

Hacking's work on social identities becomes important here. Hacking carefully analyzes social constructions and explores the idea that medicalization literature tirelessly promotes the notion that it is objective, but it is only through society's acceptance of a diagnosis that an identity is established and seen as scientifically legitimate.¹⁴ More importantly for Hacking, however, is how individuals manage their own identities. Hacking's notion of 'the looping effect' provides a framework for understanding how FASD is perceived, particularly the adult identity. The looping effect he refers to is speaking of the dual effect an identity has on the individual and the social body. An individual will engage differently with the social body as different assumptions, attitudes and expectations are placed upon an identity.¹⁵ Hacking is exploring the fluid, evolving nature of an identity and how shifts in knowledges about these identities come from society as well as the target population.

Hacking's ideas provide an excellent backdrop for understanding society's impression of adults with FASD. The looping effect is abundantly clear when research reveals that those diagnosed with fetal alcohol syndrome (FAS) instead of fetal alcohol effects (FAE) / alcohol-related neurodevelopmental disorders (ARND)¹⁶ are much less likely to suffer from secondary disabilities – including trouble with the law – because FAS is more recognizable as a disability. Thus, the expectations placed upon these individuals by others are aligned with their abilities. Those diagnosed with FAE/ARND are often perceived as 'normal' with high expectations of appropriate behaviour, learning

¹⁴ Ian Hacking, *The Social Construction of What?* (Cambridge: Harvard University Press, 1999) at 129-133.

¹⁵ Ian Hacking, "Between Michel Foucault and Erving Goffman: Between discourse in the abstract and face-to-face interaction" (2004) 33 *Economy and Society* 277 at 279.

¹⁶ According to the literature FAE/ARND are not less severe forms of FAS, but because these diagnoses do not include the facial features associated with FAS and because often those with FAE/ARND have a slightly higher IQ, those diagnosed with FAE/ARND are likely to be treated as having fewer challenges than FAS.

ability and social awareness.¹⁷ If those diagnosed with FAE/ARND come in contact with the criminal justice system, they are more likely to be recognized as ‘bad’ because their diagnosis is not classified as ‘sick’ enough. FAE/ARND appears to make being ‘bad’ more likely: “Two intrinsic characteristics are associated with a *higher* level of secondary disabilities: having FAE rather than FAS and having an IQ above 70 rather than below. Special attention should focus on patients with these “risky” characteristics in order to prevent secondary disabilities [emphasis in original]”.¹⁸ Given that Streissguth et al.’s study found that trouble with the law is the second most common secondary disability, it is no surprise that the loop is informed by and classifies FAE/ARND as bad.

Included in this critical look at identity is recognition of where the individual exists in spaces other than a master status such as FASD. Rosenberg notes that individual status is consumed by identity. As a reflection of the supposed neutrality of the psy-identity, the social body often ignores the part of the individual who exists outside of the identity. In doing so, social realities are excluded from consideration.¹⁹ Rose adds to this idea by exploring the normalization techniques that take place when an individual becomes knowable only by virtue of the psy-identity imposed upon her. By this, he means that the essence of an individual is considered only as far as her similarities and differences between others with the same psy-identity.²⁰ The existence of this identity is ‘abnormal’ and ‘bad’ because there is some deviation from the norm and so the social

¹⁷ Kathryn Page, “Fetal alcohol spectrum – The hidden epidemic in our courts” (2001) 52 Juv. & Fam. Cr. J. 21 at 26.

¹⁸ Streissguth, *supra* note 5 at 36.

¹⁹ Rosenberg, *supra* note 10 at 255.

²⁰ Rose, *supra* note 13 at 197.

body interacts only with the abnormal psy-identity through normalization techniques rather than relating to the individual herself.²¹

What I am especially interested in is how this psy-identity changes as someone with FASD moves from infancy and childhood to adulthood, which contradicts the psy-science notion that these identities are natural and static. The majority of FASD research focuses on prevention and awareness issues related to the fetus, newborns and early school aged children.²² The literature often fails to recognize that these children will inevitably grow up. This project provides an in depth investigation into why FASD has been constituted to recognize the needs of infants and children but neglect adults. There are considerable issues at stake here, including the stigma associated with an ‘irresponsible’ mother, a loss of resources and supports, and the expectation that as they age FASD individuals can (and must) take on responsibility that was acknowledged as exceedingly difficult as children. Without reference to these issues in the literature, it appears that only place for an FASD adult is within the confines of the criminal justice system. Of course, FASD adults are not alone in being treated differently and more harshly with age, but what is remarkable is that when viewed through the lens of the looping effect, it is the constitution of the diagnosis itself that shifts and takes on the ‘bad’ identity.

Interaction between all levels of the justice system and an individual with FASD poses significant challenges. Because FASD affected individuals are thought to have trouble with memory, abstract concepts, and are easily persuaded (not only to commit

²¹ Nikolas Rose, *Inventing Our Selves: Psychology, Power and Personhood* (Cambridge: Cambridge University Press, 1998) at 13, 17.

²² See, for example, British Columbia, *Fetal Alcohol Spectrum Disorder: A Strategic Plan for British Columbia*, online: http://www.mcf.gov.bc.ca/fasd/pdf/fasd_strategic_plan-final.pdf, last accessed 15 August 2006; and Public Health Agency of Canada, *supra* note 3.

crimes but to confess to a crime they may or may not have participated in), some advocacy groups suggest parents make a carrying card for their child to explain the disability to police, legal aid etc.²³ Suggestions are targeted at parents, thereby placing the onus on them to provide information to the players in the judicial system.²⁴ This strategy for knowledge dissemination assumes that there will be a third party, or ‘external brain’ as it is referred to in the FASD literature, that will support the individual in trouble with the law.²⁵ Safeguards for those with mental illness, such as fitness to stand trial and the not criminally responsible provision in s. 16 of the *Criminal Code* are rarely viable options for FASD adults. For the criminal justice system, their ‘bad’ identity is of sole interest.

I have used current critical literature as a starting point for analysis. Most apparent is the critical literature that questions how the medical constitution of FASD was formed. While scholars such as Armstrong and Golden question the fundamental science behind the FASD diagnosis, both authors focus primarily on gender issues related to women who consume alcohol during pregnancy and the legal battle that has taken place concerning the rights of the woman and the rights of the fetus. Instead, I question how and why the medicalization of the set of symptoms now known as FASD came to be and how we view those who are born and grow up with the label. This entails critically engaging with the psy-disciplines and medical knowledges pertaining to FASD such as the reluctance to diagnose adults, the supposed futility of treatment, and the behavioural abnormalities

²³ Margaret A. Michaud & Sacha K. Michaud, *Beautiful Smiles, Gentle Spirit - Fetal Alcohol Spectrum Disorder: A Misunderstood Problem* (Calgary: Detselig Enterprises, 2003) at 59.

²⁴ *Ibid.*; and Katherine Norgard, *Hard to Place: A Crime of Alcohol* (Tucson: Recovery Resources Press, 2006).

²⁵ External brain is defined by Page: “With defects in executive functioning, one needs to recruit an outside executive – someone who will help mind the store, captain the ship.” *supra* note 17 at 27.

making up the primary and secondary disabilities.²⁶ It is precisely because these knowledges are assumed to be true that I am obliged to question them.²⁷

The critical literature also questions the historical, political and social context within which FASD was created. As the critical literature attests FASD as a diagnosis was not inevitable, but came to be because of particular social and historical conditions. As Armstrong writes:

The construction of the diagnosis of FAS reflects the emergence of an epidemiological paradigm emphasizing risk factors rooted in individual behaviour and predilections; indeed, it epitomizes our modern American tendency to locate explanations for disease at the individual – whether behavioural or biological – level rather than to see disease as the consequence of social conditions.²⁸

Rather than an attack on FASD itself, this project is an investigation into which qualified discourses are able to produce knowledges about FASD and how these knowledges are used to portray the FASD adult as deviant rather than sick.²⁹

The critical literature very rarely discusses the connection between the FASD identity and the criminal justice system. Golden refers to this area briefly, but only in the context of appeals to death sentences.³⁰ This is a major gap because it neglects the complete story of the FASD identity. It fails to consider the purpose of diagnosing someone with FASD. Viewing the FASD identity through the life course lens provides a

²⁶ For example, Julianne Conry and Diane Fast, *Fetal Alcohol Syndrome and the Criminal Justice System* (Vancouver: The Law Foundation of British Columbia, 2000) at 6-10; and British Columbia, *supra* note 22.

²⁷ Rosenberg has some interesting ideas on how in reality, diseases are negotiated and are not limited to medical knowledge. See, Rosenberg, *supra* note 10.

²⁸ Elizabeth M Armstrong, *Conceiving Risk Bearing Responsibility: Fetal Alcohol Syndrome and the Diagnosis of Moral Disorder* (Baltimore: The John Hopkins University Press, 2003) at 11.

²⁹ Elizabeth Armstrong, "Diagnosing Moral Disorder: The Discovery and Evolution of Fetal Alcohol Syndrome" (1998) 47 Soc. Sci. Med. 2025. and Janet Golden, "'An Argument that Goes Back to the Womb': The Demedicalization of Fetal Alcohol Syndrome, 1973-1992" (1999) 33 Journal of Social History 269 at 271.

³⁰ Norgard, *supra* note 24; and Golden, *supra* note 2 at 152-161.

space to witness other ways of making-up the identity (such as a victim) and the governing technologies that lead to intervention from the criminal justice system.

Theoretical Perspectives

I followed a genealogical approach to assist my inquiry into FASD. Implicit here are Foucaultian understandings of normalization techniques and the construction of objects of regulation. In combination with Foucaultian analytics, the study of the medicalization literature plays a role in considering the constitution of FASD as a disability and its shift to deviancy.

Foucault's ideas of normalization are widely used to understand the subjugation of various groups throughout history. Here, normalization refers to a matter of objectifying difference.³¹ The norm allows for a distinction between what is acceptable and unacceptable through the clear marking of what values, attitudes, and behaviours denote the normalized self. Rather than a complete domination of one group over another, the norm is constituted more subtly through a variety of discourses that shape the life of the social body. More precisely, these discourses account for every detail of the social body and affirms which factors contribute to an idealized conception of how life ought to be lived; a 'normal' life.³² This norm allows individuals to be measured, seemingly objectively, so as to provide a systematic tool for judging an individual's choices of conduct and attitude.

³¹ Robert Castel, "From dangerousness to risk" in Graham Burchell, Colin Gordon and Peter Miller eds., *The Foucault Effect: Studies in Governmentality* (Chicago: University of Chicago Press, 1991) 281 at 294.

³² Gerald Turkel, "Michel Foucault: Law, power and knowledge" (1990) 17 J.L. & Soc'y 170 at 185.

These norms, according to Foucault himself, yield huge power not only in controlling conduct, but in shaping individual and collective goals and desires.³³ For those who do not adhere to these shared goals, disciplinary tactics become legitimized through the objective of normalization. This individualization of normative behaviour suggests a notion of commonality, given that there is a standard by which all individuals are held accountable. The problem in this assumption of commonality, however, is that it endorses the idea that any deviation from this common norm is ‘abnormal’.³⁴

The normalization process is essential to understanding FASD in relation to the criminal justice system given that those with FASD are labelled as abnormal. This label is useful for the criminal justice framework because it works from the assumption that individuals are able to act as ‘free subjects’ and make rational choices as to whether or not to adhere to the norm.³⁵ Normalization discourses concerning FASD consider the diagnosis a marking of ‘abnormality’ and ‘irrationality’ while the individual remains a free subject. Judgement of those with FASD as deviant rather than sick occurs because the symptoms associated with FASD contradict the norms of self control and obedience.³⁶ When a deviation occurs³⁷ such as in the case of individuals with FASD, normalization strategies take shape, which include exclusion and subjugation.

This exclusion and subjugation are essential to the construction of FASD as an object of regulation. As with normalization, objects of regulation are not static, nor are they predetermined: “There are no natural or ready-made social objects and hence no

³³ Rose and Mariana Valverde, “Governed by law?” (1998) 7 Soc. & Leg. Stud. 569 at 571.

³⁴ *Ibid.* at 573.

³⁵ Mitchell Dean, “A social structure of many souls: Moral regulation, government, and self-formation” (1994) 19 Canadian Journal of Sociology 145 at 163.

³⁶ Nikolas Rose, “Unreasonable rights: Mental illness and the limits of the law” (1985) 12 J.L. & Soc’y 199 at 205.

³⁷ Karlis Racevskis, *Michel Foucault and the Subversion of Intellect* (Ithaca: Cornell University Press, 1983) at 107.

ready-made objects of regulation. Their existence is always the outcome of some active process that creates that which is to be regulated”.³⁸

The goal of creating an object of regulation is to punish for the purpose of reshaping the will of the subject.³⁹ Punishment is a preferred form of establishing objects of regulation because it allows for the greatest degree of surveillance and acts as a safeguard from the ‘dangerousness’ of the subject.⁴⁰ Thus, being constituted as an object of regulation entails suppression, marginalization and objectification in an attempt to coerce the subject into normative conduct.⁴¹

Complementary to the Foucaultian discussion of normalization and objects of regulation, another component to the theoretical engagement is to understand the use of psy-sciences and medicalization as it applies to the label of FASD. Medicalization literature is made up of privileged discourses that do not exist in a vacuum, but are shaped and understood by larger social and political constructs.⁴² Critics of medicalization discourses demonstrate how social, political, and historical phenomena are transformed into pathologies that medical knowledges have exclusive power in producing.

This work is especially helpful because it relates explicitly to the genealogical method. For example, Rose states: “A genealogy of subjectification takes this individualized, interiorized, totalized and psychologized understanding of what it is to be human as a site of a historical problem, not as the basis for historical narrative”.⁴³ By

³⁸ Alan Hunt, *Explorations in Law and Society: Toward a Constitutive Theory of Law* (New York: Routledge, 1993) at 316.

³⁹ Turkel, *supra* note 32 at 180.

⁴⁰ *Ibid.* at 201.

⁴¹ Hunt, *supra* note 38 at 314.

⁴² Rosenberg, *supra* note 10 at 239.

⁴³ Rose, *supra* note 21 at 23.

using Foucault's genealogical method to understand the medicalization and demedicalization of FASD in the criminal justice system, I am able to explore the evolution of the FASD identity through a critical lens. In this project I problematize common assumptions about psy identities, responsabilization and deviancy. I look closely at which discourses are being privileged and which are being subjugated in order to advance the genealogical method.

Methodology

My primary approach to this research was to interview key players in disciplines related to FASD. These interviews allowed for a detailed understanding of the many ways FASD is negotiated in society. Interviews were conducted consensually and the questions related to their own experiences with FASD in a personal, professional or policy driven capacity. I am using eight of the interviews in this project. See the appendix for a list and description of the interviewees.

Ethical clearance was received through Carleton University to conduct the interviews. Participants received a letter of information, explaining the project and a consent form to sign. The interviews took place either in person or over the phone, depending on geographical location. Interviews lasted on average for one hour, but ranged from a half hour to two hours in length. The interviews consisted of open-ended questions that were specific to the participant's position. During the interview detailed, handwritten notes were taken as opposed to tape recording. This decision was made to maintain the integrity of the personal and at time sensitive nature of the answers. Afterwards, I offered the notes of the interview to the participant to look over and clarify

information. Two of the eight participants accepted this offer. One of the participants made changes.

I found participants for the interviews through a combination of cold-calling and snowball sampling. I met with some resistance from some federal government departments as well as from Aboriginal organizations (the latter will be discussed in chapter 4). Advocacy organizations, the primary recipients of the cold-calls, were eager to participate in the interviews.

I also looked at case law related to FASD. Using the keyword “fetal alcohol syndrome” in Quicklaw, I searched for any common assumptions or reactions to an accused where FASD was discussed as well as its use in sentencing hearings. The majority of these cases came from the Yukon and British Columbia. These proceedings tended to be informal and consist of verbatim conversations between the crown, defence council and the judge. There are few cases that discuss FASD directly so I was limited in the quantity of cases to analyse.

In addition to these resources, I tracked political developments through legislative debates on FASD. I began my search through *Hansard* in 1968 (the year Dr. Lemoine’s article was published in France) through to 2008 to retrieve the data. The keywords used to search Hansard were – alcohol, alcoholism, fetal alcohol syndrome, children, crime, health, Indian (later Native) and penitentiaries.

Hansard transcripts were complemented by other government documents. Pamphlets, guides and studies composed by some provinces in regards to prevention of FASD, how to cope with FASD and a small handful on individuals with FASD in the

criminal justice system were all included.⁴⁴ These documents come from government, service providers, and advocacy groups. The resources helped to uncover the political and ideological nature through which FASD was constituted and is currently maintained.

Finally, I used personal stories that have been made public to complete my research. This type of data represents the majority of published material on FASD. The first of these books was Michael Dorris' *The Broken Cord*. This book has been credited with bringing FASD into the mainstream. It is the personal story of the author's adopted son who struggled with fetal alcohol syndrome (FAS). The author, an anthropologist, began to study FASD as it relates to Native Americans and so this book is an interplay between fact and story telling.⁴⁵ Since then, this genre of writing has become the main source of information on FASD and so is a valuable resource for analysis.⁴⁶

Chapter Breakdown

The second chapter of this project maps out the short history of FASD as a medical diagnosis. This will include a critical view of the medicalization literature and the conditions in which FAS came to fruition in 1973.

The third chapter considers the child with FASD as a distinct identity. This child is worthy of saving because the behavioural and cognitive problems are not linked to the child herself. She is a victim.

⁴⁴ For example, see British Columbia, *supra* note 22; and Paul Verbrugge, *Fetal Alcohol Spectrum Disorder and the Youth Criminal Justice System: A Discussion Paper* (Ottawa: Department of Justice, 2003); and Bolland, *supra* note 6.

⁴⁵ Michael Dorris, *The Broken Cord* (New York: Harper & Row, 1989).

⁴⁶ See, Bonnie Buxton, *Damaged Angels: A mother discovers the terrible cost of alcohol in pregnancy* (Toronto: Alfred A. Knopf Canada, 2004); and Norgard, *supra* note 24; and Michaud, *supra* note 23.

In chapter four I consider the new loop that emerges as FASD individuals grow into adults and become acquainted with the criminal justice system. The FASD identity is not static. Rather, the same individual is labelled with two different identities within a single life course.

Finally, chapter five will conclude with thoughts on where the different bodies of research are going and some of the gaps that need to be filled.

Chapter 2: The FASD Identity

Introduction

Unlike most medical conditions (cancer, pneumonia, or chicken pox, for example) fetal alcohol spectrum disorder is a relatively new diagnosis. Since its discovery in 1973, the diagnosis originally known only as fetal alcohol syndrome has taken various forms and continues to be reformulated.¹ The goal of this chapter is two-fold. First, a critique of the scientific literature related to FASD is essential for this project, as this is a gap in the scholarship. This will be accomplished by breaking down the medical discourse through an exhaustive analysis of the first two articles that gave rise to the FASD diagnosis. Moreover, the diagnosis itself is problematized in the final section of this chapter. Second, I will look at the development of the diagnosis through a social and political lens. The context in which the FASD diagnosis was founded is not an accident. I am interested in how FASD becomes a problem, beginning with shifts in the social climate and the rise in power of medical and psy-knowledges. Additionally, I will relate the new diagnosis to ‘crack babies’ in the 1980s and consider the governing effects to help uncover where FASD came from and why.

In order to engage critically with scientific knowledges I am relying on Hacking’s frameworks. The looping effect is “...the ways in which those who are classified, and who are altered by being so classified, also change in ways that causes systems of classification be modified in turn”.² It will be used in this chapter as a tool to conceptualize the ways in which the FASD identity has become solidified as a ‘truth’

¹ See the University of Washington School of Medicine where the initial work on FAS took place in 1973 and where many of these same researchers continue to work on these issues today.

² Ian Hacking, “Between Michel Foucault and Erving Goffman: Between discourse in the abstract and face-to-face interaction” (2004) 33 *Economy and Society* 277 at 279.

through reinforcing discourses. Hacking's bigger project of uncovering how people are 'made-up' is also useful. Hacking references *available* classifications, meaning an individual's choices and decision making are dependent on the constraints of distinct classifications.³ Hacking warns us that some classifications appear to be objective and timeless, which blinds us to the influence time, place, and the individual have on an identity.⁴ Being classified as sick, victim, deviant, or abnormal is contingent upon today's conception of that identity. This means that how we currently perceive our self and others will inevitably change as society and the individual classified change.

Hacking's work on the social construction of child abuse is especially helpful. In his chapter on kind-making, Hacking makes clear the social and political knowledges that have changed over time to bring about varying notions of what child abuse is. He emphasizes, "how we have concepts, practices, institutions and even people being formed and molded before our very lives".⁵ Hacking's choice of child abuse as his subject is important because it demonstrates that even those classifications which currently appear to be obvious and innate are really tools used to organize and govern. Hacking walks us through the history of child abuse as an identity, remarking on the shift from child cruelty at the end of the Victorian era, to the medicalized version of child cruelty in the form of child abuse in the early twentieth century, and battered-child syndrome in the 1960s.⁶ Each of these variations on harm done to children reflects different actions, different intervening institutions and governing effects, as well as different issues around morality. This is a valuable frame of thought when uncovering the discourses that make up a

³ Ian Hacking, "The making and molding of child abuse" (1991) 17 *Critical Inquiry* 253 at 254-255.

⁴ Ian Hacking, *The Social Construction of What?* (Cambridge: Harvard University Press, 1999) at 151.

⁵ *Ibid.* at 127.

⁶ Hacking, *supra* note 3.

scientific diagnosis, as in the case of FASD.⁷ Medicalized discourses are often assumed to be objective and unequivocally 'true'. The subjectivity, adaptability and malleability of medical knowledges are in fact worth questioning.⁸

Rose's work on psy-knowledges complements Hacking's in that psy-sciences aim to classify people and do so in a way that is seemingly objective. Rose refers to 'making up' people and the malleability of an identity; however, psy-knowledges have a different way of presenting the identities that they have a stake in. Rose sees a psy-identity as constituting people as either normal or abnormal. Identities are built upon whether they buy into normalizing techniques or whether they are subject to these strategies. Classification, according to Rose, is a means for psy-sciences to manage individuals by focusing exclusively on a single identity.⁹ As he describes: "The idea of a unified, coherent, self-centered subject has been upset by the multitude of ways our selves are shaped, but psychology likes to pigeon hole into one identity".¹⁰ Rose's work explores the psy-discipline as one based on developing precise governing mechanisms for persuading the 'abnormal' to become 'normal'. His research allows us to consider that although the psy-science discipline may be deep in history, it is not deep in unequivocal fact.

⁷ It is important to note that Hacking speaks directly about fetal alcohol syndrome, but in a way that is markedly uncritical compared to his other forms of analysis. He speaks about FAS in Hacking, *supra* note 4 and in Hacking, *supra* note 2, stating in the latter: "Yet a positive effect is the heightened public awareness of maternal alcoholism and fetal alcohol syndrome. The syndrome has long been known, but perhaps only because of the child abuse movement has it finally become clear how much this has had to do with the ongoing destruction of Amerindian populations, especially in the far north at this very moment." (263) I am moving away from this acceptance of FAS as a syndrome that has long been known and as relating directly to the Aboriginal populations.

⁸ Charles E. Rosenberg does this very well in "The tyranny of diagnosis: Specific entities and individual experience" (2002) 80 *The Milbank Quarterly* 237 at 240-246.

⁹ Nikolas Rose, "Calculable minds and manageable individuals" (1988) 1 *History of the Human Sciences* 179 at 187.

¹⁰ Nikolas Rose, *Inventing Our Selves: Psychology, Power and Personhood* (Cambridge: Cambridge University Press, 1998) at 4.

By combining the ideas of Hacking and Rose in this chapter and throughout the project, I provide a meaningful critique of FASD as a collection of symptoms that were combined and are now understood through governing techniques. Rose's ideas about the dichotomy between the normal and the abnormal identity are especially helpful when we see the effect of using a single identity by the psy-sciences. Constituting an identity as abnormal allows its 'abnormality' to be quantified, measured and consequently acted upon.¹¹ In the same way, identities are disciplined for being abnormal. By getting a sense of the rationale for constituting the FASD identity as it is, I lay the ground work for the remainder of the project – uncovering how and why FASD is linked to criminality. If, as Rose suggests, diagnosis itself can be built on abnormality so too can the classification of FASD.

The theoretical lens described above will allow me to pose some critical questions in relation to the 'discovery' of FASD and its reception within the medical community. My aim is not to decipher precisely what social and political events triggered this accumulation of particular symptoms at a given time and space but rather to suggest that the political and social climate at the time FASD came to be was imperative to its existence as a diagnosis. Similarly, I assert that the formation of this diagnosis in its current state was not inevitable and will continue to adapt as those who classify and those who are classified add to the discourses surrounding FASD.

The Genealogy of FASD

In 1968 Paul Lemoine, a French paediatrician, wrote an article titled, "Les enfants de parents alcooliques. Anomalies observées". This was the first publication

¹¹ Rose, *supra* note 9 at 189.

claiming a concrete connection between prenatal alcohol exposure and a developing fetus.¹² The few who heard of his work dismissed the idea entirely, finding the assertion that alcohol negatively impacts the fetus unfounded.¹³ Five years later Smith and Jones from the University of Washington in Seattle made similar connections to those mentioned by Lemoine (although they did not come across his work until after their findings were published). Smith and Jones, along with Streissguth and Ulleland, published what is now considered the first article describing fetal alcohol syndrome. It would be named so by the same authors in an article published five months later. Both articles were published in the *Lancet* in 1973.¹⁴ It took only six months and two articles for the FAS identity to be born.

The two *Lancet* articles that instantly gave rise to a new syndrome have been subject to little criticism since their publication. Instead, the medical community was quick to embrace this new scientific discovery with few questions. Armstrong and Golden are among the few scholars who provide a thorough and valuable critique of the FASD diagnosis. Both authors pose critical questions concerning the methodology used in ‘discovering’ FASD.¹⁵ The authors find it difficult to come to terms with the limited number of cases used to construct the diagnosis. The first *Lancet* article comprises of only eight cases and the second article looks at three more patients.¹⁶ Armstrong and

¹² Michael Dorris, *The Broken Cord* (New York: Harper & Row, 1989) at 143. While beyond the scope of this project, it would be interesting to note why European countries were and in many ways continue to be skeptical of making grand claims concerning the danger of alcohol consumption while pregnant while North America and the United Kingdom embrace the idea.

¹³ Janet Golden, *Message in a Bottle: The Making of Fetal Alcohol Syndrome* (Cambridge: Harvard University Press, 2005) at 6.

¹⁴ *Ibid.* at 4.

¹⁵ *Ibid.*; and Elizabeth M. Armstrong, *Conceiving Risk Bearing Responsibility: Fetal Alcohol Syndrome and the Diagnosis of Moral Disorder* (Baltimore: The John Hopkins University Press, 2003).

¹⁶ Kenneth L. Jones et al., “Pattern of malformation in offspring of chronic alcoholic mothers” (1973) 1 *Lancet* 1267.

Golden are concerned that a new syndrome – a new identity – was created based on only eleven cases. It is troubling to these authors that a new diagnosis was constituted based on assumptions made about the data and its universal application. These critiques are indeed significant but have been limited to an exclusively gendered argument. I would like to move beyond this scholarship and analyse the *Lancet* articles in a more exhaustive way.

Besides the description of eleven patients, the articles are talking about morality, motherhood, race and deviancy. Just as Rose reminds us, the *Lancet* articles embody more than the medical discourses they present. When studied through a critical lens, they can become a gateway to making sense of the social and political context through which the medical knowledge was established.

An important objective of scientific discourses is to appear a-historical.¹⁷ The medicalized literature wants to maintain the appearance of ‘discovering’ new illnesses rather than creating them.¹⁸ This is illustrated in both articles. In the first *Lancet* article, the authors find it hard to place themselves in an historical context, as they admit that past animal and human studies of alcohol affecting a fetus have not led to a clear association. They remark, however, that the research being described will quell any doubt of such a link.¹⁹ Perhaps it is because the first article revealed a lack of deep history that the second article spends a good portion of its first page linking historical evidence to the current research. The article states explicitly that the claims made are ‘not new’. In fact, the article cites Greek and Roman mythology and British House of Commons debates to

¹⁷ *Ibid.* at 1270.

¹⁸ *Ibid.*

¹⁹ *Ibid.*

mark FAS²⁰ as a diagnosis that transcends time.²¹ I explore the creation of what I term ‘the mythology of FASD’ later in this chapter. The second article in particular attempts to establish a detailed history of FAS without mentioning the fact that the grouping of symptoms they call fetal alcohol syndrome has never existed before printing that article. There are references to sporadic but historical scientific research on the same topic. The endnotes reveal that this research is made up of four previous articles, dating from 1901, 1944, 1950 and 1960. Despite the weak historical connections, the authors of the two articles make it a priority to link their work to the past.

The bulk of the articles explain similar physical abnormalities found amongst the eleven case studies. It is interesting to note that these articles rely solely on physical characteristics; presently, FASD is attributed with any number of behavioural and cognitive issues. Apparently, this was not the intention of the doctors who coined the term fetal alcohol syndrome. The physical problems that the articles present are numerous, ranging from genital malformations, to ear, elbow, and hip problems. Many of the medical issues sound deeply concerning, yet there are some clues to indicate this may be a skewed picture. The first article, where eight of the eleven case studies are presented, provides a disclaimer that they are only looking at those children born with the most severe problems. They choose only the most severe patients because, while they are adamant in their assertion that alcohol detrimentally affects the fetus, they are not sure how this happens and so are limited to only the most obvious situations.²² If this is the

²⁰ Note that I am referring here to fetal alcohol syndrome rather than fetal alcohol spectrum disorder because at the time of the *Lancet* articles, there were no other diagnoses to warrant the latter umbrella term. They are only speaking about FAS.

²¹ Kenneth L. Jones & David W. Smith, “Recognition of the fetal alcohol syndrome in early infancy” (1973) 2 *Lancet* 999 at 999.

²² Jones, *supra* note 16 at 1271.

case and the eight patients studied display the worst symptoms, it is odd that the only recorded problem for patient six is hypoplastic second and fifth toes.²³ In the second article, the authors make a new ‘discovery’ that cardiac problems and a cleft soft palate are now symptoms of FAS even though they were only found in two of the eleven patients studied. The addition of the former is especially surprising as the research shows that many cardiac and mobility problems improved by the child’s first birthday.²⁴

The tests and markers that doctors relied upon to note deformations are equally problematic. For example, the eight patients in the first *Lancet* article had their palpebral fissures measured. Small palpebral fissures (the separation between the upper and lower eyelids), now directly associated with FASD, were assessed by comparing the measurements from these eight patients (from three different ethnic backgrounds) to the mean size for white males and females.²⁵ The racialization of this test makes the data and the consequent diagnosis questionable.

In a similar fashion, when measuring the mean daily weight increment of the infants, their measurement was first compared to upper-middle-class Seattle children and then compared to high risk, impoverished children but who participated in state-run maternal and infant care program in the city.²⁶ The mothers of the eight children in the article are not said to have participated in programming and the mean weight was drastically lower. A simple test measuring weight gain reveals so much more about whom these children are and the mothers who gave birth to them.

²³ *Ibid.* at 1268.

²⁴ Jones, *supra* note 21 at 1001.

²⁵ Jones, *supra* note 16 at 1269.

²⁶ *Ibid.*

The objectivity of scientific knowledges becomes even foggier when considering the description of alcohol in the two *Lancet* articles. At first glance, it is clear that alcohol is the only factor being considered as the cause of the medical problems in the children. There is no discussion of other possible causes, such as accessibility of pre-natal care, or maternal stress during pregnancy, for example. The first article does mention malnourishment as a potential cause but finds that the pattern of malformations is unlike those born to malnourished, non-alcoholic mothers.²⁷ Medical discourse revels in single, quantifiable categories that can be studied through tests and measurements.²⁸ Alcohol consumption is relatively easy data to obtain and compare. The focus on alcohol working alone to cause physical problems is emphasized by the selection of patients for the study. Two of the children in the first article were selected, not because they had obviously similar abnormalities as the other children, but because their mothers were known to be alcoholics.²⁹ What makes the narrow lens on alcohol so odd is that the authors do not know how alcohol affects the fetus, but are certain that the mother's consumption of alcohol is to blame for deformations. There is an "as yet unknown effect of the maternal alcoholism"³⁰ but still a diagnosis is formed exclusively on the findings in these articles. The articles undoubtedly make a connection between the mother and child in relation to alcohol as well. The second *Lancet* article describes a physician's observation upon delivery of one of the babies that there was "alcohol on his breath".³¹ This phrase makes an implicit connection between the deviancy of the mother and the similar fate of her child. From his first breath, the child studied is on the verge of alcoholism himself. This

²⁷ *Ibid.* at 1270.

²⁸ Rosenberg, *supra* note 8 at 250.

²⁹ Jones, *supra* note 16 at 1267.

³⁰ *Ibid.* at 1270.

³¹ Jones, *supra* note 21 at 1000.

statement marks the first of what will become a deep connection between FASD and deviancy.

The age of the children selected as patients (newborn to four years old) is significant. The *Lancet* articles make no mention of FAS beyond these young ages. Since then, the diagnosis has evolved into a lifelong identity that undergoes transformations at various stages of growth. The evolution of the FASD identity speaks to its fluidity as a medical diagnosis and its ability to apply governing effects to a wider group of people.

The choice of patients in the articles was deliberate and makes an interesting statement about who is diagnosed with FASD. The racialization of FASD is a fundamental component in my project of problematizing the identity. I have noted that while this first article featured children from three different ethnic backgrounds, the patients in the second *Lancet* article are all Aboriginal.³² Another common theme among those chosen for case study is the economic status of the families. Three of the children in the first article are in foster homes. The first patient studied in the second article is the youngest of seven children in her family, all of whom are in foster care.³³ This is the first piece of information we learn about the first case study and sets an unmistakable tone for the remainder of the article. At the end of the first article, the authors mention that all of the families are living on welfare.³⁴ The scientific value of this information is not apparent; the judgement is clear.

While the value-laden statements made about the children are couched in scientific rhetoric, the perception of the mothers is explicit. The doctors qualify the mothers as alcoholics by their satisfying the criteria for alcoholism as published by the

³² *Ibid.*

³³ *Ibid.* at 1000; and Jones, *supra* note 16 at 1269.

³⁴ *Ibid.* at 1271.

1972 Criteria Committee from the National Council on Alcohol, in the United States. The broad stroke of the Committee's definition of alcoholism hides the fact that these women are very different. The mothers' history of alcoholism ranges from two years to twenty-three years; quite the discrepancy. All that these two studies see are alcoholics. The first article states: "patient 3 was born while her mother was in an alcohol stupor".³⁵ The authors do not define 'stupor' as a medical term. Instead, this phrase is meant to paint a very specific picture of what kind of woman gives birth to a baby with FAS.

The sentiment that the new diagnosis of FAS is reserved for alcoholic women who are unfit mothers is reinforced in the literature that follows the birth of the syndrome, with one publication stating: "If she truly wants the baby, almost every woman will do everything in her power – including breaking such habits as smoking and drinking – to ensure a healthy pregnancy and baby".³⁶ A woman who has a child diagnosed with FASD is unequivocally cast as an unfit mother. Furthermore, an article authored by Streissguth et al., suggests that non-specific 'environmental factors' of FAS infants living with their biological mothers contribute to their poor physical and cognitive state and that a more accurate study would involve children living in foster care exclusively.³⁷ A woman who gives birth to an FAS child is represented in the medical literature as a 'bad mother' during pregnancy and this perception will continue throughout the infant's life.

The social context in which the medical research is conducted in the two *Lancet* articles in 1973 and the conclusions made regarding a cluster of symptoms now known as

³⁵ *Ibid.* at 1267.

³⁶ Barbara Luke, "Maternal alcoholism and fetal alcohol syndrome" (1977) 77 *The American Journal of Nursing* 1924 at 1926.

³⁷ Ann Streissguth et al., "Teratogenic effects of alcohol on humans and laboratory animals" (1980) 209 *Science* 353 at 355.

FASD have an enormous impact on the knowledges currently being produced. The racial, economic and moral grounds upon which the diagnosis was founded reverberate into the conception of who gives birth to FASD children and who those children become as adults.

Teratogens and 1970s Medicine

The new identity for those who have been exposed to alcohol in utero came from a re-shaping of the scientific understanding of alcohol as a teratogen.³⁸ Public awareness of teratogens was not new. Popular examples such as tobacco, excess mercury and the infamous thalidomide tragedy are well known in the mainstream.³⁹ The thalidomide crisis, which occurred at the beginning of the 1960s, had a resounding ripple effect in North America, despite the low incidence rate (ten infants were born with malformations related to thalidomide in the United States).⁴⁰ The highly severe and visible deformities that resulted from maternal ingestion of thalidomide had those who felt immune to such devastation reconsider what it meant to parent a fetus. Laws and regulations related to drug testing changed due in part to public outcry for assured safety.⁴¹ Thirty years after the thalidomide tragedy, new and innovative uses for thalidomide as a method of combating major illnesses such as acquired immune deficiency syndrome (AIDS)

³⁸ A teratogen is defined as “an agent that causes birth defects”, Bonnie Buxton, *Damaged Angels: A mother discovers the terrible cost of alcohol in pregnancy* (Toronto: Alfred A. Knopf Canada, 2004) at 239.

³⁹ Golden, *supra* note 13 at 36-41. Thalidomide was a sleeping aid that also combated morning sickness for pregnant women. It was sold in the late 1950s and early 1960s until it was discovered that the drug caused severe birth defects.

⁴⁰ Stefan Timmermans and Valerie Leiter, “The redemption of thalidomide: Standardizing risk of birth defects” (2000) 30 *Social Studies of Science* 41 at 47.

⁴¹ Peter Temin, “Government actions in times of crisis: Lessons from the history of drug regulation” (1985) 18 *Journal of Social History* 433 at 436-437.

continues to be met with significant resistance given its dark history.⁴² The household knowledge of thalidomide as a teratogen in the 1960s and 70s and the fear of history repeating can help explain the climate in which alcohol became associated with these discourses.

With increased pressure to protect the unborn from any and all dangers, it is no wonder that researchers began to intensify their search for other factors that could explain ‘imperfect’ births. Defining alcohol as one of these teratogens, however, did not come easily. Critics such as Armstrong and Golden continue to doubt alcohol as a teratogen on its own and speculate instead that other teratogenic processes such as ethanol breakdown or a combination of alcohol and other factors may explain the inconsistency in symptoms that appear in fetuses that have been prenatally exposed.⁴³ Still, there was pressure to find a clear, tangible answer to point to when no other explanation could be found to explain ‘abnormalities’. Fetal alcohol syndrome soon gained credibility and began to be used by medical experts as one of these explanations.

FASD fits within the setting of the 1970s. The diagnosis provided some answers (however accurate) to certain medical problems. The problem was limited most often to Aboriginal communities and those living below the poverty line. Just as Hacking describes, the constitution of the FASD identity serves a purpose. It quiets the fears of many and targets populations thought to be in need of normalization. In this case, both communities have become stereotyped as having a high rate of alcohol consumption. The identity assumes that a woman who consumes any alcohol during pregnancy is an abnormal woman. For Hacking, “classifications evaluate who is troubling or in trouble.

⁴² Timmermans, *supra* note 40 at 50.

⁴³ Armstrong, *supra* note 15 at 106-121.

Hence they present value-laden kinds, things to do or not to do. Kinds of people to be or not to be.”⁴⁴ The truth of the identity is not up for discussion. It is how the identity is engaged with and how it is experienced that gives the identity meaning. Whether the medical literature that created FASD is accurate is not especially relevant. Its use as a social classification is what counts. Problematizing the scientific discourses related to FASD and revealing its social and political frame is fundamental to the ultimate realization of this project – that there remains a space for knowledges that can allow for varied discourses to shape our understanding of FASD.

From the scientific evidence discussed above, the authors of the *Lancet* articles make sweeping conclusions about the link between prenatal alcohol exposure and a huge variety of symptoms that may be associated with the new diagnosis of FASD. The evidence in these articles is worth questioning, but instead the collection of symptoms known as FASD makes a swift transition from speculation to diagnosis. The disassociation between the evidence and the creation of the FASD diagnosis thirty-five years ago is being felt today. The eagerness on the part of the authors of the *Lancet* articles to make conclusions about the effects of alcohol on the fetus and the willingness on the part of the scientific community to accept these findings has left more questions than answers in terms of understanding what it truly means to be diagnosed with FASD. I speculate that it is in part because of this history of the diagnosis that FASD becomes linked with deviancy rather than a more medicalized identity. The *Lancet* articles did not provide a clear understanding of how an FAS child would grow into adulthood. There was no indication that behavioural and cognitive deficits would be associated with the diagnosis. The psy-community has not been equipped with scientific rhetoric to condone

⁴⁴ Hacking, *supra* note 4 at 131.

intervention on adults as it has been able to establish with FASD children. This gap has since been filled by the criminal justice system as a method of intervention when the medical community falls short.

The scientific community brought about FASD as a medical diagnosis despite the limited scientific evidence. In the years following the creation of fetal alcohol syndrome a multitude of publications became the foundation for the FASD literature. According to Golden, these publications from all over the world primarily focused on single case reports of suspected FASD, expanding the symptoms and medical problems that can be linked to FASD.⁴⁵ Armstrong provides an in-depth analysis of published literature following 1973. The 1970s saw a steady build of research, peaking at more than 70 articles published in 1979 alone. In the 1980s there was a huge rise in the number of articles concerning alcohol and pregnancy, with more than eight hundred in that decade. The number of articles has continued to grow throughout the years and in 1998 more than one hundred and twenty articles were published.⁴⁶ Armstrong equates this strong inclination to expand the FASD diagnosis as ‘collective diagnosis’ that she explains in this way: “the diagnosis of fetal alcohol syndrome was shaped not only by the underlying objective reality of alcohol-related teratogenesis but also by how and what doctors chose to see in the syndrome”.⁴⁷ Collective diagnosis is a helpful term in that it illustrates the subjectivity of the discovery of this diagnosis. In turn, there is subjectivity in who becomes linked with this diagnosis.

The concept of collective diagnosis fits well within Hacking’s work on child abuse and the looping effect. The sudden rise in interest about FASD is reminiscent of

⁴⁵ Golden, *supra* note 13 at 58.

⁴⁶ Armstrong, *supra* note 15 at 75-77.

⁴⁷ *Ibid.* at 80.

Hacking's explanation of child abuse as a concept that has been around for less than fifty years but has taken on such monumental importance in our social world. He describes his modesty in predicting the future of the child abuse classification. By 1990 child abuse was thought to have always been there – an unquestionable harm that transcends social boundaries. Hacking attributes this complete acceptance of the child abuse category to a series of political events, shifting ideologies, adoption by particular institutions, and how the identity interacted with those it associated with (both victim and perpetrator).⁴⁸ The birth of the FASD identity is equally startling. FASD became a diagnosis that mattered. The medical community wrote about it, had conferences about it and got institutions (schools, community groups, prisons) to take notice of it. Everyone jumped on the FASD bandwagon and began to add their own knowledges to the identity, moulding it to fit specific purposes.

This constant re-defining of the FASD identity brings us back to the looping effect. Hacking recognizes the fluidity in which a new kind of person becomes recognized and a name is given for this new classification. Rather than one coming before the other, the phenomenon that saw FASD everywhere is part of this looping effect that witnesses the identity and its governing effects 'egg each other on'.⁴⁹ Moreover, the looping effect can help explain the sudden influx in research supporting the new FASD diagnosis. Hacking borrows from C.K. Li when he describes, "...research generates more experts generates more cases generates more research".⁵⁰ The looping effect demonstrates the way in which particular classifications can become very powerful very quickly through particular knowledges being reinforced in their own field.

⁴⁸ Hacking, *supra* note 3.

⁴⁹ Hacking, *supra* note 2 at 279.

⁵⁰ Hacking, *supra* note 4 at 160.

The FASD Diagnosis in Context

“A blanket guarantee under cover of which moral obstacles, economic or political options, and traditional fears could be recast in a scientific sounding vocabulary.”⁵¹

The *Lancet* articles that created the diagnosis of FASD involved more than understanding teratogens. Fetal alcohol syndrome changed the way pregnancy, alcohol, motherhood, responsibility, public opinion and deviancy are understood. So far, I have been able to establish that the scientific discourse that led to the introduction of FASD can be problematized. This is crucial because it breaks down the idea that scientific knowledges are neutral. As I have described above, a new diagnosis does not exist in the vacuum of the scientific community; rather, it is created, accepted, analyzed and evolves within a social and political context. At this stage, a clearer picture of the conditions in which the FASD diagnosis was born will support the overall goal of exploring the FASD identity as one that is constructed to be deviant, but that is not inherently so. It is not my intention to pinpoint the precise social factors that led to the creation of FASD. I would like to offer some points of reference to factors that allowed for FASD to become a reality in 1973.

FASD is rooted in advanced liberalism. Rose defines advanced liberalism as a form of governing where the state plays an indirect role in providing services; in other words, ‘governing at a distance’. This form of governing demands increased responsabilization on the part of individuals and an emphasis on values and norms

⁵¹ Michel Foucault, *The History of Sexuality: An Introduction* trans. by Robert Hurley (New York: Vintage Books, 1978) at 55.

prescribed by popular discourses.⁵² Peoples' actions are scrutinized in conjunction with these values. Normalizing techniques seek to change any discrepancy between individuals' choices and the norm. According to the rhetoric of advanced liberalism, everyone is capable of rational decision-making: "Autonomy is now represented in terms of personal power and the capacity to accept responsibility – not to blame others but to recognize your own collusion in that which prevents you from being yourself, and in doing so, overcome it and achieve responsible autonomy and personal power."⁵³ Increasing emphasis on self-regulation and individual responsibility for 'abnormalities' coincides with the 'discovery' of FASD. The self-regulation of women's sexuality and the panic of crack babies, as described below, all buy into the advanced liberal paradigm. So too does the creation of FASD mirror the sentiment put forth by neo-liberal technologies. Although many women contest the idea of 'chosen social conditions',⁵⁴ under the auspices of advanced liberalism all women who are sexually active are meant to self-regulate by abstaining from alcohol.

The values of neo-liberalism are found in the grassroots movement's focus on individual prevention as the leading strategy for working with FASD. Above all, organizations devoted to eradicating FASD spread the message that no amount of alcohol can be considered safe at any point during a pregnancy. Many organizations, including provincially sponsored campaigns, frame this by claiming, "it is best to stop drinking

⁵² Nikolas Rose, "Government and control" (2000) 40 *Brit. J. Criminol.* 321 at 323-325; Bauman elaborates on this, especially relating to 'normal' and 'abnormal' in Zygmunt Bauman, "Social issues of law and order" (2000) 40 *Brit. J. Criminol.* 205 at 206-212.

⁵³ Rose, *ibid.* at 334.

⁵⁴ Margaret Leslie (ed.), *BTC Compendium: Volume 1 – The Roots of Relationship* (Toronto: Mothercraft – Breaking the Cycle, 2007) at 30-33.

before you get pregnant [emphasis in original].⁵⁵ How far ‘before’ a woman becomes pregnant should she abstain from alcohol is unknown. Other campaigns are much more explicit in their encouragement for women to self-regulate by categorizing “all women of child-bearing age who use alcohol” as “women at risk”.⁵⁶ One publication from Health Canada notes that “intervention strategies for women at risk” should begin at puberty.⁵⁷ The grassroots movement uses the neo-liberal rhetoric when they make claims such as the following: “Women who have unplanned pregnancies, especially college-age women, are at higher risk for inflicting binge drinking damage upon their fetuses”; and, “about 50% of pregnancies are unplanned. ‘If you drink, don’t have sex. If you have sex, don’t drink’”.⁵⁸ The prevention discourses assume that women ‘at risk’ of having children with FASD can manage their risks and the risks of their fetuses. Doing otherwise would be their choice (albeit a bad choice that will leave her socially excluded). These responsabilization techniques can potentially impact so many more women than those who give birth to babies diagnosed with FASD. As seen through the advanced liberalist context, the FASD identity is so much more than a collection of symptoms; it is a method of regulation. The social and political arena in which FASD became available in the 1970s provides a broader context to engage with the FASD discourses.

Both Armstrong and Golden highlight the controversy regarding the regulation of women’s sexuality that was taking place in the late 1960s and early 70s. First, oral

⁵⁵ Ontario, Ontario Early Years, *Be safe: Have an alcohol-free pregnancy* (Early Years Program, 2004), online: <http://www.alcoholfreepregnancy.ca/eng/index.html>, last accessed 8 February 2008.

⁵⁶ Canada, *Fetal Alcohol Spectrum Disorder: A Framework for Action* (Ottawa: Public Health Agency of Canada, 2005) at 9.

⁵⁷ Canada, *It Takes A Community: Framework for the First Nations and Inuit Fetal Alcohol Syndrome and Fetal Alcohol Effects Initiative* (Ottawa: Health Canada, 2001) at 86.

⁵⁸ n.a., *FASlink: Fetal Alcohol Spectrum Disorders Society: Research, Information, Support and Communication*, online at: <http://www.faslink.org/index.htm>, last accessed 28 March 2008; and Sanne Specht, “Zero Tolerance for Alcohol” at FASWorld, online at: <http://www.fasworld.com/shownews.asp?NewsID=110>, last accessed 12 April 2008.

contraceptives became available in 1965 in the United States⁵⁹ and in 1969 in Canada. Shortly after this, *Roe v. Wade* (1973) and later *R. v. Morgentaler* (1988) decriminalized and legalized abortion in the United States and Canada respectively.⁶⁰ Armstrong and Golden argue that the years leading up to and following the creation of the FASD diagnosis were fraught with gains and revocations of women's sexuality and reproduction rights. In any number of social situations women were negotiating standards between the modern, independent woman in the workforce and the compassionate mother fulfilling her biological obligation.⁶¹ Golden's analysis differs slightly from Armstrong's in her recount of a small window of time after the *Roe v. Wade* decision where abortion was seen as a 'solution' to FAS. Using articles from newspapers, the *Times* and *Life* magazines etc., Golden contends that abortion became an option doctors advised to patients who drank alcohol during pregnancy. This idea was also being alluded to in the media. Abortion was being advertised as a prevention tool against FAS. The campaign for abortion to be used as a technique to reduce the number of FAS births was short lived; as abortion became recognized as a highly controversial issue it was no longer characterized as an option to be openly suggested to combat FAS.⁶²

Armstrong does not speak to this debate, instead focusing on the creation of FAS as a governing technique to maintain women's subversive role in society. Armstrong describes the situation in this way: "Just as women sought greater independence in both intellectual and reproductive spheres, physicians sought to enmesh them in an ideology of maternity that made them mothers both of their own children and of the society, the race,

⁵⁹ Armstrong, *supra* note 15 at 196.

⁶⁰ *Roe et al. v. Wade* [1973] 410 U.S. 113; and *R v Morgentaler* [1988] 1 S.C.R. 30.

⁶¹ Armstrong, *supra* note 15 at 197.

⁶² Golden, *supra* note 13 at 41, 42.

and the nation.”⁶³ The context in which women became dominated by the fear of FAS and the way the diagnosis is used for self-regulation is worth considering as a precursor to the creation and acceptance of the FASD diagnosis.

The introduction of ‘crack babies’ in the late 1980s also works within the feminist arguments described by Armstrong and Golden. The creation of the term ‘crack babies’ came from an intense panic in the social and political realm that more women were using crack during pregnancy and giving birth to a ‘lost generation’ of severely cognitively disabled children. Nancy Campbell explains how the crack baby rhetoric was used as a method to normalize those women who did not subscribe to the culturally dominant group norms. Campbell characterizes these methods as surveillance techniques (sometimes through the criminal justice system) that portrayed an overall “decline of maternal instinct”⁶⁴ in targeted women. Governing techniques that pursued women and mothers were part of the social and political environment that created FASD.

The similarities between the FASD story and the crack baby story are uncanny. The crack baby ‘epidemic’ began as a way to instil fear and subsequent support for Reagan’s War on Drugs.⁶⁵ Just as the medical research that conceived of fetal alcohol syndrome was sparse and yet quickly supported, so too was the evidence of crack babies also limited. Despite the inability of the scientific community to substantiate the claims made by the political sector, fetal exposure to crack cocaine became associated with a high perinatal mortality rate, physical abnormalities such as neurological, digestive,

⁶³ Armstrong, *supra* note 15 at 64.

⁶⁴ Nancy Campbell, “Regulating ‘maternal instinct’: Governing mentalities of the late twentieth-century U.S. illicit drug policy” (1999) 24 Signs 895.

⁶⁵ The War on Drugs is a series of measures instigated by the U.S. government and participating countries to eliminate the sale and consumption of illicit drugs. This was coupled with the First Lady, Nancy Reagan’s “Just Say No!” campaign. The War on Drugs has been used internationally and criticized for its focus on particular ethnic communities and those living in poverty.

respiratory, and cardiac issues, and a host of behavioural problems such as learning difficulties, hyperactivity and not surprisingly, a link between crack babies and deviancy.⁶⁶ In addition, crack babies were said to be born with an addiction to cocaine, inevitably producing a future generation of unproductive, crack users.

Just as FASD has been unfairly characterized as an ‘Aboriginal problem’ (see chapter 4), crack babies are associated with young urban women most often from communities of colour. Targeting this population was made possible by referring exclusively to crack, which is stereotypically associated with poor, black communities and not speaking about cocaine abuse, which is associated with wealthy individuals.⁶⁷ Focusing on crack as the cause of a myriad of problems allowed for a specific response that saw mothers being blamed for social ills and as Lyons and Rittner explain crack babies became, “the center of a moral and legal battle, rather than the subject of discourse based on sound medical and social research”.⁶⁸ Politically and socially, we see the purpose of the crack baby identity in close company with FASD.

A marked difference between the creation of the FASD identity and crack babies is the exceptional coverage crack babies received as opposed to the relatively quiet introduction of FAS. A quick search of the literature finds a shocking number of published materials related to the heavy burden crack babies will cost Americans, particularly as these children enter school.⁶⁹ The ramifications of the crack baby crisis

⁶⁶ Teresa Ortiz and Laura Briggs, “The culture of poverty, crack babies, and welfare cheats: The making of the ‘healthy white baby crisis’” (2003) 76 *Social Text* 39 at 44.

⁶⁷ Peter Lyons and Barbara Rittner, “The construction of the crack babies phenomenon as a social problem” (1998) 68 *American Journal of Orthopsychiatry* 313 at 314.

⁶⁸ *Ibid.* at 317.

⁶⁹ For example, Mary Bellis Waller, “Crack babies grow up” (1994) 181 *American School Board Journal* 30; Janet Y. Thomas, “Falling through the cracks - crack-exposed children in the US Public schools: An educational policy issue” (2000) 15 *Journal of Education Policy* 575; and Shirley Cohen and Christina

became sensationalized throughout the 1990s as there was increased concern these children would leech off society. This sentiment legitimized reducing investments in particular geographic communities that were inhabited by apparent crack addicts⁷⁰ and in funding to substance-addicted women who no longer appeared worthy to receive aid.⁷¹ The ‘discovery’ of crack babies reinforces the same ideas found in FASD discourse; the identity as innate, exclusive to a marginalized population and above all, deviant.

The Mythology of FASD

Appearing a-historical is assumed to be equated with naturally occurring concepts and objectivity. Psy-knowledges look to the past to affirm present-day findings and do so in order to present an identity as a sort of linear narrative. The identity itself has always existed and never evolved; only the psy-discipline’s ability to grasp the details of the identity has grown.⁷² According to the psy-sciences, a new identity is not a re-configuration of an old identity because this would mean that a psy-identity is time and place specific.⁷³ A history of FASD was created so as to provide credibility to the scientific knowledges. In the end, the mythology of FASD says that the collection of symptoms and the way they are understood have not been created. The only change after 1973 is that we now have a name for it.

The psy-disciplines try to work against the idea of a looping effect by creating a linear history of discovery. In creating this mythology, however, the knowledges are

Taharally, “Getting ready for young children with prenatal drug exposure” (1992) 69 *Childhood Education* 5.

⁷⁰ Ortiz, *supra* note 66 at 48.

⁷¹ Lyons, *supra* note 67 at 318.

⁷² Rose, *supra* note 10 at 42.

⁷³ See, Ian Hacking, *Mad Travelers: Reflections on the Reality of Transient Mental Illness* (Charlottesville: University Press of Virginia, 1998).

added retrospectively to the looping effect. FASD was re-classified because a history of the syndromes appeared after the fact. The science in the *Lancet* articles is perceived as more credible. The targeting of specific communities can seem inevitable. The personal narratives of those with FASD no longer exist in isolation. They become part of something bigger and older than themselves. The framework of the looping effect provides an avenue to consider the historical impact of an identity. This could be a failure to take notice of historical changes in an identity⁷⁴ or, as is the case of FASD, a strained attempt to design a history.

The earliest claim of FASD symptoms is reported in the Old Testament of the Bible where an angel tells a woman not to conceive a child after drinking wine or a strong drink. Many authors, such as Buxton, cite a quote from Aristotle as a sign he understood FASD before it was given that title: “foolish, drunken and harebrained women most often bring forth children like unto themselves, morose and languid”.⁷⁵ As mentioned briefly above, the second *Lancet* article has a section devoted to an historical review of maternal alcohol consumption and fetal development. This section refers to Greek and Roman mythology as well as a quote from a British House of Commons committee in 1834 that states infants of alcoholic mothers, “had a starved, shrivelled and imperfect look”.⁷⁶ The most popular of all historical ‘references’ is a William Hogarth painting titled *Gin Lane*. This 1751 painting depicts a chaotic and grotesque village with scenes of violence, cannibalism and death, all a result of lowered taxes on gin that occurred at the time. In the centre of the picture is a half-clothed, intoxicated woman who has let her child slip from her grip and the child is falling off a staircase without his

⁷⁴ Hacking, *supra* note 4 at 157.

⁷⁵ Buxton, *supra* note 38 at 42.

⁷⁶ Jones, *supra* note 21 at 999.

mother's notice.⁷⁷ These references and others have an essential role in legitimizing FASD as a diagnosis and as an identity. The mythology of FASD is consistent with psychology attempts to appear a-historical and a-social. The fact that Jones and Smith felt it necessary to include this mythological history in their scientific literature demonstrates the power this knowledge has in creating an identity that is beyond the scope of the two *Lancet* articles; instead, it is one that has been a part of society (and society's problems) for centuries.

Not surprisingly, this new found information clearly demonstrates and reinforces the link between the FASD identity and deviancy. All of these references are related to supposedly irresponsible parenting that lead to 'defective', 'imperfect' and 'moody' children. The validity of these references as speaking of the effects of exposure to alcohol in utero is being debated elsewhere.⁷⁸ It is the relationship between these sources and the FASD identity as deviant that I am concerned with. Finding alleged references to FASD in historical sources makes credible and reinforces the scientific discovery of the disorder in 1973. It concretizes the medical literature as well as the social implications of maternal alcohol consumption. These sources appear to confirm the discourses that present those with FASD as unproductive and undesirable.

FASD as a Medical Diagnosis

⁷⁷ William Hogarth, *Gin Lane*, 1751; and Golden, *supra* note 13 at 18, 19.

⁷⁸ For example see, RH Warner and HL Rosett, "The effects of drinking on offspring: An historical survey of the American and British literature" (1975) 36 *Journal of Studies on Alcohol* 1395; Ernest L. Abel, "Gin Lane: Did Hogarth know about fetal alcohol syndrome?" (2001) 36 *Alcohol and Alcoholism* 131; and Ernest L. Abel, "Was the fetal alcohol syndrome recognized by the Greeks and Romans?" (1999) 34 *Alcohol and Alcoholism* 868.

So far this chapter has set the stage for a critical discussion about FASD by highlighting its conception in 1973 and the social context that made its existence as an identity worthwhile. The next logical step in problematizing FASD is to step back and consider the diagnosis itself, as a scientific entity. Here, I am arguing that the medical diagnosis is a social construction that exists in this form as a way to make sense of certain behaviours and target particular people.

Rosenberg can help us engage in a discussion about the diagnosis as a bureaucratic structure through which clinical knowledge can be organized and acted upon. He is interested in the accumulation of data through technologies like case records in order to prescribe different identities. This identity will determine whether you receive medical intervention, and if you do what kind and what degree of intervention will take form.⁷⁹ Rosenberg's assessment of the bureaucratic and political nature of disease identities is useful in making us aware of the powerful knowledges that circulate within the detailed act of creating and controlling the disease itself. In the case of FASD, we can use Rosenberg's framework to take note of how the medical tests and knowledges themselves contribute to the FASD identity.

In order to gain a sense of the bigger picture, Rose's ideas about the psy-discipline work well with Rosenberg to understand how these minute details work. Rose refers to data collection through observation and tests as a predictable and manageable space for psy-knowledge to be produced. He describes the creation of scientific identities in this way: "Science, that is to say, not only entails techniques that render phenomena visible, so that they may form the focus of conceptualization, but also requires devices that represent the phenomena to be accounted for, which turn these phenomena into an

⁷⁹ Rosenberg, *supra* note 8.

appropriate form of analysis”.⁸⁰ Codifying behaviours and actions into categories - such as disease, syndrome, and disorder - creates a space for these behaviours to be acted upon for the sake of normalization. In the case of psy-identities, Rose asserts, “psychological assessments use essentially the same techniques for quantifying all the qualities of the human soul”.⁸¹ Classification orders those things that cannot be ordered. Through psy-identities, individual thoughts, ideas, comportment, etc. can be compared to the norm. Using this critical perspective, FASD as a group of syndromes can be studied as a tool to categorize certain actions and people.

Rosenberg addresses the use of the *Diagnostic and Statistical Manual* (DSM) as an administrative tool that needs to be touched on briefly. The *DSM* claims to be a precise and complete record of all mental disorders. It is a tool used by psy-experts to attribute consistency and stability to the profession.⁸² A countless number of critics discredit this view of the *DSM* and argue instead that the collection of mental disorders only reasserts the social and political nature of the psy-science discipline.⁸³ Currently, FASD cannot be found in the *DSM-IV-TR*, published in 2000. This is shocking when we consider the scientific rhetoric that is attached to the diagnosis. FASD is widely cited as the leading cause of preventable mental disabilities but it has not found its way into the catalogue of disorders. The rhetoric surrounding FASD makes the diagnosis appear to be a solidified scientific reality that has been a part of our society for centuries and was keenly discovered in 1973. Yet, it is not in the *DSM*. The executive director at the Public

⁸⁰ Rose, *supra* note 10 at 107.

⁸¹ *Ibid.* at 112.

⁸² Herb Kutchins & Stuart A. Kirk, *Making us Crazy – DSM: The Psychiatric Bible and the Creation of Mental Disorders* (New York: The Free Press, 1997) at 239.

⁸³ See, for example, Paula Caplan & Lisa Cosgrove, eds., *Bias in Psychiatric Diagnosis* (Lanham: Jason Aronson, 2004).

Health Agency of Canada I interviewed says it is a reliable prediction that FASD will be found in the *DSM-V* (scheduled to be released in 2011).⁸⁴ It will be fascinating to watch how the FASD identity changes upon its inclusion. For the time being, we need to consider just what the FASD diagnosis is that produces governing techniques in spaces ranging from women's relationship with alcohol to child saving to criminality.

Fetal alcohol spectrum disorder is an umbrella term that encompasses all possible effects of pre-natal exposure to alcohol. It is not a diagnosis of its own but is made up of all the possible diagnoses.⁸⁵ A diagnosis of FAS requires pre and/or postnatal growth retardation; specific facial anomalies; and central nervous system dysfunction. A diagnosis of FAS also requires confirmation of maternal drinking during pregnancy (see problems with diagnosis below). Since the creation of FAS, a number of related diagnoses have emerged from the literature that have re-classified the diagnosis.⁸⁶ This is an example of Hacking's looping effect, where new knowledges allow for new lines to be drawn around what an identity means and who is targeted. In the past thirty-five years FASD has come to encompass FAE/ARND⁸⁷; partial fetal alcohol effects (pFAE); alcohol-related birth defects (ARBD); and static encephalopathy alcohol exposed (SEAE). Of these, FAE/ARND is most often diagnosed. The difference between this syndrome and FAS is the absence of the facial features when making a diagnosis.

⁸⁴ Interview of Executive Director at Public Health Agency of Canada (3 August 2007).

⁸⁵ Diane K. Fast and Julianne Conry, "The challenge of fetal alcohol syndrome in the criminal legal system" (2004) 9 *Addiction Biology* at 161.

⁸⁶ Ernest L. Abel and John H. Hannigan, "Maternal risk factors in fetal alcohol syndrome: Provocative and permissive influences" (1994) 17 *Neurotoxicology and Teratology* 445 at 445; Margaret A. Michaud and Sacha K. Michaud, *Beautiful Smiles, Gentle Spirit - Fetal Alcohol Spectrum Disorder: A Misunderstood Problem* (Calgary: Detselig Enterprises, 2003) at 25-30.

⁸⁷ There is a great deal of confusion in the literature about the appropriate use of FAE or ARND, and so in this project I use the term FAE/ARND.

Interestingly, only ten percent of children diagnosed with FASD maintain the 'FAS face' after childhood.⁸⁸

What do all of the diagnoses that fit under the term FASD mean? The diagnosis has grown exponentially since its conception in 1973. Now, any number of people can be targeted and labelled. The lines have become so blurred that one can have pFAE. A partial diagnosis attaches the label without a complete medical basis. The net has been cast so much wider than if the criteria for diagnosis had remained those for FAS. Proof of maternal alcohol consumption is one of the few threads tying all of these syndromes together. This means that women who consume alcohol, or are suspected of consuming alcohol, can be targeted for intervention even when they do not bear a child with an 'FAS face'. It means that those who want to impose normalizing strategies on people who behave inappropriately may opt to use FASD. It means that FASD is not only an identity based on scientific criteria, but encompass a whole host of social factors that would bring about its use as an identity. It means that there is no inherent truth to what FASD is.

The medical underpinnings of FASD present important critical questions. Some fetuses exposed to alcohol are said to not be affected. At the same time, some of the research suggests that even small amounts of alcohol administered at a crucial stage of development can have detrimental effects on the fetus. The number of potential primary disabilities associated with FASD is monumental. The *Lancet* articles referred only to physical disabilities, which remain part of the diagnosis. The diagnosis has since expanded to potentially include cognitive problems, such as concentration skills or problems with abstract concepts like math and time. Behaviour problems such as impulsivity, attention deficit hyperactivity disorder (ADHD) and anxiety also accompany

⁸⁸ Michaud, *supra* note 86 at 27.

the diagnosis.⁸⁹ An individual diagnosed with FASD can have any combination of physical and cognitive disabilities. Such a broad range of symptoms allows for discretion in who is assigned the FASD label. There is even greater latitude in who is diagnosed given that many of the primary disabilities only become apparent when a child reaches school age, but the research tells us that the most accurate diagnoses are made in the first six years (see chapter 3). The discrepancy in the literature may prove advantageous for the psy-discipline. If symptoms are not apparent until after the prime diagnosis period, those who diagnose someone with FASD can do so on less than perfect medical evidence and blame the parents/caregivers for having missed the signs earlier. I am also making the claim in this project that those who are diagnosed after the age of six are the ones more likely to be associated with deviancy. Those who did not receive child saving intervention are targeted to receive intervention by the criminal justice system.

The research claims that behaviour problems associated with the FASD diagnoses are most common among individuals with FAE/ARND but are not always labelled as such because they can be indicative of other disorders. This becomes even more complicated when secondary disabilities become part of the FASD identity.⁹⁰ Secondary disabilities associated with FASD include mental illness, substance abuse problems and homelessness.⁹¹ These are not medical issues. These 'disabilities' are not part of the body. They are social problems that have been afforded the label of disability. They

⁸⁹ Public Health Agency of Canada, *Fetal Alcohol Spectrum Disorder – Knowledge and Attitudes of Health Professionals about Fetal Alcohol Syndrome: Results of a National Survey* at 25, online: http://www.phac-aspc.gc.ca/publicat/fasd-surv-etcaf-enquete/pdf/fasd-surv-etcaf-enquete-2005_e.pdf, last accessed 12 August 2007.

⁹⁰ Secondary disabilities are those problems that are not inherent to FASD but arise because of the difficulties associated with the syndrome. These disabilities are not necessarily permanent and given the appropriate support and resources, are said to be manageable or preventable altogether.

⁹¹ Ann Streissguth (ed.) et al., "Primary and secondary disabilities in fetal alcohol syndrome" in Jonathan Kanter ed., *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (Seattle: University of Washington Press, 1997) 25 at 27, 33-34.

become part of the medical diagnosis when they are described in the same breath as physical and cognitive symptoms.

Diagnosing one of the FASD syndromes is considered a specialized task, taken on by teams of doctors from various fields. There are no biological markers or neurological tests that a doctor can point to and say that ‘this’ is FASD.⁹² Individuals with FASD are said to have an extensive vocabulary (although we are told they do not often understand the words they are using) and a relatively normal IQ. FASD is assessed primarily through cognitive and behaviour tests. So what does it mean to have FASD? As Kathryn Page states: “The diagnosis is not a black-or-white decision, FAS or no FAS, because this is a whole fabric of disorders occurring in varying severities – and because many of the findings may be attributable to factors other than prenatal alcohol exposure”.⁹³ This comment raises questions about the scientific merit of FASD if the same symptoms can be any number of other disorders. The purpose of the diagnosis appears to have more to do with applying governing strategies such as special programming or through the criminal justice system than it has to do with science. We return once again to Rose’s analysis of psy-science identities to gain clarity on the governing effects of constituting such an inconsistent and subjective diagnosis. Rose explains that the use of specific test(s), performed by specific experts, and in a specific allocation of time and place offers the predictability sought after by the psy-sciences. When devised in this way, the diagnosis of FASD appears objective.⁹⁴ This set up provides the illusion of rationality. Structuring the FASD assessment in this way allows a select few to control who is

⁹² Julianne Conry and Diane Fast, *Fetal Alcohol Syndrome and the Criminal Justice System* (Vancouver: The Law Foundation of British Columbia, 2000) at 12.

⁹³ Kathryn Page, “Fetal alcohol spectrum: The hidden epidemic in our courts” (2001) 52 Juv. & Fam. Crt. J. 21 at 28.

⁹⁴ Rose, *supra* note 9 at 194.

assigned the FASD identity and shape what the identity means. The malleability and subjectivity of prescribing FASD to select people is reminiscent of Hacking's looping effect. The identity is re-classified based on who is labelled with FASD. This is how the diagnosis can appear to be an 'Aboriginal problem' or a problem for those of low socio-economic status. FASD is classified in such a way that it is often limited to the targeted populations.

In 2005, Chudley and a team of FASD experts put together the Canadian guidelines for diagnosing FASD.⁹⁵ The intent of these guidelines is to provide greater awareness and consistency in diagnosing FASD in Canada, but the authors note that substantial research is left to be conducted, in particular with making the guidelines culturally relevant.⁹⁶ Despite the goal of objectivity, the criteria upon which this guideline is based remains equally subjective and ad-hoc as its inception in 1973. It becomes a matter of who will be diagnosed as children, who will be diagnosed too late as adults and who will not be diagnosed at all. There is a false sense of security that comes with guidelines, assuming that subjectivity can be removed from the equation and the assessment of FASD is reliable. Turning a blind eye to the nature of the guidelines and how they are applied increases the power afforded to the FASD identity from the psychology perspective.

One of the most prevalent obstacles noted in the research is the confirmation of maternal drinking to support a diagnosis of FASD. Seventy-seven percent of individuals with suspected FASD do not live with either biological parent. Most are adopted or living

⁹⁵ Albert E. Chudley et al., "Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis" (2005) 172 Can. Med. Assoc. J. S1.

⁹⁶ *Ibid.* at S13.

in foster homes.⁹⁷ Without a confirmation of alcohol consumption during pregnancy, the only diagnosis that can be made is ‘suspected FAS/FAE’. Once again, the biological mother becomes the site of governing strategies as steps are taken to try and have her not only ‘confess’ to drinking during pregnancy, but provide the details of when and how much. Only those individuals who have maintained some sort of relationship with their mother and/or family can be eligible to receive the medical diagnosis. Otherwise, ‘suspected’ FASD does not carry any clout in the psy-science or criminological discipline. This means that there is a select group of individuals who become identified as having FASD and who become recognized as in need of support. Those who do not have the means to receive a diagnosis are more likely to find themselves involved in the criminal justice system.

When maternal alcohol consumption can be confirmed and a diagnosis can be made, the diagnosis of FAS rather than FAE/ARND has a significant impact on the opportunities for the individual diagnosed. A list of seven protective factors to prevent secondary disabilities includes, “having a diagnosis of FAS rather than FAE”.⁹⁸ This is the case because often the symptoms of FAE/ARND are said to be more subtle and the individuals appear ‘normal’. In turn, FAE/ARND is singled out as being less in need of services and resources and more capable of taking responsibility for the self-management of their disability. Therefore, it is at the diagnostic level that those with FAE/ARND are cast into the deviant identity rather than the severe illness identity. If FAE/ARND is less

⁹⁷ Fred J. Boland et al., *Fetal Alcohol Syndrome: Implications for Correctional Service* (Correctional Service Canada, 1998), online: http://www.csc-scc.gc.ca/text/rsrch/reports/r71/r71e_e.shtml, last accessed 9 August 2006 at 25.

⁹⁸ Page, *supra* note 93 at 26. The list of protective factors are: 1) Living in a stable and nurturing home of good quality; 2) Not having frequent changes of household; 3) Not being a victim of violence; 4) Having received developmental disabilities services; 5) Having been diagnosed before the age of 6; 6) Having a diagnosis of FAS rather than FAE; and 7) Having an IQ score below 70.

medicalized what is the purpose of the diagnosis? The FAE/ARND identity explains abnormal behaviour without excusing it. The medical knowledges get to claim a stake without taking full responsibility for its management.

Conclusion

Medical knowledges are highly influential in the constitution of many identities; FASD is among these identities. Since its ‘discovery’ in 1973 the FASD identity has been constituted from its value as a medical diagnosis. It is this appeal for legitimization that spawned hundreds of articles in the 1970s and 1980s similar to the two *Lancet* articles to solidify its position in the medical literature. Since that time research related to diagnostic criteria, how exactly alcohol interacts with the fetus and even an attempt to find a biological marker have all taken place, with the same overall objective; giving more power to the medical discourse surrounding FASD. The discourse is so dominant that it inevitably plays a role in the deviant identity also associated with FASD. The power given to these knowledges make it appear to be a truth claim, but as Hacking tells us, it is just one of the many ways of knowing.

The medical literature contributes to the deviant identity by deciding who becomes diagnosed with FASD, especially during the crucial 0-6 year time constraint. The interview with the executive director of the research network on FASD revealed that there are specific communities where a general practitioner may, upon seeing specific symptoms, be more inclined to consider FASD than in other communities. She offers the example of First Nations, Métis and Inuit communities where the high rate of FASD diagnosis may be due in part to its notoriety with the population. Other populations with

high rates of alcohol consumption, such as military bases, do not see the same rate of FASD diagnoses.⁹⁹ The interviewee from the Public Health Agency of Canada concurs with this finding, stating that women in certain populations are disproportionately targeted as at risk of bearing a child with FASD, specifically those living in poverty and those who are socially and/or geographically isolated.¹⁰⁰ By restricting which individuals will receive the FASD diagnosis and who will receive a diagnosis such as ADHD, the medical knowledges place emphasis on populations more likely to be in contact with the criminal justice system. The exclusionary nature of this phenomenon can be related to the ideas of normalization referred to in chapter 1. The example of the military base is a useful one, as those who serve in the military and their families are poster children for good citizens. The population exemplifies the qualities associated with being ‘normal’. Conversely, the culture and practices of the First Nations, Métis and Inuit peoples have long been condemned as ‘abnormal’ and have been subjected to assimilation processes.¹⁰¹ The FASD diagnosis allows for various surveillance and regulatory techniques to be imposed on those sitting outside of ‘normal’ ways of being. These techniques appear first through parents and the community and later through the criminal justice system. With the foundation of the FASD identity built on such questionable grounds, it is no wonder those labelled as having FASD find themselves also labelled as deviant.

⁹⁹ Interview of Executive Director of research network on FASD (10 July 2007).

¹⁰⁰ Interview, *supra* note 84.

¹⁰¹ See, for example, Melissa Gorelick, “Discrimination of Aboriginals on native lands in Canada: A comprehensive crisis” (2007) 44 UN Chronicle 50; and Jacqueline Hookimaw-Witt, “Any changes since residential school?” (1998) 22 Canadian Journal of Native Education 159.

Chapter 3: The FASD Child

Introduction

There is a disparity between the discourses that constitute children with FASD as sick and adults with the same syndrome as deviant. A shift in identity takes place during adolescence where the knowledges produced about those with FASD change dramatically. In this chapter I seek to uncover how various discourses shape children with FASD as victims and the transformation these discourses undergo to constitute deviancy. The social and political context that allowed for the creation of the FASD identity, as explored in the previous chapter, provides the foundation to examine the victim identity constituted for FASD children and later, the responsabilized adult identity.

Theoretically, this conception of the shift from a victim to deviant identity builds upon the framework established in chapter 2. Hacking and Rose present the notion of socially constituted identities and the governing effects that arise from these identities. Hacking's notion of the looping effect, as previously presented, provides a theoretical foundation on which to understand the victim identity applied to FASD children.¹ Those who classify and those who are classified are mutually reinforced by the identity.² I am pursuing the more ambitious endeavour, however, of expanding the looping effect to take on a new dimension. Within the next two chapters, I intend to demonstrate how two interconnected loops form to create the FASD identity. The first loop, described in this chapter, classifies the FASD child as an innocent, vulnerable victim, who is worth saving. The second loop, described in chapter 4, is markedly different as it portrays a responsible, undeserving and hopeless criminal. While these two loops appear to be contradictory, the

¹ Ian Hacking, *The Social Construction of What?* (Cambridge: Harvard University Press, 1999).

² Ian Hacking, "Between Michel Foucault and Erving Goffman: Between discourse in the abstract and face-to-face interaction" (2004) 33 *Economy and Society* 277 at 279.

essential link between them is the characteristics used to constitute the identity. The attitudes and behaviours that are attributed to FASD are remarkably similar in adulthood as in childhood, but they are used as descriptors for two opposing personas.

By paying close attention to the specific discourses related to FASD in childhood and then in adulthood I am able to show the specific governing effects that result from the victim and deviant identity, respectively. I also consider how these discourses are being interacted with (the multiple looping effect). Borrowing from Rose's conception of governmentality, the consequences of these discourses is found in the way authority figures make certain calculated decisions about those with FASD related to their identity.³ Hacking reinforces Rose's argument with his claim that it is the institutions and their methods that provide validity to an identity.⁴ The way the community, advocates, and government interact with FASD children paints a clear picture of how FASD adults become linked with deviancy.

Victim Discourses

In order to grasp how the victim identity becomes constituted for FASD children, we must first take note of the critical literature concerning childhood generally. Just as I am attempting to problematize truth claims related to the FASD identity, scholars such as Chen, Henderson, and Jenkins deconstruct the inevitability of childhood as we currently understand it. Jenkins points out: "childhood is not timeless but, rather, subject to the

³ Nikolas Rose, "Calculable minds and manageable individuals" (1988) 1 *History of the Human Sciences* 179 at 184.

⁴ Hacking, *supra* note 2 at 285.

same historical shifts and institutional factors that shape all human experiences”.⁵ As specific political and social discourses change, so too does the image of childhood and society’s response to children. It is the adults that produce the knowledges concerning children, rather than children themselves. Adults in all sorts of authoritative positions are able to construct the identity of what it means to be a child in any given historical period.⁶ Not only are adults producing these knowledges, but it is society rather than parents who have the power to create these knowledges: “children *belong* to the community, they are *entrusted* to parents [emphasis in original]”.⁷ Allowing parents to be viewed as subject to the will of society’s conception of childhood will prove to be a source of knowledge production for the victimization of FASD children. Society places expectations upon children as a homogenous group and deviation from this can be blamed squarely on parents.

The critical literature concerning children points to the ideological shift that took place after the Second World War and that has been gaining momentum since. The entitlement of children to certain protections and rights as citizens began to appear at this time. The current mentality of intervening in the lives of children at their very youngest to provide the best chance at a productive adulthood is rooted in the discourses concerning children as deserving of accommodation and equal treatment.⁸ From this incentive to make children a priority comes the prevailing discourse that young children

⁵ Henry Jenkins (ed.), “Introduction” in *The Children’s Cultural Reader* (New York: New York University Press, 1998) 1 at 4; see also Xiaobei Chen, *Tending the Gardens of Citizenship: Child Saving in Toronto 1880s-1920s* (Toronto: University of Toronto Press, 2005) at 3-18.

⁶ Jenkins, *ibid.* at 26.

⁷ John T. Bruer, *The Myth of the First Three Years: A New Understanding of Early Brain Development and Lifelong Learning* (New York: The Free Press, 1999) at 15.

⁸ Jane Jenson, “Canada’s shifting citizenship regime: The child as ‘model citizen’” in Michael Keating and Trevor C. Salmon eds., *Decentralisation and Regionalisation: Canada and the United Kingdom Compared* (Montreal: McGill-Queen’s University Press, 2000) 107.

are an investment worth making. Young children are deserving of state intervention because they are said to be innately ready for success if they are given the developmental opportunities to maximize this potential.⁹ Children are an ‘investment target’. Issuing the proper investment early in life is supposed to guarantee dividends of responsible adults in the next generation.¹⁰

Conceptualizing childhood as a brief window of opportunity in which to entrench their value as productive adults limits the necessity and motivation to provide resources for those other than young children. Using scientific rhetoric as a foundation to support the solitary focus on young children legitimates the exclusion of older children and adults. As one psychologist noted, although, “we should never write children off, it can be difficult to change long-lasting, maladaptive patterns later in life”.¹¹ The proceeding chapter demonstrates the power this knowledge has in shaping FASD adults as hopeless and deviant. It is believed that if sufficient intervention does not take place in these youngest years (often before FASD is diagnosed) the individual is destined to become a criminal.

The quintessential focus of the victim identity prescribed to FASD children comes from the early years programming found throughout Canada. While research and programming vary in the age range,¹² the target population are infants and young children who are described in the literature as innocent and in need of nothing more than help

⁹ Jennifer Henderson, “The years before five: Discourse and pedagogy of neoliberal childhood” (Cultural Studies in Education panel: Canadian Association Cultural Studies Conference at the University of Alberta, 21 October 2005) [unpublished].

¹⁰ *Ibid.*; and Jenson, *supra* note 8.

¹¹ Bruer, *supra* note 7 at 6.

¹² The most popular are: from 0-3, 0-5 and 0-6 years of age. It is rare to see the age range go beyond the age of six, which is most often when children begin the first grade in a public education setting.

maintaining that innocence so as to become successful adults.¹³ The primary source of interest for government funding, advocacy groups and programming is based upon this ‘0-6’ mentality. This rhetoric, clearly professed in Ontario but visible in all the provinces, defines the intervention period to be from pre-natal care until the age of six. Known as *Ontario’s Best Start Programs*, support services that offer early learning and child care and promote healthy development are funded until children reach the first grade. The first six years of a child’s life are seen as the most important.¹⁴ Children ages 0-6 are perceived as budding with potential and limitless in their opportunities if only these first few years are handled properly. The mantra for *Ontario’s Best Start Programs* is stated as the following: “Healthy babies are more likely to develop into healthy children, and healthy children are more likely to grow up to be healthy teenagers and healthy adults”.¹⁵ The focus of these programs is to screen and assess infants for any risks to the child’s healthy development; support new parents; and find community recourses related to breastfeeding, nutrition and health programs, parenting programs and family literacy.¹⁶ This exclusive focus on children until the age of six poses a number of questions related to children with FASD. What of those children who are diagnosed after the age of six? What supports are left for them? What of those children who require ongoing support after the age of six? Finally, what of those children who receive supports early on but do not become ‘successful’? What happens when the investment does not pay off? I argue

¹³ Jenkins, *supra* note 5 at 2.

¹⁴ Ontario, Ministry of Children and Youth Services. *Programs and Services, Best Start* online: <http://www.children.gov.on.ca/mcys/english/programs/beststart/health/index.asp>, last accessed 11 October 2007.

¹⁵ *Ibid.*

¹⁶ *Ibid.*

that it is these supposedly ‘unsuccessful’ children who become constituted as deviant in adulthood.

Specific programming for children with FASD is not common. There are some programs available, such as *Breaking the Cycle*, offered by Mothercraft in conjunction with Sick Kids Hospital in Toronto, Ontario, which provides support to biological mothers of children ages 0-6 with FASD. This unique program works within a maternal/child framework. The mission is to change the pattern of relationships between mothers and children so as to create new opportunities for families.¹⁷ The program sees alcohol and/or drug addiction as the tip of the iceberg that has more to do with trauma, violence and poverty. Thus, the program targets parenting skills by offering counselling and home visitation and provides medical and mental health services as well as basic needs support (provides breakfasts and lunches, clothes and tickets for public transportation to get to and from the program office).¹⁸ This program is limited in its accessibility in that it is one of a kind, in downtown Toronto only; it serves only those children between the ages of 0-6; and works on the relationship between the biological mother and child alone. For the majority of children with FASD supports can only be found through generalized programs for children with special needs. Most often, special needs programs that follow the *Best Start* mandate gauge success on reaching the ‘optimum potential’. Most often, optimum potential is achieved when the child becomes ready for school entry.¹⁹

¹⁷ Interview of Executive Director of early intervention centre (20 June 2007).

¹⁸ *Ibid.*; and Margaret Leslie (ed.), *BTC Compendium: Volume I – The Roots of Relationship* (Health Canada, 2007); Mary Motz et al., “Breaking the Cycle: Measures of progress 1995-2005” (2006) 4 Special Supplement, *Journal of FASD International*, Toronto: Hospital for Sick Children 22.

¹⁹ Interview of Manager of support services for children with special needs (12 June 2007).

The notion of optimum potential is congruent with the rhetoric that understands children as an investment in the future. Optimal potential works within the neuro-developmental discourses that have dominated early years policy in the last two decades. It states that children who receive optimal developmental experiences will become increasingly productive. Optimal potential, also described as ‘indicators of readiness’, measures the success of a young child through specific criteria, including a lifelong readiness to learn, social awareness, efficiency, and adaptability, to name a few. These indicators allow for a normative milestone by which all children are assessed to determine their potential value as citizens, regardless of personal circumstances.²⁰ This sort of narrow conception of childhood preparedness is conceived of through the neuro-developmental literature that insists that social problems can be solved through state intervention on society’s youngest children. The literature claims that teenage smoking “and apparently any other social ill one could possibly think of” can be solved if children can be reached before the age of school entry.²¹

The rhetoric that endorses the use of optimum potential in early years programming is built from and encourages a specific looping effect. Optimum potential is built from the knowledges of psy-disciplines, social work, education discourse etc. It also reinforces the loop by delegating which children are being saved and thus worth investing in, and which are not. This evaluation of success is a problematic one. Children with FASD are compared to a standardized assessment with the expectation that sufficient programming will cure what ails them. Cognitive ability, irrespective of a child’s emotional and/or behavioural level, can be quantified in terms of the optimum potential.

²⁰ Henderson, *supra* note 9.

²¹ Bruer, *supra* note 7 at 15, 64.

The literature convinces policy makers, community workers and parents alike that ‘any social ill’ can be solved through developmental intervention before the age of six. The primary and secondary disabilities associated with FASD can, under this rhetoric, also be ‘solved’. It appears to be inevitable that when such a blanket statement is put into practice through policy development, many FASD children will be excluded and marginalized.

The focus of the 0-6 programs and especially those programs working with special needs children is on hope and success. Underlying the programming is a clear objective that by providing young children with the necessary resources, this should invariably eliminate the need for more resources as children age. Creating this climate of hope significantly narrows the focus of the programming. Programs are designed to work on children’s needs at an individual level; this includes structuring their learning environment and curbing behavioural and cognitive deficits.²² The manager of support services for special needs children told me that her programs work on the premise of true inclusion. This means that the program strives to ensure that no child falls through the cracks of the system. Those who make it into programs for special needs children work with integration advisors who find ways to meet all the unique needs of each child. For more challenging cases a program assistant is provided that stays at a program with a child but does so in a way that does not promote exclusion.²³

Exclusion, however, does occur in terms of which children access programming and how this programming is administered. Only those with ‘severe mental illnesses’ are eligible for the program. As the manager of support services mentioned, doctors are

²² Martine Roberge et al., *Intervene Before Reacting: A Positive Integrated Approach to Behaviours in the Child Care Environment* (Ottawa: Children’s Integration Support Services, 2003).

²³ Interview, *supra* note 19.

diagnosing children with more serious labels so that they might receive resources.²⁴ In turn, the problems the children face are narrowed and easily categorized into the realm of medical knowledge. Doing so ignores the marginalization that children may face because of race, economic status etc. Those factors that may be conducive to problems in childhood and beyond but that cannot be explained within medical discourses are ignored. Still, it is maintained that children's needs have been met.

This narrowness is especially problematic for FASD children. Programming specifically designed for FASD children focuses on seven areas of intervention: medical status; sensory integrative problems; self-regulatory issues; developmental issues; communication; social skills; and behaviours.²⁵ A significant portion of the interventions relate to changing the environment such as painting the walls a calming colour, lowering noise-levels, working out a routine etc.²⁶ Focusing on these areas of interest is limiting and the overall social implications of having a diagnosis of FASD is not reflected upon. By targeting these specific areas as children, there is an assumption that the illness can be intervened on in such a way that it can almost be 'cured'; if not, effectively managed. It is thought that if a child learns at a young age how to work with their unique needs, then many of the primary disabilities can be minimized and secondary disabilities can be avoided altogether. This being the case means that programs devoted to adults coping with FASD are not necessary. Adults, according to the literature, are not good

²⁴ *Ibid.*

²⁵ Interview, *supra* note 17; and Gary Roberts, *Nurturing change: Working effectively with high-risk women and affected children to prevent and reduce harms associated with FASD* (Mothercraft and Canadian Centre on Substance Abuse, 2004) at 72-74.

²⁶ *Ibid.* at 86-87.

investments.²⁷ By adulthood, those FASD individuals who have not learned to manage their cognitive and behavioural problems are responsabilized.

One of the issues regarding programs offered for special needs children, specifically FASD affected children is a required diagnosis for access to support programs. While these programs sometimes aid in obtaining assessments, the manager of the special needs program and the director of the early intervention centre both recognize the difficulty many children have in reaching even these levels of support.²⁸ Often, specific types of diagnoses are required before access to supports is possible. Issues related to availability of information and education about, and funding for FASD are all part of the problems facing FASD children in the first six years. Moreover, special needs programs are most often offered to those children with significant cognitive and developmental delay.²⁹ This is problematic for children with FAS as it remains very difficult to receive a diagnosis but this problem is witnessed to a greater degree by those children with FAE/ARND. Support systems for these children are simply not available but at the same time, parents/caregivers complain that non-specialized programs are unable to manage the specific needs of an FAE/ARND child. From these first programs there is a division in conceptualizing FASD as an illness worth working on. Those who appear on the surface to be less severely affected are understood as being more capable of self-management. This trend continues into adulthood where those diagnosed with

²⁷ Bruer, *supra* note 7 at 6.

²⁸ Interview, *supra* note 17; and Interview, *supra* note 19.

²⁹ Suzanne Luckham, Julian Luckham & Susan Spence, Brochure, "Ideas for group leaders regarding the inclusion of children with special needs (Ottawa: Andre Fleck child care services, n.d.).

FAE/ARND are less likely to be recognized as suffering from a debilitating illness and are found to be more likely criminalized.³⁰

This concept is reinforced by the looping effect. Those children who are not only told they are worth saving but are given supports are often the same that are constituted as 'redeemable' in adulthood (see chapter 4). Singling out certain types of individuals to be classified in the child loop necessitates a space for the others; the deviant adult loop.

Many of the services in place attempt to reach those in society in greatest need of support; but often, they are the children who are unreachable. As the director of the early intervention centre explained, marginalized women who are claimed to be at highest risk of bearing a child with FASD are often unable to be referred to these services. This may be due to issues with literacy, unavailable pre-natal medical attention, issues related to alcohol abuse or often, ignorance of any developmental difficulty their children may be experiencing.³¹ Any combination of these factors, as well as unpredictable factors related to personal circumstances, leaves special needs supports most often to those in a stable living environment. By stable, I mean a home life where the parent/caregiver has the opportunity to make informed decisions about the health and well being of her children.

It appears then, that special needs supports are not being accessed by all children with FASD; conversely, it is the most vulnerable children who are receiving the fewest supports. It is those parents who have the knowledge, experience and assistance in navigating the rules of provincially funded programming who gain access to the services.

³⁰ Fred J. Boland, et al., *Fetal Alcohol Syndrome: Implications for Correctional Service* (Correctional Service Canada, 1998), online: http://www.csc-scc.gc.ca/text/rsrch/reports/r71/r71e_e.shtml, last accessed 9 August 2006.

³¹ Interview, *supra* note 17; and Elizabeth M. Armstrong, *Conceiving Risk Bearing Responsibility: Fetal Alcohol Syndrome and the Diagnosis of Moral Disorder* (Baltimore: The John Hopkins University Press, 2003).

A quick scan of the Ontario Ministry of Children and Youth Services provides ample evidence of this reality. Not only are access to the Internet and literacy skills required, but only a parent/caregiver skilled at sifting through government documents would be able to find specific information. The Ontario site provides some information and proceeds to suggest that a researcher may be able to find more information through links and other resources. Application to *Best Start* programs requires the researcher to find her local Ministry of Community and Social Services regional office and to call or visit to receive any details. This access to information requires a specific skill set, time and resources that may be debilitating for some parents/caregivers.

This means that those individuals most likely to be criminalized as adults are not provided with the necessary supports in childhood that are meant to avoid this future. It places additional stigma upon the mothers and families affected by FASD who are told by the dominating ideology that they were not responsible enough to have found supports for their children. These parents are ‘condemned as perpetrators’ for having corrupted their children of any innocence they may have had.³² These children are never part of the victim discourse associated with childhood FASD; instead they are found to be constituted in a negative way from the beginning of their lives. It is no surprise then that these children above all become criminalized as adults.

These challenges are made especially clear with regards to Aboriginal specific programming for children with FASD. Provinces that develop prevention strategies and special needs programming are most often unable to disseminate the necessary

³² Chen, *supra* note 5 at 17.

information to the First Nations, Métis and Inuit populations.³³ Aboriginals find themselves without resources to aid those at risk of giving birth to an FASD diagnosed baby or for children with FASD. As the research officer describes, it is often because of this lack of resources that diagnosing seems futile and more damaging than helpful.³⁴ Challenges regarding services for the Aboriginal community are obviously not limited to those with FASD; however, it is interesting to note the struggle in obtaining diagnosis and applicable services to this population. It is plausible to connect these concerns as one piece of the complex puzzle that results in the staggering over-representation of Aboriginal peoples in Canada's correctional system.

As mentioned above, there are very few FASD specific social support services. Most children who gain access to services for their primary disabilities between the ages of 0-6 work within integrated support services. These programs are designed as a governing technology with the aim of managing the primary disabilities so as to ensure they become healthy, successful adults.³⁵ In order to demonstrate progress towards reaching a child's optimum potential, the primary disabilities are isolated rather than assessed collectively.³⁶ This results in the FASD diagnosis being recognized and understood in a completely different way. It appears that through these support programs the FASD diagnosis is broken down into independent, manageable symptoms. Because of this, many of the disabilities associated with FASD are not viewed as permanent and

³³ Mark Buell, Catherine Carry & Marja Korhonen, *Fetal Alcohol Spectrum Disorder: An Environmental Scan of Services and Gaps in Inuit Communities* (Ottawa: National Aboriginal Health Organization, 2006).

³⁴ Interview of research officer on Inuit specific issues (19 August 2007).

³⁵ Jenson, *supra* note 8.

³⁶ Thomas Wentz, "A national survey of state directors of special education concerning students with FAS" in Ann Streissguth and Jonathan Kanter eds., *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (Seattle: University of Washington Press, 2002) 89.

unchangeable.³⁷ There is an assumption that with programming these children can move past many of the cognitive and behavioural barriers that result in much of the problems in adulthood.

The Narratives of the FASD Child

The stories told about children with fetal alcohol spectrum disorder come in two forms. The first are those children whose biological or more often adopted parents persevere through the many challenges that face a family coping with FASD and believe they can overcome the primary and secondary disabilities. Conversely, the stories not often heard are those FASD children who are moved from one living environment to another, most often foster homes, and do not receive the attention and special care expected for a child with FASD. Although the medical literature says otherwise, those who work closely with FASD children do not always acknowledge the permanency of the diagnosis. Instead, there is a common assumption that, unlike autism or downs syndrome, FASD is a transitory state that can be altered (but not cured).³⁸ This is especially true of children with FAE/ARND. The interviewee from the Public Health Agency of Canada explains that the less visibility and knowledge associated with FAE/ARND means that the significance of the diagnosis is lost. Unlike other special needs children, those with FAE/ARND are regarded as having had a bad start in life, poor parenting or simply the

³⁷ Recently, more educational resources have been developed to take a holistic approach, See, Alberta Learning – Special Programs Branch, “Teaching students with Fetal Alcohol Spectrum disorder: Building strengths, creating hope” (Edmonton: Crown in Right of Alberta, 2004); United States, Department of Health and Human Services, *Reach to Teach: Educating Elementary and Middle School Children with Fetal Alcohol Spectrum Disorders* (Rockville, MD: Center for Substance Abuse Prevention, Substance Abuse and Mental Health Services Administration, 2007).

³⁸ Michael Dorris, *The Broken Cord* (New York: Harper & Row, 1989); and Bonnie Buxton, *Damaged Angels: A mother discovers the terrible cost of alcohol in pregnancy* (Toronto: Alfred A. Knopf Canada, 2004) at 154-157.

reality of a slow learner.³⁹ Those with FAE/ARND are recognized as deprived children that when given the right tools will undoubtedly succeed.

FASD children are constituted as victims because the blame for their deficiencies is placed elsewhere. In cases where children are removed from their biological parents and have been adopted, blame is often placed on the biological mother for having drank during pregnancy and/or on society for not having forced the mother to stop drinking. The biological mother (the father is almost always omitted from the discussion)⁴⁰ is said to have induced trauma onto the lives of their children and it becomes the responsibility of the community and state to 'save' the child.⁴¹ This interpretation of the biological mother as the perpetrator against the victimized child fits within the child saving paradigm explored above. This is especially significant given that more than half of FASD children live in foster care and/or adoptive homes.⁴² Those parents who are identified as perpetrators and those children who are deemed worth saving are targeted as requiring social intervention by way of governing techniques.

Moreover, a great deal of responsibility and subsequent guilt is placed upon non-biological parents/caregivers of FASD children. Even when children are offered services, parents are criticized for not trying hard enough or in the right way to facilitate the success of the FASD victim. Parental programs for working with FASD children are even scarcer than programming for the children. The result is blame transferred from the

³⁹ Interview of Executive Director at Public Health Agency of Canada (3 August 2007).

⁴⁰ For a historical account of when the role of the father was eliminated from the discourse, see Armstrong, *supra* note 31.

⁴¹ Chen, *supra* note 5 at 4.

⁴² Sterling Clarren & Susan Astley, "The FAS diagnostic and prevention network" in Ann Streissguth and Jonathan Kanter eds., *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (Seattle: University of Washington Press, 2002) 40 at 48.

failure of the child to the parents/caregivers.⁴³ In an interview conducted by CBC Radio One, the adopted mother of Russ, a thirty year old man diagnosed with FAS, tells the story of a dramatic child who was continually behind on developmental milestones. She explains that given the lack of knowledge and resources about FASD, the blame for Russ' multiple terms of incarceration fell upon her and her husband's shoulders. She states that because they were not able to keep track of Russ twenty-four hours a day, they were told they were bad parents.⁴⁴ The message told by these stories are that parents must continue to strive for success from their FASD children and that this blind perseverance will result in achieving this success. Blame for FASD children failing to meet the targets set by programs and in school is almost never placed on the child herself.⁴⁵ As the looping effect is mutually reinforcing, when parents buy into the notion that their child's failure to reach the optimum potential is their fault, this discourse is embedded more deeply into the identity.

Additionally, guilt is associated with parents for not having dealt with psychological issues an FASD child may encounter, for example issues with adoption. Referred to as 'stack attack' victims by Buxton and others, children who endure a turbulent and inconsistent family life at a young age are deeply affected by these transitions; FASD children more so. The odds are against them and it becomes the responsibility of the parents/caregivers to account for all of these 'stacked' factors. When this does not occur, the parents/caregivers rather than the FASD children are blamed. For example, an editorial in the *Winnipeg Free Press* writes of the author's sadness when children with FASD are labelled as bullies rather than children who have not been

⁴³ Buxton, *supra* note 38 at 106.

⁴⁴ CBC Radio, Ottawa, *Sounds Like Canada* (24 October 2007).

⁴⁵ Interview of mother and advocate (18 June 2007).

adequately cared for.⁴⁶ Placing the blame on parents/caregivers results in the constitution of the victim identity but it also has an impact on the constitution of FASD adults as deviant. As individuals age, parents play a much less significant role in an adult's life and so the responsibility once placed on the shoulders of parents/caregivers gets transferred to the FASD adult.

Justification for the victim label is further reinforced in the FASD child discourse as they reach school age. Their status as victim is heightened as the cognitive and behavioural problems that became linked to the diagnosis in the 0-6 programming are intensified by the structure and content of public school. Here the double loop becomes apparent. While children aged 0-6 are identified as victims a new loop begins to take shape as children enter school. Children over the age of six are recognized as undeserving victims but the discourses that epitomize the potential of young children is lost. The beginnings of the adult discourse takes shape as older children witness a dramatic change in the expectations placed upon them, along with a swift reduction in access to services. Public education is characterized by the FASD literature as having the potential to further victimize the child but also as a source of hope and inspiration given the right knowledge and tools. The contradictory nature of the older child loop acts as a link between the opposing discourses of victim and deviant.

FASD children are recognized as being grossly victimized in the public education system given the lack of awareness and services offered by schools. There is a great deal of literature stressing the problems found in public schools and programs that could improve the success rate of FASD students. Through academic research, support groups

⁴⁶ Gordon Sinclair, "They're just kids living in hell on earth" *Winnipeg Free Press* (16 August 2007), online: <http://www.winnipegfreepress.com/subscriber/columnists/top3/story/4023085p-4635356c.htm> last accessed 26 August 2007.

and parent advocacy, schools are being pressured to contribute significantly to the management of primary disabilities and the elimination of secondary disabilities.

Schools are noted as potentially damaging to youth who have FASD because teachers often have little knowledge about the collection of symptoms or how a student should be 'managed'. The literature is littered with stories of teachers who are constantly angry at and give up on FASD children. Many parents recall being accused of being bad parents by teachers and told that they have bad kids. According to the principal in one of the stories relayed by Buxton, "the slim rewards of teaching a child like this simply aren't worth the challenges she presents. [The child with FASD] will probably not become a taxpayer".⁴⁷ Suggestions for improvements made by the academic literature and community groups include educating teachers on strategies to care for affected children, integrating children with FASD into the school model, and working positively with these students.⁴⁸ A low-stimulus work environment, routine and repetitiveness are also recommended learning tools. Social issues such as self-esteem are also noted.⁴⁹

These strategies for working with and managing FASD children are generally accepted in the literature but are those that I seek to problematize. Across the board, these sorts of programs and training sessions are not being applied. An American study conducted by Wentz uncovered the significant lack of knowledge special education programs have about FASD. Among the findings, no American state specifically serves the category of fetal alcohol syndrome and almost none of the states have specific

⁴⁷ Buxton, *supra* note 38 at 157.

⁴⁸ Janet McGrath, *Ikajuqtigiinniq: A resource for fetal alcohol syndrome prevention and intervention work* (Ottawa: Pauktuutit Inuit Women's Association, 1998) at 10.

⁴⁹ n.a., *Let's Talk FASD: Parent Driven Strategies in Caring for Children with FASD* (Ottawa: VON Canada, 2007) at 6; and Patricia Tanner-Halverson, "A demonstration classroom for young children with FAS" in Ann Streissguth and Jonathan Kanter, eds., *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (Seattle: University of Washington Press, 2002) 78.

educational interventions for FASD students. Moreover, the vast majority of states have no training for special education teachers regarding strategies for working with FASD students.⁵⁰ There is no Canadian study to the same effect but the results are likely to be similar. So while there is an assumption that these students can be helped and ‘fixed’, in reality children are not receiving the supports that are understood to be the saving grace. It becomes apparent that the identity constituted for young children conveying the notion of complete innocence does not translate in precisely the same way for children who have reached school age. There is less emphasis on the entitlement of older children to have access to support services and an expectation that these children will adapt to their environment, rather than the environment accommodating them. As understood through the looping effect, this identity is reinforced by parents/caregivers and FASD children in that it becomes solely their responsibility to find and fight for services. This is in contrast to young children who are saved by society.

The stories told by FASD parents/caregivers are that a good parent must pursue these strategies at all costs to ensure a meaningful place in society when the children reach adulthood. First, it becomes the responsibility of the parents/caregivers to educate those teachers who do not know about FASD. For each new teacher the FASD student encounters, parents are required to provide information on how to best manage their child.⁵¹ Alternatively, there is a strong movement in the FASD community towards specialized schools and home schooling to accommodate the needs of their children and to provide the specialized environments and activities prescribed above.⁵² Second, parents are also responsible for facilitating the social development of their children in

⁵⁰ Wentz, *supra* note 36 at 89.

⁵¹ Interview of Director of research network (10 July 2007).

⁵² *Let's Talk FASD*, *supra* note 50 at 6.

school. Public education is built on group activity and social interaction; a quality said to be lacking in FASD children and thus in need of intervention on the part of teachers and parents.⁵³ This is where the discourse of hope and optimism lies. With intense involvement by teachers, staff and parents it is believed that the potential victimization produced by the education system can be reversed. School provides numerous obstacles but even more opportunities for managing FASD, when the ‘right’ attitude and the ‘right’ information are deployed.⁵⁴

This discourse makes a number of assumptions worth challenging. It continues to assume that all parents/caregivers of FASD children are able to promote and access resources despite the pitfalls of the public education system. The discourse does not recognize the social context in which many parents/caregivers of children who receive the FASD diagnosis live; one of poverty and marginalization.⁵⁵ The task of illustrating to each new teacher or support person the hurdles faced by their children, having the time and capacity to do so, and/or looking for and being able to access alternative education is not a viable option for many parents/caregivers. Related to this, the FASD discourse assumes that an FASD child will receive supports in some way or another. Whether through community services, the education system or parental advocacy, by the time an FASD child reaches adulthood she is expected to have accessed resources to manage her illness. Adults, the literature will try to tell us, are not worth saving. Bruer sums up the discourse: “Viewed through the prism of birth to 3, bad early childhood experiences – especially, it seems, among the nation’s inner-city poor – cause permanent and detrimental brain changes. These brain-damaged individuals have a lifelong propensity

⁵³ *Ibid.* at 8.

⁵⁴ CBC Radio, *supra* note 44; Buxton, *supra* note 38.

⁵⁵ Leslie, *supra* note 18 at 30-33.

for violence and criminal behaviour”.⁵⁶ Similarly, Buxton asserts that had her daughter been diagnosed and been given access to services before the age of seventeen, she is certain many of her experiences with homelessness and drugs would have been avoided.⁵⁷ Those FASD adults who did not access these resources have not only missed the opportunities provided to them in childhood but are constituted as destined for deviancy.

The stories that constitute the FASD child as victim dominate the FASD literature. These narratives are disseminated through books, online communities, and support groups with the goal of making others see the struggles that parents/caregivers have overcome. This portion of the FASD literature becomes murky, however, when we look more closely at whose knowledges are being heard. It is worth questioning whether the narratives being made powerful speak to everyday encounters with FASD children.

Personal accounts of adopted parents and their struggle to understand and diagnose their child make up a substantial portion of the FASD literature. The first to write this sort of story and gain popularity was Dorris’ *The Broken Cord*. The story he tells is of his son’s struggle with the effects of pre-natal exposure to alcohol; told by himself, a professor at Dartmouth College who studied anthropology and literature.⁵⁸ Other works that followed *The Broken Cord*’s liking are written by middle-class, educated individuals with the know how to seek out supports, work their way through a confusing system, and have the intellectual and financial capability to share their story in a book or through advocacy work. By limiting the knowledge production about FASD exclusively to those within a particular social sphere leaves the impression that this way

⁵⁶ Bruer, *supra* note 7 at 14.

⁵⁷ Interview, *supra* note 45.

⁵⁸ Dorris, *supra* note 38.

of life is the norm for how parents/caregivers should be raising their FASD child; as a victim.

The narratives of most biological mothers are not being heard, even those who have maintained custody of their children. There are few accounts of a mother and her child coming to understand FASD. This is most likely because few biological mothers retain custody of a child diagnosed with FASD but also because of the stigmatization that a biological mother faces. Furthermore, we are not hearing the stories of many of the FASD children who frequently change foster homes but never secure a permanent living space. Many caregivers are simply not able to tell their child's story. As the executive director at Public Health Agency of Canada explains, any number of issues that typically plague a child diagnosed with FASD such as socio-economic status, level of education, geographic isolation etc.⁵⁹ prohibit many caregivers from gaining access to social programs. By excluding these stories it is easier to depict FASD children as victims. Ridding them of the stigma and the unpleasantness of an irresponsible mother and a sure-to-disappoint child, FASD children can be constituted as success stories as they will make the most of an investment in resources. This comes to be understood as the narrative that drives all FASD children's lives; but the subjugated knowledges from the marginalized children constitute them as deviant instead.

We are not hearing the stories from the perspective of First Nations, Métis and Inuit populations. As we will see in chapter 4, Aboriginal populations are associated with the deviant identity but this occurs in part because their stories in childhood are not told. Very rarely are the experiences of parents/caregivers caring for an Aboriginal FASD child heard, with the exception of those children who have been adopted by non-

⁵⁹ Interview, *supra* note 39.

Aboriginal parents. Without this victim identity in childhood, those with FASD who belong to Aboriginal communities appear to be marked as deviant without question.

In order to understand how FASD individuals come to be understood as deviant, it is important to assess certain characteristics that aid in their constitution as victim in childhood. Young children with FASD are noted as extremely affectionate. As part of the early signs of social inappropriateness, toddlers and young children diagnosed with FASD are very likeable and outgoing to strangers and family. They require an insatiable amount of affection and seek embraces from anyone who will give them and also readily accept new individuals into their lives.⁶⁰ This indiscriminate appeal for affection is noted as a positive attribute in the FASD stories, especially when describing the first encounter between an adopted FASD child and her new parents. This same trait, however, becomes reconstituted in adulthood as a major cause of responsabilized sexual deviancy.

It is important to note that with reference to children, the FASD literature focuses almost exclusively on primary rather than secondary disabilities. By limiting the discussion about FASD children to primary disabilities alone, the characteristics that may explain involvement with the law later in life (secondary disabilities such as mental illness, unstable childhood etc.) are ignored leaving only a victimized child.

⁶⁰ Dorris, *supra* note 38.

Chapter 4: The FASD Adult

Introduction

FASD children are not only able to be saved, they are worth saving. A number of interviewees mentioned the political advantage of supporting child programs. The director of the research network noted that funding child based initiatives gives the ‘best bang for your buck’.¹ The political rhetoric is informed by the child paradigm, which asserts that those children who receive intervention will be assured a good quality of life. By the same token, those who do not receive supports are destined for failure and criminality.² FASD adults are framed as hopeless, and are consequently relegated to the criminal justice system. Therefore, the justice system produces the knowledges that make the FASD adult loop. In this chapter, I will consider how the deviant discourse manifests itself through ideological and socio-structural means.

Such a stark contrast between the FASD child and adult can be explained in part by the demedicalization of FASD in adulthood. Golden’s definition of demedicalization is useful here, describing it in part as: “a political and social process, reflecting the interests of particular groups in returning definitions of deviance to the legal arena, the moral realm, and the court of public opinion”.³ Pertaining specifically to FASD, Golden emphasizes that demedicalization does not mean the diagnosis is not being referred to

¹ Interview of Director of research network (10 July 2007); and interview of mother and advocate (18 June 2007); and Executive Director at Public Health Agency of Canada (3 August 2007).

² John T. Bruer, *The Myth of the First Three Years: A New Understanding of Early Brain Development and Lifelong Learning* (New York: The Free Press, 1999) at 14; Jennifer Henderson, “‘The years before five’: Discourse and pedagogy of neoliberal childhood” (Cultural Studies in Education panel: Canadian Association Cultural Studies Conference at the University of Alberta, 21 October 2005) [unpublished].; and Jane Jenson, “Canada’s shifting citizenship regime. The child as ‘model citizen’” in Michael Keating and Trevor C. Salmon, eds., *Decentralisation and Regionalisation: Canada and the United Kingdom Compared* (Montreal: McGill-Queen’s University Press, 2000) 107.

³ Janet Golden, “‘An argument that goes back to the womb’: The demedicalization of fetal alcohol syndrome, 1973-1992” (1999) 33 *Journal of Social History* 269 at 271.

and used in the medical community; however, the “explanatory power of the diagnosis is eroding as the diagnosis does little to afford special consideration to those classified as FASD”.⁴ Golden uses the term as a practical explanation when studying appeals to the death sentence. I am using it in an ideological sense to understand how a new loop appears for FASD adults and is connected to but distinct from the FASD child. The loop in childhood grants significant power to the medical knowledges that make up the FASD identity. In adulthood, this power shifts to the criminal justice system as the authority on what it means to be constituted with FASD.

There is an obvious question about where youth fit into the paradigm of the child and adult loops. The body of research on youth as a distinct entity in the criminal justice system is well established.⁵ Surprisingly though, with reference to the FASD identity, there is no indication that youth are distinguished from the adult identity. So whereas an FASD youth may receive a more lenient sentence due to the fact that she is being tried under the *Youth Criminal Justice Act*, in terms of the justice system’s reaction to her diagnosis she is demedicalized and subsequently criminalized to the same extent as FASD adults. Therefore, when I refer to the use of the FASD adult identity in the criminal justice system, FASD youth are part of this loop.

In this chapter I consider how FASD becomes constituted as deviant by looking at which FASD adults become linked to criminality and their relationship to the criminal justice system. I also consider the connection between psy-discourses and the criminal

⁴ *Ibid.*

⁵ To name a few, see chapter 2 in Anthony Doob and Carla Cesaroni, *Responding to Youth Crime in Canada* (Toronto: University of Toronto Press, 2004); Lauren D. Eisler, “An application of Foucauldian concepts to youth in the criminal justice system: A case study” (2007) 15 *Critical Criminology* 101; Jane B. Spratt, “Do youthful offenders reject adult punishment norms?” (2003) 45 *Canadian Journal of Criminology and Criminal Justice* 243; and Ian Waters, “The policing of young offenders” (2007) 47 *British Journal of Criminology* 635.

justice system more generally. The unique situation that First Nations, Métis and Inuit populations find themselves in with relation to the FASD identity is touched upon. In the final section of the chapter I describe how FASD adults come to be regarded as hopeless.

The Redeemed and the Lost Cause

Just as the FASD story is told from the perspective of selected children – those who warrant saving – in the creation of the victim identity, not all adults with FASD are being heard. In fact, there is a dichotomy in the adult FASD identity between what I term the FASD ‘redeemed’ and the FASD ‘lost cause’. The former are those FASD individuals who beat the odds and lead a happy and ‘successful’ life.⁶ They are highlighted by FASD advocates as the reason to keep fighting and use these individuals as poster children for increased awareness about programming, support, etc. The redeemed adults are those who received the supports talked about in chapter 3 and are therefore managed in such a way as to appear ‘redeemed’.

The CBC radio broadcast with Russ, the thirty year old man diagnosed with FASD, is an illustration of the redeemed. The story begins on a sad tone. It is about the trouble Russ had in school and his slow development. He describes the decade he spent in and out of jail, despite the undaunting support of his parents. The interview then takes on a much more optimistic message. With his parents as guides, Russ finds a support program run by Mennonites that offers a support worker to stay with him twelve hours a day; drives him to and from work; stays with him at work; and helps him manage his money. Because of this high level of intervention the interview concludes with a

⁶ Here is an example of the success stories told: Kleinfield, J. B. Morse & S. Wescott, eds., *Fantastic Antoine Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome* (Fairbanks: University of Alaska Press, 2000).

promising outlook for Russ now that he is involved in a structured support program. Without this and the guidance of his parents, the outlook would be much grimmer.⁷ Despite Russ' jail time (or perhaps because of it) Russ is portrayed as a success story for two reasons. First, a lot of emphasis is placed on the role of his adoptive parents as well as foster care in the lives of FASD children generally. That Russ' adoptive parents hold none of the stigma of the biological mother and have taken all the right steps is important in making-up Russ as redeemed. Second, the imposition of governing techniques through intensive programming appears to be Russ' saviour. There is a clear message that without this sort of normalizing strategy, he would have likely retained his relationship with the criminal justice system.

Buxton's book has an abundance of these same stories. A woman accepts a six year old girl as a temporary foster care child and falls in love, despite the fact the social workers tell her the child 'is not teachable' and 'is hopeless'. Through many medical and cognitive struggles, the child grows up healthy and with a tailored education, thanks to home schooling. Her mother has fought tirelessly over the years to access information and supports from the medical and social community. The story emphasizes that it is because of this perseverance that the child is now an intelligent and sociable woman. She runs her own small business from her home with her mother and speaks at conferences about her life with FAS. The final paragraph of this story explains that the young woman made contact with her biological brother. Her brother, raised by a foster family who were not sensitive to his needs as an FASD child, was, "frequently in trouble with the law [as] he 'did not get the help and support he needed'". He committed suicide at age twenty-

⁷ CBC Radio, Ottawa, *Sounds Like Canada* (24 October 2007).

one.⁸ This is a telling contrast between the young girl and her brother. The girl, who received support and education, is recognized as successful not only as a person with FASD but as an entrepreneur and spokesperson for FASD. Numerous grassroots organizations concerning FASD tell stories similar to this young woman.⁹ Her brother, on the other hand, who did not receive these strategies in childhood, becomes the antithesis of his sister. She has been redeemed. He is the embodiment of a lost cause. We do not hear about him, or other lost causes until they reach the criminal justice system. Only then do we become aware of their diagnosis which, I will argue here will most likely lead to increased criminalization.

The Adult Loop

The FASD adult is subject to the neo-liberal characteristics of rationality and responsibility. As explored in chapter 2, the neo-liberal paradigm embodies the ideas of self-regulation and normalization.¹⁰ This rhetoric is not found amongst FASD children but is instead specific to FASD youth and adults; hence the need for a new loop. FASD children are expected to have behavioural and cognitive problems as a part of their diagnosis. This same diagnosis does not yield a similar response in adulthood. FASD adults who make connections between undesirable behaviour and their diagnosis are viewed as making excuses.

⁸ Buxton, Bonnie. *Damaged Angels: A mother discovers the terrible cost of alcohol in pregnancy* (Toronto: Alfred A. Knopf Canada, 2004) at 249-253.

⁹ See, for example, n.a., *FASD Connections*, online: www.fasdconnections.ca/id33.htm, last accessed 26 April 2008; n.a., *Fascets*, online: <http://www.fascets.org/positive.html>, last accessed 26 April 2008; n.a. *FAS Link: Fetal Alcohol Spectrum Disorders, Information, Support and Communications Link*, online: www.faslink.org, last accessed 28 March 2008

¹⁰ Nikolas Rose, "Government and control" (2000) 40 *Brit. J. Criminol.* 321.

Those who advocate on behalf of FASD youth and adults claim that seemingly simple tasks such as changing classes between periods, using a locker and finding a job are often extraordinarily difficult.¹¹ The literature asserts that increased complexity and demands on the life of an FASD youth set unrealistic targets but in a different way than in childhood. Alberta's report *Teaching students with Fetal Alcohol Spectrum Disorder* explains this as part of "the weakness of FASD individuals..."¹² This work portrays FASD as fairly needs intensive, however when referring to 'older students' self-management vocabulary plays a prominent role. This is not found with reference to children.¹³ In childhood, the victim identity disallows personal responsibility for less than ideal circumstances (such as poor grades in school, social problems, angry outbursts, stealing etc.) and so blame is most often attributed to parents/caregivers. In adulthood this same blame moves onto the FASD individual herself. Schonfeld, Mattson and Riley refer to these actions as a lack of moral maturity on the part of FASD youth and adults.¹⁴ Page uses the term 'moral retardation' when referring to children who grow up never having learned life lessons: "It is one of the most heartbreaking experiences for adoptive families that their children persist in behaving like street urchins in spite of the good parenting they have received".¹⁵

This moral immaturity is not consistent with the governing technologies that exist and rely on a neo-liberal subject. In the case of *R v. E.L.J* the judge contemplates the accused's diagnosis of FASD and appropriate sentencing for the numerous petty crimes

¹¹ Alberta Learning – Special Programs Branch, "Teaching students with Fetal Alcohol Spectrum disorder: Building strengths, creating hope" (Edmonton: Crown in Right of Alberta, 2004) at 13.

¹² *Ibid.*

¹³ *Ibid.*

¹⁴ Amy M. Schonfeld, Sarah N. Mattson & Edward P. Riley, "Moral maturity and delinquency after prenatal alcohol exposure" (2005) 66 J. Stud. Alcohol 545.

¹⁵ Kathryn Page, "The invisible havoc of prenatal alcohol damage" (2003) 4 Journal of the Center for Families, Children and the Courts 67 at 78.

he committed, such as theft, vandalism, failure to appear in court etc. :“... we simply cannot throw up our hands and do nothing. Neither will we help by labelling FAS and FAE youth as victims of alcohol abuse or as mental defectives, incapable of change...to hold such an attitude is ultimately to deny the humanity of such individuals”.¹⁶ Placing the standards of the neo-liberal subject on someone who is otherwise considered completely irrational is characterized as compassionate and humane. The judge does not disregard the diagnosis but sees it as an impediment to self-regulation. The discourses that make up the adult FASD identity presumes that she can make informed choices and so any move away from normalized behaviour can be squarely blamed on the adult herself.

Observing this shift from the child loop to the adult loop allows us to consider once again the child saving literature discussed in chapter 3. There I presented the ideas of scholars such as Chen and Henderson who critically explore the notion of childhood (specifically ages 0-6) as a time of unrelenting knowledge absorption and where the foundation for moral, normalized citizens takes place. The authors also allude to what is said to happen to those who do not receive all the programs and supports necessary before the age of six. Those children who do not reach their ‘optimum potential’ by six years old do not have the tools to become productive adults. If ‘the years before five last the rest of their lives’¹⁷ then this is the case for both a productive childhood and one that had few opportunities.¹⁸ This plays out in a dramatic way for those children slotted to be deviant before their childhood is over. We see this with crack babies, where: “by the time

¹⁶ *R v. E.L.J.* [1998] Y.J. No. 19 (QL) at 4.

¹⁷ Henderson, *supra* note 2.

¹⁸ *Ibid.*; and see, Jenson, *supra* note 2; and Xiaobei Chen, *Tending the Gardens of Citizenship: Child Saving in Toronto 1880s-1920s* (Toronto: University of Toronto Press, 2005).

children were six or seven...they were so damaged by the effect of the culture of poverty that they were essentially doomed to repeat the impoverished lives of their parents”.¹⁹ So too are many FASD children pegged to become deviant FASD adults. The adult loop is made up of discourses that promote the association between FASD and deviancy and that exclude alternatives.

True to the neo-liberal paradigm, the adult FASD identity is supported by the perception that they constantly fail to meet basic expectations. Poor grasping of advanced curriculum in mathematics and science, low rates of high school graduation and ineffective communication skills to function in daily life are all equated with the diagnosis.²⁰ The literature characterizes these concerns as failures. The FASD child is described as having ‘weaker achievements’ but success in subjects such as art. When FASD youth do poorly in school it is connected to other behaviours: “By high school these students often achieve very low marks and frequently skip school, start smoking, abuse alcohol and drugs to control their pain, and engage in crime...and sexual promiscuity”.²¹ Connecting underachievement with deviancy reinforces the need for the FASD adult to be governed through disciplinary means.

We find evidence of a new deviant loop emerging when we consider which institutions govern the FASD adult. As Hacking notes: “Which labels stick depends less on their intrinsic merits than on the network of interested parties that wish to attach these

¹⁹ Teresa Ortiz & Laura Briggs, “The culture of poverty, crack babies and welfare cheats: The making of the ‘healthy white baby crisis’” (2003) 21 *Social Text* 39 at 43.

²⁰ Jennifer Wemigwans, *FASD Tool Kit for Aboriginal Communities* (Toronto: Ontario Federation of Indian Friendship Centres, 2005) at 21; and Ann Streissguth, (ed.) et al., “Primary and Secondary Disabilities in Fetal Alcohol Syndrome” in Jonathon Kanter ed., *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (Seattle: University of Washington Press, 2002) 25 at 34; and FAS Link, *supra* note 9.

²¹ Wemigwans, *ibid.* at 22.

labels”.²² Chapter 3 explored the various groups interested in prevention work and children with FASD, most notably government funded campaigns, early years centres and community programs. These groups are less interested (if at all) in FASD adults. The resources offered to children are not available to FASD youth and adults.²³ Only the most obvious cases and those with the most severe special needs are able to access resources. While the issue of child centered programming receiving sole attention is not exclusive to FASD, the party that takes on the identity after childhood, the criminal justice system, is rather unique.

I conducted an analysis of available resources for youth and adults using the *Directory of Fetal Alcohol Spectrum Disorder Information and Support Services in Canada*. I limited my analysis to national services to allow for consistency across the country. While I initially wanted to categorize the services between those dealing specifically with adults, those specifying that they work with children and adults, and dividing FASD specific programs from general community support programs, there were so few resources for youth and adults that these categories were not useful. My analysis revealed that of the thirteen national services listed, there are no services that work specifically with adults and address their needs while four of the thirteen services target children only. It is interesting to note that in a database meant to detail resources concerning FASD, more than half of the services listed (seven out of thirteen) were

²² Ian Hacking, *The Social Construction of What?* (Cambridge: Harvard University Press, 1999) at 152.

²³ One article notes that once FASD children turn eighteen, they “fall off a cliff”. n.a., “Groups call for more services for adults with FASD” CBC News, Manitoba, 14 September 2007, online: <http://www.cbc.ca/canada/manitoba/story/2007/09/14/fasd-adults.html>, last accessed 31 December 2007.

organizations that did not deal specifically with FASD, and three of the seven programs do not mention FASD in their abstract.²⁴

Part of the reason there are no adult specific services is because resources and accessibility issues are not a concern until someone reaches the criminal justice system. The director of the research network says that support for youth and adult in spaces other than the criminal justice system has only begun to be considered in the past three years.²⁵ Behavioural and cognitive disabilities associated with FASD children are now linked to ‘manageable’ problems rather than the FASD diagnosis. Falling in with the wrong crowd or laziness is more likely to be seen as the cause of poor grades or bad behaviour than FASD. There is little incentive to support adult programs when the discourse asserts that they are a lost cause.

FASD adolescents and adults are linked with high risk situations that connect them to the deviant identity. The FASD identity is associated with an increased risk of living on the streets, using alcohol and illicit drugs, and having unprotected sex.²⁶ No data can be found to demonstrate that FASD youth are more likely to runaway from home, experiment with drugs and engage in sexual activity than the general youth population, but these actions are depicted as far more dangerous and therefore associated with the criminal justice system when taken on by FASD youth. Almost every discussion of youth and adults with FASD uses statistics to demonstrate the high rate of risky

²⁴ Canadian Centre on Substance Abuse, *Directory of Fetal Alcohol Spectrum Disorder (FASD) Information and Support Services in Canada* (Ottawa: CCSA, 2005) at 1-8.

²⁵ Interview of director of research network, *supra* note 1.

²⁶ n.a. *Let's Talk FASD: Parent Driven Strategies in Caring for Children with FASD* (Ottawa: VON Canada, 2007) at 12-13; and Erica Clark et al., “Secondary disabilities among adults with fetal alcohol spectrum disorder in British Columbia” (2004) 2 J FAS Int 13; and Streissguth, *supra* note 20 at 33-34.

behaviours, although they do not compare these rates to non-FASD youth.²⁷ Reducing the FASD adult identity to these sorts of activities allows the criminal justice system to intervene and impose governing strategies. Indeed, the standard statistic in the literature is that sixty percent of those with FASD have had trouble with the law.²⁸ The behaviours of the middle-class, Caucasian teen who tries marijuana or runs to her friend's place because she's mad at her mom are not perceived and subsequently governed in the same way as FASD youth. The most negative stories are the ones picked up by the media that paint a generalized picture of FASD adults as capable of heinous crimes.²⁹

Throughout the literature there are examples of 'dangerous' FASD youth and adults and their need for tough governing strategies. These strategies are markedly different from their child counterpart, as they rely more heavily (and sometimes exclusively) on retribution. A radio broadcast from Minnesota conveys the danger FASD youth can be to themselves and to others. In profiling a residential care centre for adults with FASD, the piece relates the troubles caused by FASD youth because of their

²⁷ Paul Verbrugge, *Fetal Alcohol Spectrum Disorder and the Youth Criminal Justice System: A Discussion Paper* (Ottawa: Department of Justice, 2003) at 3; Fred J. Boland, et al., *Fetal Alcohol Syndrome: Implications for Correctional Service* (Correctional Service Canada, 1998), online: http://www.csc-scc.gc.ca/text/rsrch/reports/r71/r71e_e.shtml, last accessed 9 August 2006 at 20; and Page, *supra* note 15 at 79.

²⁸ Margaret A. Michaud and Sacha K. Michaud, *Beautiful Smiles, Gentle Spirit - Fetal Alcohol Spectrum Disorder: A Misunderstood Problem* (Calgary: Detselig Enterprises, 2003) at 45; and Diane K. Fast & Julianne Conry, "The challenge of fetal alcohol syndrome in the criminal legal system" (2004) 9 *Addiction Biology* 161 at 163.

²⁹ The association of FASD and 'social ills' is seen in abundance in the media, for example: Steve Lambert, "Leaders predict more tragic deaths unless governments fix aboriginal poverty" *Canadian Press NewsWire*, Winnipeg, (19 August 2007); Colleen Simard, "Adam can be a statistic or a turning point" *Winnipeg Free Press* (20 August 2007) A11; n.a., "Boys accused of killing six-year-old part of reserve's tortured history: leader" *Canadian Press Newswire*, Paucingassi, Manitoba (16 August 2007); Mike McIntyre, "Picture emerges of tragic lives of three children who drowned boy" *National Post*, Don Mills (16 August 2007) A4; Byron Christopher, "Man gets jail time for sexually attacking a young girl: Edmonton" AM630 CHED, Edmonton, (8 August 2007), online: http://www.630ched.com/news/news_local.cfm?cat=7428109912&rem=71896&red=80110923aPBlny&wids=410&gi=1&gm=news_local.cfm, last accessed 25 August 2007.; and Chris Eby "Repeat rapist spared indefinite prison sentence: Toronto" CTV Toronto (6 November 2007) online: http://toronto.ctv.ca/servlet/an/local/CTVNews/20071106/rapist_sentenced_071106/20071106?hub=TorontoHome, last accessed 31 December 2007.

diagnosis. The manager of the centre recalls the youths' screaming, swearing and property destruction as a result of their FASD. He goes on to describe the youth as 'hyper-sexual' and claims that they would likely be in prison if not for the centre.³⁰ One resident, Billy Nelson - who has been diagnosed with FASD - connects his illness to his dangerous behaviour. He links his reduction in activities such as using drugs, alcohol and being 'prone to violence' is linked with being in the residential centre. Nelson says: "I need to take the punches and say, hey, just get my stuff together so I can move on in life and better myself. Because if you don't better yourself, you're not going anywhere".³¹ Nelson connects intensive supervision and intervention with participating in fewer dangerous behaviours and becoming a 'better' (normalized) person. He is an example of the FASD adult loop being mutually reinforced by those classified. Nelson has bought into the idea that left to his own devices, his FASD diagnosis would inevitably lead him to deviancy.

There is some literature that questions the assumptions about FASD youth and adults as dangerous. A study by Sullivan found that youth who had been exposed to alcohol in utero did not self-report any more delinquent behaviours when compared to a non-exposed group of youth.³² Sullivan concludes that the connection between FASD youth and dangerousness is not as clear as the criminal justice and psy-discourses assert. With reference to the Aboriginal population (as will be discussed later in this section), a comprehensive study by the Aboriginal Healing Foundation suggests that the secondary

³⁰ Tom Robertson, "Adults with fetal alcohol syndrome face huge challenges" Minnesota Public Radio (21 November 2007).

³¹ *Ibid.*

³² Arthur K. Sullivan, "Fetal Alcohol Spectrum Disorders (FASD) in the adult: Vulnerability, disability, or diagnosis - a psychodynamic perspective" in Kieran D. O'Malley ed., *ADHD and Fetal Alcohol Spectrum Disorders (FASD)* (New York: Nova Science Publishers Inc., 2007) 215 at 224.

disabilities associated with FASD that leads to dangerousness can be found

disproportionately amongst the general Aboriginal population. The report finds:

...social marginalization, colonist articulation strategies, including the residential school system, and systematic racism are replaced with substance abusing mothers and brain damaged offspring as central contributing factors to high incarceration rates of Aboriginal men. However, Aboriginal inmates, in general, experience all of the 'secondary disabilities' attributed to FAS/FAE".³³

The diagnosis that makes FASD adults 'dangerous' is part of a larger discourse that seeks to portray FASD as deviant. This invokes governing strategies for the purposes of normalization.

The governing effects of classifying the FASD identity as dangerous seek to intervene in the life of the FASD adult and normalize external factors, such as friends. The assumption is, "...that the peer group they attract may be unpredictable and a source of deviant behaviour, such as the use of alcohol and drugs, out of control sexual activity, as well as violence and vandalism".³⁴ Many advocates for FASD youth and adults point to self-interested trouble makers or even gangs who take advantage of an FASD individual's eagerness to please and who provoke the questionable activities FASD youth partake in. We see this trend throughout the literature. Norgard's book about her adopted FASD son on death row is filled with stories of questionable friends. It was her son and a friend who break probation; a friend who helps him escape from prison; friends who are with him when he robs houses; and friends who do not return his calls when he needs help and who beat him up in prison.³⁵ These groups are said to have FASD youth participate in the most dangerous activities and those with the greatest likelihood of being

³³ Caroline L. Tait, *Fetal Alcohol Syndrome Among Aboriginal Peoples in Canada: A Review and Analysis of the Intergenerational Links to Residential Schools* (Ottawa: Aboriginal Healing Foundation, 2003) at 246.

³⁴ Boland, *supra* note 27 at 20.

³⁵ Katherine Norgard, *Hard to Place: A Crime of Alcohol* (Tucson: Recovery Resources Press, 2006).

caught.³⁶ In a similar fashion, young women with FASD are easy targets for the sex trade.³⁷ An FASD adult's social group and use of free time are part of the rhetoric that responsabilizes her actions as a series of poor choices, in turn making it a site for intervention and normalization. Targeting not only the FASD individual's body and mind, but also these sorts of external parameters provides a space for increased governing. Relationships that are not conducive to normal behaviour are pathologized as part of the FASD diagnosis while still maintaining its responsabilized nature.

The activities many FASD youth find themselves participating in are commonly those behaviours that society recognizes as bad, irresponsible or unproductive. Whether voluntary or coerced, they are considered 'adult' behaviours. It becomes more challenging to view FASD youth and adults as victims when they are participating in criminal acts that create others as victims. The knowledges concerning FASD youth and adults become inseparable from these negative behaviours. FASD individuals are constituted as choosing deviancy, and in turn rejecting the sick child image. This disassociation between the FASD child and adult is consistent with the child-saving literature that finds those who are not successfully targeted in childhood as destined to become unproductive adults. It is because of the sharp distinction between FASD children and adults that I require two loops to make clear how these identities are being

³⁶ Bill Graveland, "Lethbridge cop tries to keep FASD kids out of the court system" *Canadian Press* (30 July 2007) online: <http://www.cbc.ca/national/070730/n73038A.html#skip300x250>, last accessed 6 August 2007.; Robin LaDue & Tom Dunne, "Legal issues and FAS" in Ann Streissguth and Jonathan Kanter, eds. *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (Seattle: University of Washington Press, 1999) 146.

³⁷ Hon. M.E. Turpel-Lafond, "Fetal Alcohol Spectrum Disorder: The perspective of a First Nations judge" in Kim Anderson and Heather Levecque, eds. *Undue Trials: Justice Issues Facing Aboriginal Children and Youth* (Toronto: Ontario Federation of Indian Friendship Centres, 2004) 6 at 7; and Buxton, *supra* note 8 at 201.

constituted. As I will show, the narrow lens of the criminal justice system often leaves few alternative narratives for the FASD adult identity.

The Criminal Justice System and Psy-Sciences

The reciprocal relationship between the criminal justice system and the psy-sciences holds fast because of their common values of objectivity and individuality. By limiting the scope to individual blameworthiness, practical governing techniques (such as incarceration, targeted programming, etc.) can be administered only to those deemed abnormal, in this case those with FASD. Likewise, the objective and scientific veil used by the psy-sciences legitimate these governing strategies as necessary for the well being of the individual and the safety of society. Indeed, the relationship between these two discourses has fundamentally changed the nature of constituting identities. Identities have now become more frequently related to deviance and criminality and, as McCallum asserts, reflect a psycho-medical understanding of the criminalized individual.³⁸

Keeping in mind this relationship between the criminal justice system and psy-sciences, it is clear that conceptions of deviant and criminal are no more scientific or objective than any other psy-science identities. As pointed out in chapter 2, there is no behaviour that is innately criminal, only a set of accepted values that determine deviancy and normalcy. Referring to Goffman's work, Hacking describes the constitution of deviancy: "Deviance is not something inherent in behaviour, but an outcome of how individuals or their behaviour are labelled".³⁹ Hacking goes on to describe how deviancy

³⁸ David McCallum, "Mental health, criminality and the human sciences" in Alan Petersen and Robin Bunton eds. *Foucault, Health and Medicine* (London: Routledge Press, 2000) 53 at 55.

³⁹ Ian Hacking, "Between Michel Foucault and Erving Goffman: Between discourse in the abstract and face-to-face interaction" (2004) 33 *Economy and Society* 277 at 296.

comes from more than the association of certain behaviours to evilness, but requires a specific identity, 'the criminal' to pinpoint, observe, and blame.

Narrowing their scope to the individual so as to remain 'objective', the criminal justice system and psy-disciplines do not make a space for studying the social as part of the criminal justice context. By social, I am referring to the effects of poverty, marginalization, racism etc. Upon analysing psy-science literature, it becomes apparent that although there are times when the social is acknowledged in the explanation of criminality, it is written in such a way that the individual is responsabilized for social ills.⁴⁰ We have seen this with FASD adults who are blamed for not having used the opportunities afforded to them in childhood. The sensibility involved in condemning an individual who does not conform to the standard rationality is too convenient to ignore. Rose remarks: "The institutions function in certain respects like telescopes, microscopes or other scientific instruments: they establish a regime of visibility in which the observed is distributed within a single common plane of sight."⁴¹ By both disciplines limiting their sight in this way, acknowledgement of the social seems counterproductive to establishing power over the individual.

At its most basic, the aim of the knowledges concerning objectivity and individuality is to manage those who are deemed abnormal. The management of criminal behaviour by the psy-sciences is similar to the management of any bureaucratic institution. Rather than focus on effective treatment or rehabilitation, the criminal justice

⁴⁰ As one of many examples, see Chapter 4 in Dennis Howitt, *Forensic and Criminal Psychology* (Harlow: Pearson Prentice Hall, 2002).

⁴¹ Nikolas Rose, "Calculable minds and manageable individuals" (1988) 1 *History of the Human Sciences* 179 at 187.

system is one centred on managing its clients.⁴² As Castel points out, the goal becomes efficiency rather than retribution or even rehabilitation.⁴³ Instead, the criminal justice system seeks to minimize risk through the use of numbers and categories.⁴⁴ This assessment of the criminal is, in essence, data management of normative categories. Categories in assessing dangerousness such as ‘emotionality’, ‘tolerance’ and ‘manipulation’⁴⁵ are highly discretionary and are meant to calculate the risk of dangerousness in an objective manner.

The psy-sciences play an integral role in allowing an individual to be objectified in such a way so as to make her manageable. Rose describes the psy-science discipline as being capable of manipulating human capacities so that it becomes calculable criteria to understand subjects. In doing so, efficient regulatory schemes are able to be constructed, forming a “rational regulation of individuality”.⁴⁶ The FASD diagnosis itself may be viewed as a grouping of calculable criteria. The ‘4 Digit Diagnostic Code Criteria for FASD’ breaks into ranks growth deficiency, facial phenotype, central nervous system damage and gestational exposure to alcohol. Measurements that determine which rank an individual is classified in depends on determinants such as ‘probable’ dysfunction, ‘some risk’ of exposure, and height and weight percentiles.⁴⁷ Moreover, a recommendation for

⁴² Kelly Hannah-Moffat, “Moral agent or actuarial subject: Risk and Canadian women’s imprisonment” (1999) 3 *Theoretical Criminology* 71 at 72.

⁴³ Robert Castel, “From dangerousness to risk” in Graham Burchell, Colin Gordon and Peter Miller eds., *The Foucault Effect: Studies in Governmentality* (Chicago: University of Chicago Press, 1991) 281 at 295.

⁴⁴ Charles E. Rosenberg, “The Tyranny of Diagnosis: Specific Entities and Individual Experience” (2002) 80 *The Milbank Quarterly* 237 at 249.

⁴⁵ Robert Menzies et. al. “The dimensions of dangerousness revisited: Assessing forensic predictions about violence” (1994) 18 *Law and Human Behavior* 1 at 12.

⁴⁶ Rose, *supra* note 41 at 185.

⁴⁷ Mansfield Mela, “Accommodating the fetal alcohol spectrum disorders in the diagnostic and statistical manual of mental disorders (DSM V)” (2006) 4 *J FAS Int* 1 at 2.

the establishment of Canadian guidelines includes neurobehavioural assessments (such as memory and academic achievement) to be added to the diagnostic criteria.⁴⁸

The criminal justice system has adopted these principles of calculability to allow for a precise measure of individuality and to use this individuality to manage the abnormal shortcomings of its clients.⁴⁹ Thus, creating these managing structures allows for the freedom of psy-science experts to observe individuals, limit their space and enforce self-regulatory strategies and consequently impose normative behaviours upon individuals so that their risk of unwanted behaviour is minimized.

The use of the psy-science disciplines is fundamental to the current conception of the criminal justice system as an institution. The principles of objectivity and individualization have helped shape the criminal justice system into a managerial tool used to assess and administer normative techniques onto those who do not participate in acceptable behaviour. Equating FASD with deviancy fits just this purpose. The identity pinpoints precise areas of abnormality (cognitive and/or behavioural) and seeks to manage these areas without going so far as to consider the individual irrational and incapable of becoming 'normal'.

'Deviant' Discourses

Many FASD individuals find themselves in trouble with the law. Often, the first encounter occurs in adolescence and escalates in adulthood. The estimated number of individuals with confirmed FASD in the Canadian prison population usually ranges from

⁴⁸ Albert E. Chudley, et al., "Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis" (2005) 172 Can. Med. Assoc. J. S1 at S9.

⁴⁹ *Ibid.* at 187.

ten to thirty percent, while one study suggests seventy percent suffer from FASD.⁵⁰ There is little information on how these numbers are reached. This discrepancy is why the executive director at the Public Health Agency of Canada argues that those who advocate for people with FASD try to come up with a monetary figure to gain momentum behind their cause and demonstrate the impact of FASD in Canada.⁵¹ Using numbers and statistics to manage the FASD identity is consistent with the ideals of efficiency and management explored in the above section.

Beyond the ability or inability of researchers to determine precise statistics, there is an understanding by the FASD community that there is a significant risk that FASD youth and adults will confront the criminal justice system. Actions taken by FASD adults appear to be self-destructive and dangerous but the appeal for medicalized intervention is increasingly difficult with age. As an FASD individual reaches adulthood there is an expectation that the primary and secondary disabilities that plagued FASD children have been outgrown. Most often, the physical anomalies associated with the disability diminish with time and there is an assumption that the cognitive and behavioural disabilities are eliminated as well.⁵² These discourses are not only adopted, but are substantiated by the criminal justice system's involvement with FASD persons. As described earlier, Hacking's kind-making helps to lay out this transition well. As a new

⁵⁰ Patricia MacPhearson, "Fetal Alcohol Spectrum Disorder (FASD) in the correctional population: Determining incidence and next steps" (31st Canadian Congress on Criminal Justice, Toronto, 1 November 2007) [unpublished]; Hon. C. Cunliffe Barnett, "A judicial perspective on FAS: Memories of the making of Nanook of the North" in Ann Streissguth and Jonathan Kanter eds., *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (Seattle: University of Washington Press, 2002) 134 at 135; Julianne Conry & Diane Fast, *Fetal Alcohol Syndrome and the Criminal Justice System* (Vancouver: The Law Foundation of British Columbia, 2000); and Cunliffe C. Barnett, "A judge's perspective" *Fetal Alcohol Syndrome and the Criminal Justice System – Understanding the Offender with FAS*, Video 2/3 (Maple Ridge: The Asante Centre, 2004) (respectively).

⁵¹ Interview of Executive Director at Public Health Agency of Canada, *supra* note 1.

⁵² Ann Streissguth, Robin LaDue & Sandra Randels, *A Manual on Adolescents and Adults with Fetal Alcohol Syndrome With Special Reference to American Indians* (Seattle: US Department of Health and Human Services, 1988) at 29.

loop and a new identity take shape concerning FASD adults, the medicalized discourses are no longer interested in governing the identity. As Golden describes, "...politicians, agents of the criminal justice system, and members of the media captured from physicians the responsibility for framing this syndrome".⁵³ The intent of this section is to witness the shifting paradigm that strips FASD of its pathological identity and re-invents it as criminal.

The crimes most commonly associated with FASD are small, petty crimes. The constable I interviewed describes these crimes as based on impulsivity, a lack of forethought and characterized as 'crimes of opportunity'.⁵⁴ A common example amongst FASD individuals is theft. In her book, Norgard describes a number of incidents in her son, John's childhood and into adulthood where he stole anything from a tennis racquet, money from his mother's purse, his sister's notebook, coin collections, and credit cards.⁵⁵ The rhetoric during his childhood describes John as 'not a bad kid'. One friend tells Norgard, "He just doesn't think like the rest of us...he's wired differently".⁵⁶ As an adult, however, the criminal behaviour supersedes the medicalization discourses that prevail in childhood.⁵⁷ Norgard's story provides a context for this shift to deviancy. She reveals that when John reached sixteen years old, she saw no other option but to send him to juvenile court for his misbehaviour (although he did not commit nor was he charged with a crime) with encouragement from her counsellor. Once there, he became fully enveloped in the criminal justice system. Those in the juvenile court told Norgard, "John is hard to place.

⁵³ Janet Golden, *supra* note 3 at 271.

⁵⁴ Interview of Constable (10 August 2007).

⁵⁵ Norgard, *supra* note 35 at 20-25. These are some of the many examples provided in the book.

⁵⁶ *Ibid.* at 20.

⁵⁷ Buxton, *supra* note 8; and Michael Dorris, *The Broken Cord* (New York: Harper & Row, 1989).

My only option is to send him to the juvenile correctional lock-up facility”.⁵⁸ John became part of the criminal justice system before he had ever been convicted of a crime.

In their article on the criminal justice system’s ability to determine fitness to stand trial for FASD adults, LaDue and Dunne relate the story of Tony, who was accused of assaulting his mother. The authors write that although the seventeen year old displayed the ‘FAS face’ and, “showed a rudimentary understanding of the charges against him and the legal process” his special needs were ignored.⁵⁹ In many instances, there is little progression between the behaviours exhibited as children and as adults. The severity of the offences often remains low but these small crimes more readily lead to intervention from the criminal justice system. While there is very little case law regarding FASD explicitly, those that exist exemplify this claim.

The cases of *R. v. R.B.M.*, *R. v. R.F.*, and *R. v. E.L.J.* all consider the extensive criminal records of the accused who have been diagnosed with or suspected of some form of FASD. Charges include: failure to appear in court; mischief; breaking curfew or residence and house rules; and consuming alcohol. The most serious of charges in these cases are auto theft, uttering death threats, carrying a concealed weapon and resisting arrest. Far from being the crimes of the ‘most dangerous’ of offenders, one judge seeks to break the criminal cycle the accused finds himself in.⁶⁰ The judges in these cases sympathize with the negative impact FASD has had on the lives of the accused, but use the diagnosis as cause to hand down tough sentences that may otherwise have been avoided. In *R. v. R.F.* the justice summarizes the testimony of Dr. Nanson, an expert in psychology and fetal alcohol syndrome. The judge finds: “...that R.F.’s moral reasoning

⁵⁸ Norgard, *supra* note 35 at 26.

⁵⁹ Robin LaDue and Tom Dunne, “Legal issues and fetal alcohol syndrome” (1995) 3 The FEN Pen 6 at 6.

⁶⁰ *R. v. R.B.M.* (1990) 54 C.C.C. (3d) 132 at 8.

is not sufficiently developed so that she applies society's standards, rather she applies her own standards; she is very ego-centric in this regard." He goes on to say, "...she may develop sufficient sophistication of moral judgement when she is older, say 16 or 17 years of age, so that she would participate in the social contract which is simply to do the right thing because it's good for society".⁶¹ Similar to the assessment of moral retardation suggested by Page, in this case the FASD diagnosis conveys the message that the accused is both mentally ill and therefore criminally responsible. In *R. v. R.B.M.* the accused won his appeal to reduce his prison sentence (which is rather inconsequential, the records mention, as the accused was set to be released on parole anyway), but only after the court considers his entire life history and ability to be productive in society. Just as in the above case, the justice in *R.B.M.* makes specific judgement claims about the accused with FASD: "At some stage in his life he must be educated or trained to become self-sufficient, and he must be made to understand that at some early date, if he continues his present path, even a tolerant and caring society or community will give up on him so that longer and longer terms of imprisonment may become the only possible future for him".⁶² The judge in this case is clearly stating that in order for the accused to remove himself from the criminal justice system he must change the very behaviours that are attributed to FASD. These examples demonstrate the responsabilization of those with FASD as an ideology embedded in the system.

⁶¹ *R. v. R.F.* [2002] S.J. No. 742 (QL) at para. 82.

⁶² *R.B.M.* *supra* note 60 at 5.

More serious crimes that are associated with FASD adults are crimes of a sexual nature. Crimes range from small infractions to charges of sexual assault.⁶³ As described briefly in chapter 3, in childhood displays of social ineptitude and even sexual inappropriateness are considered part of the behavioural problems associated with FASD. As an adult, an individual with FASD may have a limited social and sexual understanding but their bodies are those of grown adults. The innocence, inexperience and ignorance of childhood allows for leniency in interpreting the questionable behaviours of FASD children which is no longer applicable in adulthood.⁶⁴ Buxton's book relays the story of a 2001 case where an elderly gentleman was convicted of fifty-seven charges of gross indecency, indecent assault and sexual exploitation on young boys he met at his part time usher job for the Toronto Maple Leafs. Advocates for FASD offenders are quick to tell the accused's sad story in conjunction with that of their victims. In this case, the offender had been mentally, emotionally and sexually assaulted in his childhood living in an orphanage. Buxton notes that the man was depicted as the 'monster of Maple Leaf Gardens' and that perhaps his guilt was misrepresented: "despite numerous indications of FASD, the court never bothered to assess him".⁶⁵ An FASD diagnosis is regarded as irrelevant in adulthood because the neo-liberal ideology contends that criminal behaviours surely must be understood as wrong by the FASD adult and it is a choice to engage in these activities. The criminal justice system is set up to work exclusively with adult bodies, and does not react smoothly when the body does not match the mind.

⁶³ Natalie Novick, "FAS: Preventing and treating sexual deviancy" in Ann Streissguth and Jonathan Kanter, eds., *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (Seattle: University of Washington Press, 2002) 162.

⁶⁴ *Ibid.*

⁶⁵ Buxton, *supra* note 8 at 211.

Adults with FASD become acquainted with the criminal justice system for a host of crimes, such as break and enter, theft, arson, assault, sexual assault and murder. FASD advocates challenge the prevailing discourse by asserting that the criminal knowledges about FASD can (and should) be substituted for a more medicalized approach. Advocates point to the symptomatic nature of the crimes. Rather than being elaborate and mischievous, the constable notes that the vast majority of these incidents are immediate, impulsive responses to the individual's emotions.⁶⁶ According to grassroots organizations, the irresponsible behaviour that causes disruption in childhood is a result of the same symptoms that cause crime in adults. In fact, many of those working with FASD clients remark the behavioural functioning of some FASD adults as that of a child.⁶⁷ Theresa Kellerman, a prominent advocate of FASD issues, describes her twenty year old son as not having changed much since his childhood in terms of academic and emotional level.⁶⁸ This sort of advocacy is not often heard outside the walls of the FASD community. Perhaps dissemination is problematic because we rarely hear about FASD adults outside the context of the criminal justice system. Adulthood in this setting means expectations of rationality and control are to be met by all people, including those with FASD.

Deviant discourses are further exemplified as the symptoms associated with the FASD population become equated with, rather than exempt them from, criminal responsibility. The knowledges produced by the criminal justice system reinforce this new classification as the system is designed to work with rational, responsible

⁶⁶ Michaud, *supra* note 28 at 45; Interview, *supra* note 54.

⁶⁷ Interview of Executive Director at Public Health Agency of Canada, *supra* note 1.

⁶⁸ Gabrielle Fimbres, "A boy in a man's body" *Tuscon Citizen* (1 December 1997) online: <http://come-over.to/FAS/boyman/>, last accessed 10 May 2008.

individuals. Exploring this body of research in-depth is beyond the scope of this project; however, it is important to highlight some of the most pressing links between the FASD identity and deviancy by looking at the legal process and the nature of recidivism amongst FASD offenders.

The grassroots movement emphasizes the legal process as a culprit to the criminalization of FASD adults through its inaccessibility. Advocates are eager to point out the abstract nature of the system citing the first contact with police, understanding their rights and obligations, and being unable to appreciate the court system as examples. Advocates compare an FASD individual's struggle to tell time and manage money with activity that is conceived of as criminal. In what he terms a rare 'creative solution', Judge Barnett substitutes jail time for a woman with suspected FASD convicted of two counts of assault with intensive probation. Among the conditions is programming for basic life skills, such as using a calendar, performing transactions and cleaning.⁶⁹ These skills are designed as an integral part of the larger plan to reduce the woman's criminal activity. The symptoms of the diagnosis are constituted as the symptoms of criminality. The judge notes at the end of the article that these interventions were unsuccessful for this woman. At all levels of criminal justice intervention, an FASD adult's challenges in coping with the system enhance the system's perception of her guilt, rather than illness.⁷⁰ For example, the literature asserts that FASD adults make statements they think the police, lawyers and/or judges want to hear to please them, resulting in self-incrimination or even false confession. Brian Tate confessed to a murder that took place while he was

⁶⁹ Barnett "A Judicial Perspective", *supra* note 50.

⁷⁰ Timothy Moore and Melvyn Green, "Fetal Alcohol Spectrum Disorder (FASD): A need for closer examination by the criminal justice system" (2004) 19 Criminal Reports 99.

incarcerated for an unrelated crime because of pressure from police.⁷¹ In effect, “the legal waters are too complicated for the FASD individuals to navigate without help”.⁷²

Claims of inaccessibility are not exclusive to FASD discourses. Those who advocate for FASD adults single out this population as different and especially lacking in equal treatment. FASD advocates separate the needs of their target group from others by claiming a lack of knowledge about FASD at all levels of the justice system. Michaud and Michaud suggest parents/caregivers of FASD youth and adults have their child carry a ‘Medical Information for Police’ card, designed specifically for FASD.⁷³ Tools such as these are characterized by advocates as safeguards to protect those with FASD from further criminalization stemming directly from their diagnosis.

The grassroots movement claims that FASD adults are further criminalized because of their high recidivism rates.⁷⁴ Many of the offences FASD adults commit leading to re-incarceration are breaches of probation, such as missing meetings with probation officers or failing to make scheduled appointments for programming, etc.⁷⁵ Those who advocate for FASD adults remark that these offences relate more to FASD symptoms than a desire to break the rules. David Boulding, a defence lawyer who is an activist for FASD offenders remarks on his FASD clients’ constant breaches of their

⁷¹ Lori Vitale Cox, *FASD – Implications for Legal Professionals: Police, Duty Council, Crown, Bench and Restorative Justice* (Elsipogtog: Nogemag Healing Lodge, 2005) at 14.

⁷² Michaud, *supra* note 28 at 61.

⁷³ *Ibid.* at 59. The example card reads: “I have the birth defect Fetal Alcohol Spectrum Disorders (FASD), which causes brain damage. If I need assistance, or if you need my cooperation, you should contact the person listed on the back of this card. / Because of this birth defect, I do not understand abstract concepts like legal rights. I could be persuaded to admit to acts that I did not actually commit. I am unable to knowingly waive any of my constitutional rights, including my right to counsel. / Because of my disability, I do not wish to talk with law enforcement officials except in the presence of and after consulting with an attorney. I do not consent to any search of my person or property”.

⁷⁴ Jeanice Dagher-Margosian, “Representing the FAS client in a criminal case” in Ann Streissguth and Jonathan Kanter eds., *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (Seattle: University of Washington Press, 1997) 125 at 131.

⁷⁵ Interview, *supra* note 54.

probation orders: “My assumption that my clients were not interested or did not care was wrong: they could not structure the pieces of the puzzle together in a logical and meaningful way”.⁷⁶ Despite this, many FASD adults who have already been in trouble with the law are likely to find themselves in the confines of the legal system again.

First Nations, Métis and Inuit Communities

An analysis of the FASD identity must include a discussion of the identity as ‘an Aboriginal problem’. Not only do we need to recognize that the FASD identity is being shaped in this way, but it is also important to uncover why First Nations, Métis and Inuit have been targeted and what this connection means to those communities and to the conception of FASD.

I consider this aspect of the identity within the context of the FASD offender for three reasons. First of all, First Nations, Métis, and Inuit groups of all forms (government departments, grassroots organizations, authors) talk about FASD adults and their relationship with the criminal justice system when no one else will. Prevention and child based work continue to dominate, but a thorough reading of FASD adult literature reveals that when people do talk about this loop, the First Nations, Métis and Inuit communities do not hesitate to share knowledge and ask questions. Second, it is important to work through the link between Aboriginal groups and FASD in the context of the criminal justice system given the disproportionate number of Aboriginals diagnosed with FASD and the Aboriginal populations in the criminal justice system. This will be addressed below. Third, in studying the adult loop, I am hoping to understand why it is that FASD

⁷⁶ David Boulding, “Mistakes I have made” *Fetal Alcohol Syndrome and the Criminal Justice System – Understanding the Offender with FAS* Video 3/3 (Maple Ridge: The Asante Centre, 2004).

adults become ‘lost causes’. Literature from First Nations, Métis and Inuit communities relates a similar (although distinct) sense of abandonment.

Throughout this project we have seen the development of the FASD identity as specific to the First Nations, Métis and Inuit communities. The analysis of the *Lancet* articles in chapter 2 revealed the racialization of FASD within medical discourses. The personal stories and books that have been cited often have Aboriginals as their subject. Michael Dorris’ book speaks explicitly about the link between Native Americans and FASD. Many of the stories in Buxton’s book are about Aboriginals as well as countless stories highlighted on FASD online support networks. Michaud and Michaud refer to stories that cannot be “...white washed or cast as a Native issue and dismissed...”⁷⁷ Judge Barnett uses stories about an offender’s band to highlight awareness in Aboriginal communities. Likewise, Boulding’s piece specifies Aboriginal women in his storytelling. Indeed, many of the FASD stories being heard (both positive and negative) are those of First Nations, Métis and Inuit communities, solidifying the relationship with the FASD identity.

The political rhetoric certainly places an emphasis on the FASD identity as Aboriginal. It is readily apparent given the government departments responsible for addressing FASD. The Public Health Agency of Canada does the most work on the subject. With the exception of the FASD Team, a great deal of the research comes from the First Nations and Inuit Health Branch. Likewise, the Canadian Institute on Health Research often funds FASD work through the Institute of Aboriginal Peoples’ Health. CSC also conducts research on FASD and while not exclusively, much of this work comes from the Aboriginal Initiatives Branch.

⁷⁷ Michaud, *supra* note 28 at 48.

When studied carefully, the *Hansard* debates shed more light on the development of FASD as an Aboriginal political issue and adds to the analysis of adults as ‘lost causes’. FASD was referred to for the first time in 1985 and named explicitly in 1988 in the House of Commons.⁷⁸ However, before that time, the negative effects of alcohol and alcoholism were connected with ‘Indians’, so much so that in 1984 Reid refers to an “epidemic” in northern Ontario reserves.⁷⁹ Alcoholism among First Nations, Métis and Inuit peoples is also connected with the high incarceration rate and a low quality of life.⁸⁰

As FASD became a topic in the House of Commons debates, a more explicit connection is made between the identity and First Nations, Métis and Inuit communities. The increased attention given to the subject is apparent when it is referenced in the 2001 Throne Speech. Here, the FASD identity is solidified in the Aboriginal context:

The Government of Canada will also co-operate with Aboriginal communities and provinces and territories on the measures required to reduce the number of Aboriginal newborns affected by fetal alcohol syndrome. No child should experience this syndrome, but Canada's immediate aim must be to significantly reduce its incidence in the Aboriginal population by the end of this decade.⁸¹

Singling out Aboriginal communities as those dealing with FASD paints a very specific picture. The social context that FASD conjures up (poverty, alcoholism, poor parenting) is directed specifically at the First Nations, Métis and Inuit peoples and is depicted as having little hope of changing.

Referencing the 2001 Throne Speech, Paul Szabo, a Member of Parliament and long-time advocate for warning labels on alcohol bottles, notes the narrow lens through

⁷⁸ *House of Commons Debates*, 33rd Parliament, 1st Session, (20 June 1985) at 6076 (Iain Angus) and *House of Commons Debates*, 33rd Parliament, 2nd Session, (19 August 1988) at 18587 (Sheila Copps).

⁷⁹ *House of Commons Debates*, 32nd Parliament, 2nd Session, (6 February 1984) at 1098 (John M. Reid).

⁸⁰ *House of Commons Debates*, 30th Parliament, 1st Session, (12 June 1975) at 6692.

⁸¹ *House of Commons Debates*, 37th Parliament, 1st Session, (30 January 2001) at 1530 (Speech from the Throne).

which FASD is contextualized. Under the auspices of budget talks, Szabo makes his discontent clear when he explains that the only funding for FASD is through Aboriginal health issues. He laments that there is an assumption that FASD can be dealt with through this group alone.⁸² Little has changed in terms of political affiliation with FASD. Most recently FASD was said to have reached, “epidemic proportions among aboriginal people on and off reserve”. Martin goes on to connect this to the high incidence of FASD people incarcerated.⁸³

The literature speaks at length about the connection between FASD and First Nations, Métis and Inuit peoples; however, there is little research on why Aboriginal communities specifically have been targeted. Through a variety of available sources, three themes emerge: the impact of residential schools; the assertion that there is increased substance abuse in First Nations, Métis and Inuit populations; and leadership in studying FASD.

When conducting the interviews for this project, I asked all relevant participants how they account for the disproportionate number of First Nations, Métis and Inuit diagnosed with FASD. It became clear that this was an uncomfortable question. Most participants offered a quick response about alcohol consumption and looked to change the subject. Of those interviewees who considered the question more deeply, a common answer was found: FASD being diagnosed today is a result of the residential school system throughout the twentieth century in Canada.⁸⁴ Residential school systems, according to the executive director at the Public Health Agency of Canada, severed the

⁸² *House of Commons Debates*, 37th Parliament, 2nd Session, (25 February 2003) at 1305 (Paul Szabo).

⁸³ *House of Commons Debates*, 39th Parliament, 2nd Session, (13 May 2008) at 1635 (Keith Martin).

⁸⁴ For a fascinating look at media coverage of residential schools from 1955-2002, see CBC Digital Archives, “A lost heritage: Canada’s residential schools”, online at: <http://archives.cbc.ca/society/education/topics/692/>, last accessed 13 May 2008.

familial and cultural bond. In turn, “FASD is one symptom of the fallout from an assault on Indigenous cultures; if anything it is the *loss of culture* rather than the cultures themselves that is related to the predominance of FASD [emphasis in original]”.⁸⁵ The research officer interested in the Inuit experience with FASD adds that the disruption in culture happened so fast that natural ties to elders and long held beliefs about children and wellness were lost.⁸⁶ This had led to, “an intergenerational cycle of physical, psychological, sexual abuse, and loss of spiritual practices [that] has sprung from this history of devaluation and control, providing fertile soil for addictions, alcoholism and substance abuse”.⁸⁷ The deep history described here is not acknowledged in the medical and political realm; but for many working with FASD on an intimate level there can be no separation between the two.

The most common response to my question was the high level of substance abuse in First Nations, Métis and Inuit communities. The same response is given throughout the FASD literature.⁸⁸ Some of the interview participants consider more complex reasoning. As described in chapter 2, increased levels of alcohol consumption occur in communities besides First Nations, Métis and Inuit. The director of the research network says that Aboriginal communities are stigmatized in a different ways than others with substance abuse problems. The executive director at the Public Health Agency of Canada reports that more than substance abuse, there is a disproportionate level of health inequality lived by Aboriginal communities. She refers to this as ‘cultural isolation’ and suggests it plays

⁸⁵ Wemigwans, *supra* note 20 at 9; and interview of Executive Director at Public Health Agency of Canada, *supra* note 1.

⁸⁶ Interview of research officer at Inuit organization (19 August 2007).

⁸⁷ Canada, *It Takes A Community: Framework for the First Nations and Inuit Fetal Alcohol Syndrome and Fetal Alcohol Effects Initiative* (Ottawa: Health Canada, 2001) at 4.

⁸⁸ Interview, *supra* note 86; and Jen Skerrett, “Disability rates worry First Nation groups” *Winnipeg Free Press* (20 August 2007) B4.; and Boland, *supra* note 27 at 14.

a major role in the stigmatization faced by the communities.⁸⁹ The research tells us that the amount of substance abuse in First Nations, Métis and Inuit communities cannot explain FASD in its entirety.

Participants in the interviews also pointed to the leadership role that First Nations, Métis and Inuit groups have taken that have led to their stigmatization. The director of the research network notes that Aboriginal groups were among the first to identify a problem and were eager to find solutions. This willingness to participate in research and talk openly about FASD has left them mistakenly branded as the sole populations to encounter FASD, making it easier to be labelled as 'lost causes'. When the FASD identity began to emerge, First Nations, Métis and Inuit groups invited researchers into their communities, only to find themselves without any control over the research.⁹⁰ The medical and political discourses have taken advantage of this research and have used it to identify FASD as an Aboriginal problem.⁹¹ I encountered this disinclination in allowing outside research when I attempted to find interview participants. A number of First Nations and/or Inuit specific groups were interested in my work but were hesitant to agree to an interview. One non-governmental organization asked me to submit a more intensive ethical clearance and research background than I was able to provide, given the short time frame to complete this project. The uncertainty I noticed from these groups towards myself and my research speaks volumes about the way research has been conducted on FASD in the past.

⁸⁹ Interviews, *supra* note 1.

⁹⁰ *Ibid.*

⁹¹ *House of Commons Debates*, 38th Parliament, 1st Session, (5 October 2004) at 1630 (Speech from the Throne).

First Nations, Métis and Inuit groups have not abandoned research on FASD. As the executive director at the Public Health Agency of Canada says, they are not participating less, just differently. Aboriginal groups are taking control of work on FASD in a culturally sensitive and region specific way.⁹² There have been countless different approaches to taking on the subject of FASD, each unique to the region and community.⁹³ For example, the Community Council Program is part of the Aboriginal Legal Services of Toronto. This program diverts Aboriginal offenders away from the criminal justice system and addresses the criminal activity before their own community.⁹⁴ Another example is the Wrap Around Model, which embraces traditional Inuit practices in fostering a holistic approach to helping children and youth with FASD by working with families, schools, elders and others who are part of their environment.⁹⁵ Producing research, programming and awareness using their own resources and on their own terms is one way First Nations, Métis and Inuit communities are fighting to reduce the stigma of FASD as being exclusively Aboriginal.

Part of this stigma felt by Aboriginal populations comes from the disproportionate incidence of FASD diagnosis. The director of the research network attributes this in part to FASD being one of the first illnesses considered when seeing an Aboriginal patient in contrast to other diagnoses that might be prescribed to a non-Aboriginal patient, such as

⁹² Interview with Executive Director at Public Health Agency of Canada, *supra* note 1; and interview, *supra* note 86.

⁹³ See, for example: Kim Anderson, ed., *Aboriginal Approaches to Fetal Alcohol Syndrome/Effects* (Toronto: Ontario Federation of Indian Friendship Centres, 2002).

⁹⁴ Doug Anderson, "Traditional Aboriginal justice: A Toronto agency helps offenders with FAS and FAE through its Community Council Program" in Kim Anderson, ed. *Aboriginal Approaches to Fetal Alcohol Syndrome/Effects* (Toronto: Ontario Federation of Indian Friendship Centres, 2002) 38.

⁹⁵ n.a., *Working together to understand FASD: Participant Handbook* (Ottawa: Pauktuutit Inuit Women of Canada, 2006) at 28.

ADHD.⁹⁶ The medical community and society in general fail to, “remember that FAS/FAE occurs in any society. While there are no statistics to show how many Inuit have FAS/FAE, the incidence is not necessarily any higher than that of other groups”.⁹⁷ This is precisely what is being forgotten or ignored. Larger issues addressed by the research officer studying the Inuit experience concerning poverty, disenfranchisement and disconnectedness make FASD an easy diagnosis to fit within the communities.

The rate of FASD diagnosed in First Nations, Métis and Inuit communities is ‘epidemic’. This word could also describe the over-representation of Aboriginal peoples incarcerated in federal and provincial institutions. Aboriginal peoples represent approximately three percent of the Canadian population and occupy more than eighteen percent of the prison population.⁹⁸ In 1999 Member of Parliament John Duncan made the connection between this statistic and the high incidence of FASD diagnosis:

I have often thought about two statistics that are not normally linked. I wonder if the member has some independent thoughts on them. I would like him to share them with the viewers and listeners. They relate to what we all know so sadly as fetal alcohol syndrome which affects the aboriginal population in a statistically high way. We also know that victims of fetal alcohol syndrome have traditionally and statistically provable high rates of incarceration.

If we look at those two statistics independently in the broad population there is a definite linkage. If we look at them specifically in the aboriginal population, it would be very interesting to know what the link is. We are possibly understating the true impact of fetal alcohol syndrome and how it is ravaging the population, particularly in terms of the rate of incarceration of aboriginal peoples.⁹⁹

Making this connection is not without its problems. While contextualizing the discourse involving First Nations, Métis and Inuit peoples and FASD, it also reiterates that those

⁹⁶ Interview with Director of research network, *supra* note 1.

⁹⁷ Janet McGrath, *Ikajuqtigiinniq: A resource for fetal alcohol syndrome prevention and intervention work* (Ottawa: Pauktuutit Inuit Women’s Association, 1998) at 5.

⁹⁸ Steven Vago and Adie Nelson, *Law and Society: Second Canadian Edition* (Toronto: Pearson Prentice Hall, 2008) at 83.

⁹⁹ *House of Commons Debates*, 36th Parliament, 1st Session, (16 March 1999) at 1135 (John Duncan).

with FASD are inherently criminal and unredeemable. The FASD identity continues to be criminalized and linked with Aboriginal populations. What this statement does is reveal the true complexity of the identity and affirms its existence within a particular social and political framework.

FASD Adults as Hopeless

The relationship between FASD and the criminal justice system becomes less clear when we look at the FASD identity as something other than an absolute truth. As FASD individuals grow older the childhood connection between cognitive and behavioural deficits and the FASD diagnosis becomes associated with poor choices and an unwillingness to learn. The shift begins in adolescence with a reduction in social supports, increased influence from potentially negative social groups and an overall sense of responsibility and blameworthiness becoming part of the FASD discourse.¹⁰⁰ If FASD youth become involved in the criminal justice system their diagnosis is minimized or disregarded altogether. As discussed earlier, the criminal justice system is not equipped to deal with a condition such as FASD. The system has a mechanism to cope with mental disorder of sufficient severity to warrant the use of section 16 of the *Criminal Code*. If an accused is anything less than inflicted with a 'severe' mental disorder there is no middle ground; an accused is either responsible or not. For those with mental health issues, there is a dichotomy in the criminal justice system between being absolutely incapable of appreciating the nature of the criminal act and being unequivocally aware and

¹⁰⁰ Streissguth, *supra* note 52.

responsible.¹⁰¹ In the remainder of this chapter I will explore the discourses surrounding adults with FASD and how the knowledges produced are those of a criminalized identity. Studying in greater depth the limitations on adult diagnosis and the broader theme of hopelessness as woven into the constitution of the FASD adult identity will provide a more complete sense of the extent to which the adult loop differs from the child loop.

One of the ways this population is demedicalized is through the inaccessibility of a diagnosis. I must distinguish this analysis from the discourses explored in chapter 3 in that here I would like to uncover adult-specific issues related to diagnosis. As discussed in the previous chapter, diagnosing FASD is limited almost exclusively to the first six years of childhood – citing that as secondary disabilities begin to reveal themselves it becomes impossible to know whether symptoms arise due to particular life factors or because of fetal exposure to alcohol. These sorts of life factors are not considered in childhood diagnosis; instead relying solely on physical, cognitive and behavioural traits. Furthermore, once an individual reaches puberty, obtaining a diagnosis, “may not be possible or may only be possible with a skilled clinician experienced in adult and youth diagnosis”.¹⁰² Not surprisingly, this sort of expertise is difficult to come by and until recently there has been little interest in finding tools to diagnose adults.¹⁰³ The difficulty in diagnosing adults leaves little space for the production of medical knowledges to

¹⁰¹ For an interesting debate, see Roberto Mangabeira Unger, “Liberal political theory” in Allan C. Hutchinson, ed. *Critical Legal Studies* (Totowa: Rowman & Littlefield Publishing Inc., 1989) 15; and Alan Brudner, “On intervening causes, thin skulls and fault-undifferentiated crimes” (1998) 11 Can. J. L. & Jur. 89. Note that FASD would not fit into Brudner’s claim of severe disabilities as a limited exception to his notion of neutrality and rationality. Please note as well that although FASD is defined as a neurological disorder, the symptoms associated with the syndromes have continuously been equated with issues concerning mental health.

¹⁰² Clark, *supra* note 26 at 14.

¹⁰³ Sarah Nunweiler, “Disability often undiagnosed” *Star-Phoenix* (20 December 2007) A8.

constitute the FASD adult identity and allows for a monopolized response by the criminal justice system.

The largest obstacle to receiving a diagnosis in adulthood is obtaining confirmation of maternal consumption of alcohol during pregnancy. This information is often unavailable for these individuals who have been marginalized and often disconnected from their families, particularly their biological families. The requirement of this and other difficult-to-obtain information severely limits the number of adults who can be diagnosed with FASD.¹⁰⁴ As described in chapter 2, a mother's confession is a requirement of the diagnosis. Foucault notes the power of confession as engrained in all parts of society, such as justice, medicine, education, relationships etc.¹⁰⁵ He also refers to ways confession is constituted in scientific terms. Although he is referring to sexual confession here, it is not too far a leap to see how the ideas can be translated (especially given the obvious relationship between sexuality, pregnancy and motherhood). Most important for our study is the clinical codification of confession. A woman's confession to consuming alcohol during pregnancy is directly codified in the diagnosis. Without this code, the only diagnosis that can be made is 'suspected FASD'. Foucault also refers to general causality. He is suggesting that during the time that science took on the confession, sexual activity became the cause of any and everything, one example being the "bad habits of children".¹⁰⁶ This is clear too when we consider the myriad of symptoms that the FASD diagnosis is linked with. Finally, the linking of science and confession provides validation. Confession is characterized as an important piece to

¹⁰⁴ Chudley, *supra* note 48.

¹⁰⁵ Michel Foucault, *The History of Sexuality: An Introduction* trans. by Robert Hurley (New York: Vintage Books, 1978) at 59.

¹⁰⁶ *Ibid.* at 65.

finding the ‘truth’. The solidification of a woman’s confession in the FASD diagnosis has important implications in who is part of the FASD identity.

With reference to diagnosis and the criminal justice system, a recent study of screening tools for FASD at Stoney Mountain Prison in Winnipeg, Manitoba revealed that ten percent of those screened and assessed had a confirmed diagnosis of FASD. Of the offenders who were screened for FASD, seventeen percent presented a result of no FASD because of an inability to obtain necessary information.¹⁰⁷ The interviewee at CSC says that the assessment program is looking for an easier way to access the history of prenatal substance use, such as using risk factors to make an educated guess about the mother’s drinking habits.¹⁰⁸ This means that regardless of whether or not a woman drank during pregnancy, undisclosed ‘risk’ factors can make a value judgement about her. This study demonstrates the unlikelihood that adults will receive a diagnosis. In addition, as stated above, a significant barrier to a confirmed diagnosis of FASD is the myriad of secondary disabilities that is said to be too difficult to distinguish from potential neurological damage and so a diagnosis cannot be made. Secondary disabilities are used by the medical and criminal justice disciplines as a way to deflect a medicalized identity. Overall, there is no opportunity to shift away from a criminalized identity without other knowledges gaining power; in this case, medical knowledges.¹⁰⁹

Finally, there is the complex issue of payment with regards to an FASD assessment for an adult in the criminal justice system, most commonly realized through

¹⁰⁷ MacPherson, *supra* note 50.

¹⁰⁸ Interview of research officer at Correctional Service Canada (3 December 2007).

¹⁰⁹ Although I am asserting that medical knowledge may influence the criminal identity associated with FASD, relying on this sort of expertise is not without its own harms (see chapter 2). Other knowledges, such as social and subjugated knowledges can play an important role in re-identifying FASD but currently cannot be found in the literature.

the courts. The cost of an assessment, usually twenty five hundred dollars, is fought over by the Attorney General and other provincial departments such as the Ministry of Health or ministries focused on children. Even when the legal system recognizes the potential for a move beyond the criminal identity, the economic barrier concerning where the money for the assessment should come from often puts an end to any discussion. In his video, Judge Barnett reveals that a judge's request for an assessment holds little clout as it by no means assures that a department will pick up the tab. He asserts that in the majority of cases where a judge requests an assessment, none are provided.¹¹⁰ An assessment is most often accessible when the parents/caregivers pay to have the tests completed. This limits those who receive a diagnosis in adulthood to someone who has the education/supports/financial means to access an assessment. By restricting the availability of FASD assessments and by making the likelihood of a confirmed diagnosis in adulthood minimal, the identity for those with FASD symptoms remains that of a deviant. Reducing the number of FASD individuals in the criminal justice system allows for a more standardized approach to corrections.

The FASD adult identity is constituted as deviant and thus hopeless through particular discourses. The expectation to act reasonably and responsibly is placed upon FASD adults in a manner virtually the same as an adult without a diagnosis of FASD or other special needs. Consistent with the neo-liberal rhetoric found in the FASD adult loop, there is an assumption that by adulthood FASD individuals will have learned to appreciate the consequences of their actions and make sensible choices.¹¹¹ Interventions in the form of support services and specific school environments targeted for children

¹¹⁰ Barnett "A Judicial Perspective", *supra* note 50; and Turpel-Lafond, *supra* note 37.

¹¹¹ However, this is not necessarily the case: "...patients with FAS and FAE do not appear to be outgrowing their early intellectual deficits as they mature". Streissguth, *supra* note 51 at 24.

with FASD are meant to reduce and even eliminate the risk of undesirable behaviours that could lead to criminal justice intervention in adulthood. FASD youth often hit their academic peak between ages eleven and fifteen¹¹² and as they enter secondary school many teachers are under the impression that if they have not picked up the necessary tools such as communication, learning, and social skills by this age there is little chance for improvement. The belief that the behavioural and cognitive problems associated with FASD are ‘cured’ in childhood is a major component to the shift from a sick identity to a deviant one. It appears that an FASD adult cannot escape the deviancy label. Any inappropriate behaviour on her part will be a sign that either she has not been cured because she did not take advantage of the services offered to her or otherwise she has been cured and is simply deviant.

Due in part to the issues highlighted above, treatment and rehabilitation for FASD adults in the criminal justice system is equally regarded as hopeless. Research on managing FASD and support groups in the community are severely limited in adulthood. For the criminal justice system, the hopelessness of FASD offenders comes from the idea that ‘nothing works’ in a system that otherwise views itself as effective in reducing harm.¹¹³ Given that the deterrent effect of prison is thought to be lost on people with FASD, those who work in corrections find themselves confronted by the same offenders

¹¹² *Ibid.* at 29. and Bolland, *supra* note 27 at 12; and Patricia Tanner-Halverson, “A demonstration classroom for young children with FAS” in Ann Streissguth and Jonathan Kanter, eds., *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (Seattle: University of Washington Press, 2002) 78.

¹¹³ D.A. Andrews & James Bonta, *The Psychology of Criminal Conduct* 3rd ed. (Cincinnati: Anderson Publishing, 2003). The validity of this effectiveness is debated elsewhere, for example; Menzies, *supra* note 45; and Margaret A. Hagen, *Whores of the Court: The Fraud of Psychiatric Testimony and the Rape of American Justice* (New York: Regan Books, 1997); and McCallum, *supra* note 38.

over and over again.¹¹⁴ CSC admits the current penal set up is incongruent with FASD offenders, but action has not been taken to resolve the issues.¹¹⁵ Necessary accommodations do not fit the actuarial system currently in place.¹¹⁶ The FASD offender appears to be inherently bad for not learning her lesson on previous occasions and not making smarter choices. There is a sense that she has failed. Advocates are quick to point out, however, that there is no programming that can support or that is made specifically for FASD offenders, despite the relatively large number found incarcerated. In the recent case of sex offender Wayne Mumford, who is diagnosed with FASD, it was noted: “...Correctional Service Canada offers no programs geared to inmates with FASD, or any other mental disorders that reduces an adult’s learning skills to those of a young child. Rather, CSC’s programs are taught at a Grade 9 level”.¹¹⁷ At the same time, calls for programming appear to be contradictory to the idea that there is nothing that can be done. Judge Barnett shows this explicitly when he finds that programming he offers FASD offenders is rarely effective. He says, “in this work, the real success stories are hard to come by”.¹¹⁸ Indeed, there is a question as to whether programming can be developed when there is still little sense of what FASD means: “I think we are standing on the tip of an iceberg. We might have a statistic, but I’m not sure anyone knows what that

¹¹⁴ Sharon J. Williams, “Is there justice in the juvenile justice system? Examining the role of fetal alcohol spectrum disorders” (2006) 3 Justice Policy Journal, online: http://www.cjcj.org/pdf/is_there.pdf, last accessed 27 March 2008.

¹¹⁵ Interview, *supra* note 108.

¹¹⁶ For a theoretical understanding, Garland’s piece is helpful: David Garland, “The limits of the sovereign state: Strategies of crime control in contemporary society” (1996) 36 Brit. J. Criminol. 445.

¹¹⁷ Interview, *supra* note 108.; and Timothy Appleby, “Disability spares man dangerous tag: Ontario” *Globe and Mail* (12 November 2007), online: <http://www.theglobeandmail.com/servlet/story/LAC.20071112.OFFENDER12/TPStory/TPNational/Ontario/>, last accessed 14 November 2007; and Eby, *supra* note 29.

¹¹⁸ Barnett, *supra* note 50 at 145.

means”.¹¹⁹ The criminal justice system has so far adopted the latter point of view; without being able to pinpoint FASD nothing can be done. With the subjective nature of the FASD diagnosis, as explained in chapter 2, it is worth questioning if there is even an iceberg underneath that tip. For individuals with FASD, this means that those who encounter the legal system have failed themselves rather than the system having failed.

In the community, the resources and supports offered to children are not offered to adults. One article claims that when FASD youth turn eighteen, they “fall off a cliff” in terms of services.¹²⁰ A number of programs would like to help adults and attempt to find resources for them, but as the constable described to me, there is a greater push to focus on providing support for children and families coping with the syndrome.¹²¹ Embedded in these programs is the unspoken notion that it is too late to help adults. The interviewee at the Public Health Agency of Canada offers her insight that when allocating funding it appears more compassionate and more resourceful to support organizations devoted to prevention and resources for young children than manage those who have already failed. Added incentive comes from the fact that children are cute and make for pleasant, optimistic candidates for programs in a way adults do not.¹²² An extensive review of *Hansard* debates from 1968 to 2008 reveals only a single mention of FASD adults in a context other than criminal justice.¹²³ A study done in Manitoba reports that seventy-five percent of adults with FASD have absolutely no access to support services. They do not qualify for financial support and there are often no services available for them. This leads

¹¹⁹ Tim Cook, “Experts: More needs to be done about fetal alcohol exposure” *CNews* (1 August 2007) online: <http://cnews.canoe.ca/CNEWS/Canada/2007/08/01/4385636-cp.html>, last accessed 2 August 2007.

¹²⁰ *Supra* note 23.

¹²¹ Interview, *supra* note 54; NOFAS, one of the largest and most popular support and advocacy group for FASD do not mention FASD adults specifically on their website (nofas.com).

¹²² Interview with Executive Director at Public Health Agency of Canada, *supra* note 1.

¹²³ *House of Commons Debates*, 35th Parliament, 2nd Session (17 April 1997) at 1830 (Joseph Volpe).

to the very predicament being assessed in this chapter: “The majority of FASD-affected adults don’t qualify for any support whatsoever...so the only program that can take them, if you can call it that, is the criminal justice system”.¹²⁴ FASD adults are characterized as being impulsive, socially inept and unable to fully appreciate the consequences of their actions, but missed their chance to receive support and so now must self-regulate to achieve the rationality expected of them. The criminal justice system re-defines these individuals so as to allocate them a place in society – as the deviant.

Those who are diagnosed with FASD are pathologized in a particular way. In childhood, they are constituted as sick in order to provide support services and accommodate the special needs they may have. In adulthood, however, if these behavioural and cognitive problems persist the individual is constituted as a failure and a deviant. No longer are support services provided, but rather the criminal justice system takes up the role of constituting the FASD identity where the medical knowledges left off. In essence, there is a complete disconnect between the FASD child and the FASD adult, hence the need for two distinct loops. This separation in identities is echoed in a speech made by California Governor Pete Wilson when denying a reversal of the death sentence for double-murderer Robert Harris, who was found to be suffering from FASD. The Governor claimed: “As great as is my compassion for Robert Harris the child, I cannot excuse or forgive the choice made by Robert Harris the man”.¹²⁵ There is no singular truth that constitutes someone labelled with FASD. The identity is malleable depending on the current social and political climate as well as the person being labelled.

¹²⁴ Jen Skerritt, “Help needed for adults living with disorder: experts” *Winnipeg Free Press* (15 September 2007) online: <http://www.winnipegfreepress.com/local/story/4039332p-4648245c.html>, last accessed 26 October 2007.

¹²⁵ Golden, *supra* note 3.

Chapter 5: Conclusion

The Project

In this project, I add to the theoretical and empirical literature concerning FASD in a number of ways. At its foundation I am contributing the growing body of literature about identity, specifically psy-identities. Using FASD as an example of the power psy-knowledges have in producing and maintaining criminalized identities, I am able to add to the critical work that considers certain ways of knowing individuals and provides a space for alternative conceptualizations. I also chose fetal alcohol spectrum disorder because it is a unique identity that, when questioned, can illustrate the nature of psy-discourses more broadly. FASD is a grey diagnosis. It does not fit comfortably within the medical or social (especially criminological) realm. In investigating FASD as a medical and psy-identity and as one that lives in a social context, I am looking to break down the conception that there is a distinction between the two. As I have demonstrated, FASD is a perfect example of identity straddling the two worlds. Throughout the project, I constructed a genealogy of the FASD diagnosis. The purpose of a genealogy is to trace the history of an identity, concept, technology etc. This method allows me to look at factors other than medical discourses that created the diagnosis in 1973 and its evolution. While Armstrong and Golden open the door to critical thought on FASD, my research moves beyond their argument about controlling women with the fear of having an FASD child¹ to show that FASD is used to govern the children of these women from birth into adulthood.

¹ Elizabeth M Armstrong, *Conceiving Risk Bearing Responsibility: Fetal Alcohol Syndrome and the Diagnosis of Moral Disorder* (Baltimore: The John Hopkins University Press, 2003); and Janet Golden, *Message in a Bottle: The Making of Fetal Alcohol Syndrome* (Cambridge: Harvard University Press, 2005).

Several themes became apparent as I was conducting this research. First, there are different discourses pertaining to FASD children and adults. It is not a coincidence that this shift takes place along the age continuum. The child saving literature explored in chapter 3 provided the conceptual structure to understand why age plays a vital role in the constitution and re-constitution of the FASD identity.² FASD children are considered victims. They are not responsible for cognitive or behavioural difficulties and are instead understood as needing public supports and programs in order to reach their optimum potential. The discourses surrounding FASD children emphasize the potential these children have if given the appropriate tools from programs like *Best Start* in the first six years.

This positive tone changes as FASD children age. As children grow out of the important first six years, there is no longer a discussion of optimum potential; instead, greater emphasis is placed on the deviant attitudes and actions displayed by FASD youth and adults. Provincial programming and support are no longer interested in the FASD identity, so the constitution of the FASD adult is taken up in large part by the criminal justice system.³ The criminal justice system does not consider FASD a mental illness and/or neurological disorder. The impulsivity, cognitive deficit and lack of social awareness touted by grassroots advocates are not taken up by the system which

² Xiaobei Chen, *Tending the Gardens of Citizenship: Child Saving in Toronto 1880s-1920s* (Toronto: University of Toronto Press, 2005); and Jennifer Henderson, "The years before five: Discourse and pedagogy of neoliberal childhood" (Cultural Studies in Education panel: Canadian Association Cultural Studies Conference at the University of Alberta, 21 October 2005) [unpublished]; and Henry Jenkins (ed.), "Introduction" in *The Children's Cultural Reader* (New York: New York University Press, 1998) 1; and John T. Bruer, *The Myth of the First Three Years: A New Understanding of Early Brain Development and Lifelong Learning* (New York: The Free Press, 1999).

³ See, for example Fred J. Boland, et al., *Fetal Alcohol Syndrome: Implications for Correctional Service* (Correctional Service Canada, 1998), online: http://www.csc-scc.gc.ca/text/rsrch/reports/r71/r71e_e.shtml, last accessed 9 August 2006.

responsibilizes the adult. This in turn shifts the FASD identity from victim to deviant and from redeemable to hopeless.

The FASD diagnosis is attributed to particular people. While the stories we most often hear are from devoted adopted parents/caregivers working tirelessly to provide support for their children, there are consistently voices being silenced. Those children whom we do not hear from until they enter the criminal justice system are those who were not saved by adopted parents. They are marginalized children and families. They are mothers who are told they require normalization and this abnormality is passed to their children. The First Nations, Métis and Inuit communities have become stigmatized as having a high rate of FASD, but I question whether this comes from increased surveillance and assumptions made about prenatal alcohol exposure and deviancy in a population that has shown to be over-represented in the criminal justice system.⁴

In terms of a theoretical understanding of FASD, little critical work has been done. Only Armstrong and Golden have taken a theoretical approach, but rely solely on feminist theory and almost exclusively in relation to the mothers of FASD infants. I used a combination of theoretical tools to frame the research. Rose's work on psy-sciences' emphasis on normalization techniques helps to explain how FASD becomes viewed as abnormal and in need of programming. Strategies such as 'optimum potential' become guidelines upon which children are measured and assessed, the results being a normal or

⁴ Caroline L. Tait, *Fetal Alcohol Syndrome Among Aboriginal Peoples in Canada: A Review and Analysis of the Intergenerational Links to Residential Schools* (Ottawa: Aboriginal Healing Foundation, 2003); and Melissa Gorelick, "Discrimination of Aboriginals on native lands in Canada: A comprehensive crisis" (2007) 44 UN Chronicle 50; and Jacqueline Hookimaw-Witt, "Any changes since residential school?" (1998) 22 Canadian Journal of Native Education 159.

abnormal identity. This identity becomes the only way of knowing the individual.⁵

Limiting knowledge to a psy-diagnosis narrows the scope of identity to calculable criteria alone and ignores the social context.⁶

Hacking's notions of kind-making and the looping effect are necessary links between the powerful discourse of psy-identities and its impact on those classified. These ideas have been described at length throughout the project and have provided a space to bridge the theoretical and the practical.⁷ Kind-making and the looping effect use theoretical conceptions to point out which institutions and their knowledges have an enormous impact on how those classified understand themselves and how this can reinforce psy-knowledges on the ground level, giving the identity increased power over those labelled.

In chapter 2, I use assertions about neo-liberalism to explain the social and political climate that brought about the diagnosis of FASD. In chapter 3, the child saving literature was used to fill the theoretical gap about the discourses that make up the FASD child. Using specific theoretical tools in different chapters is helpful in two ways. First, it allows for a specific understanding of the nuances of the topic in question. Second, and perhaps more importantly for this project, these theories are brought together (such as in chapter 4) to make a link between the child and the adult and break down life course distinctions between the two. Children and adults are often studied in their distinct realms, but the reality is that the same individual that once occupied the child space now

⁵ Nikolas Rose, "Calculable minds and manageable individuals" (1988) 1 *History of the Human Sciences* 179 at 184; and Nikolas Rose, *Inventing Our Selves: Psychology, Power and Personhood* (Cambridge: Cambridge University Press, 1998).

⁶ *Ibid.* This is supported by the work of Charles E. Rosenberg, "The Tyranny of Diagnosis: Specific Entities and Individual Experience" (2002) 80 *The Milbank Quarterly* 237.

⁷ Ian Hacking, *The Social Construction of What?* (Cambridge: Harvard University Press, 1999); and Ian Hacking, "Between Michel Foucault and Erving Goffman: Between discourse in the abstract and face-to-face interaction" (2004) 33 *Economy and Society* 277.

occupies the adult identity. By pointing out the links between theoretical paradigms, I am recognizing that as individuals grow, their identity can and is altered, regardless of whether their symptoms change. This is part of a wider contribution to the literature about identity. Life course changes identity and we can understand identity better if we consider this shift as part of a single story.

Policy Implications

I have intentionally not addressed policy issues in this project because critical research regarding FASD is in its infancy. The FASD literature does discuss policy, but in a solely normative sense that regards the diagnosis as based on medicine alone and the identity that accompanies the diagnosis as innate.

The problem with current policy is that it does not address a number of factors: alternative discourses; recognition of the life course; and the constitution of identity.

By alternative discourses, I am referring to knowledges that are currently being subjugated by the psy-discourses. In order to make helpful policy, the FASD identity must be recognized as anything but a singular truth. By opening up a space for alternative stories to be heard, the FASD identity can be understood as complex and unique. Hearing from people who have been diagnosed with FASD in their own voice and from various social places will allow policy makers to see those labelled as real people rather than an identity that must be worked on and normalized.

Policy cannot be made only for pre-natal prevention, infants, and those 0-6 years, or youth and adults. When she is recognized as a person from birth to adulthood, value

laden distinctions based on worthiness or an ability to be saved sits less comfortably and may be replaced with an appreciation for the life long story of the individual with FASD.

The narrow lens of policy is not encouraging of critical research. An FASD individual may or may not consider herself a victim and she may or may not be deviant in childhood or adulthood. Associating these master narratives to an identity through policy disallows an appreciation for the varying ways someone with FASD will understand herself and her needs. Someone with FASD may or may not live in poverty; be part of the First Nations, Métis or Inuit communities; and she may or may not consider herself sick. Helping those who choose to access support and enforcing normalization are two very different avenues policy can take.

The Practical

What does the FASD identity really do? It marginalizes people. It marginalizes those living in poverty and targets First Nations, Métis and Inuit communities. It marginalizes people and families. The grassroots movement aims to eliminate this marginalization but they have been criticized for their strategies to do so. Of key concern to those critical of the movement in Canada is the focus on passing a bill in parliament that would require warning labels on alcohol bottles but that misses the bigger picture.⁸ This project has tried to show just what that bigger picture is. By raising questions about the validity of the diagnosis itself, I do not mean to devalue the difficult experiences many people diagnosed with FASD face. Some of the challenges of those labelled, however, may be due to the way the FASD identity is constituted rather than the

⁸ Armstrong, *supra* note 1 at 201-203; and Golden, *supra* note 1 at 74-94. This idea is also supported by the interview I conducted with the executive director at Public Health Agency of Canada (3 August 2007).

symptoms associated with the diagnosis. Even those symptoms that an FASD individual identifies with can be understood in a less formal and clinical way, and may provide greater relief and a sense of self. Perhaps this is a direction that advocates for FASD can take to create a positive approach and avoid reinforcing judgement claims. A fundamental shift in the way FASD is thought about is necessary so as to understand those diagnosed as people and not simply a label.

Future Directions in Research

There is little critical research on FASD and the mental health identity and so there are many gaps to fill. By encountering some of the limitations in my own research, I hope to highlight where my continued interest in mental health research can help to address these gaps and where experienced scholars can add to the literature.

The most significant limitation I recognize in my own research is its exploratory nature. Given time and funding constraints, I was not able to achieve specific, country-wide analysis that would be valuable to the research. I am fortunate to have been given access to and speak with a number of key people in terms of interviews but there are many more people worth talking to if constructing a more detailed project.

On the same note, I was not able to hear directly from FASD individuals themselves. This was due to difficulties in achieving ethical approval in such a short period of time. Someone with access to the research group and advanced skills in conducting ethical interviews with a vulnerable population would be a great asset to this literature.

Equally sensitive and important would be a project devoted to critically engaging with FASD in the First Nations, Métis and Inuit populations. The grassroots movement is involved in this area and it would be beneficial to conduct research on what kind of work is being done, what assumptions are being made and/or debunked, and how the communities understand their connection to this diagnosis.⁹ Once again, I did not have to this type of research. Currently in the literature, if a debate about the over-representation of FASD in First Nations, Métis and Inuit communities is taken up, it is either critical of resources but not of the diagnosis itself, or makes a single remark on the validity of these statistics. An in-depth study of the impact that the FASD identity is having on the communities is a worthwhile project.

Regrettably, due to time and space restraints, I was unable to fully capture the theoretical issues related to mothers, stigma and alcohol. The critical research on alcohol and alcoholism is rich¹⁰ but an important link between the stigma associated with the mother being projected onto the child warrants deeper consideration. Beyond this important area of research, however, the gap I found at the beginning of my research must be highlighted – the study of FASD adults specifically. FASD research needs to move beyond a discussion of prenatal issues and consider those who are born and grow up with the FASD identity.

Indeed, there is much work left to be done. Thinking critically about psy-identities and their relationship with the medical, social and political context is important so that a

⁹ For example, the work done by Roberta Stout, *Before I was Born: Preventing FAS/FAE in Inuit Communities* (Ottawa: Pauktutit Inuit Women's Association, 2001); and Canada, *Fetal Alcohol Spectrum Disorder: A Framework For Action* (Ottawa: Public Health Agency of Canada, 2005); and Mark Buell, Catherine Carry & Marja Korhonen, *Fetal Alcohol Spectrum Disorder: An Environmental Scan of Services and Gaps in Inuit Communities* (Ottawa: National Aboriginal Health Organization, 2006).

¹⁰ Mariana Valverde, *Diseases of the Will: Alcohol and Dilemmas of Freedom* (Cambridge: Cambridge University Press, 1998).

space is created for alternative knowledges. Ultimately, the most essential contribution that can be made in this area is to allow for subjugated knowledges to be heard and actively participate in defining what it means to be classified through psy-knowledges. The intention of this research is to specifically target those identities that are thought to be static, objective and deviant. As in the case of fetal alcohol spectrum disorder, just as one identity can be built upon ideas of abnormality and hopelessness, critically engaging with these knowledges can redefine what it means to be diagnosed with a mental illness.

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Appendix A – List of Interviewees

Executive Director, early intervention centre – A Toronto based program that works with children diagnosed with FASD age 0-6 and their biological mothers. The program works to build the relationship between mother and child and provide life skills and parenting strategies.

Executive Director, FASD research network – This inter-provincial research group addresses research questions and informs policy.

Executive Director, Public Health Agency of Canada – Heads a team that works specifically on issues related to FASD.

Manager of support services – Is in charge of numerous care programs for children with special needs. The program does not offer specific tools to working with children with FASD but there are clients with the diagnosis.

Parent/advocate – Parent of an adult daughter who was diagnosed with FAE at seventeen. She is also president of an advocacy group promoting awareness of FASD.

Police Constable – Runs a program that diverts FASD youth under the age of eighteen from the justice system

Research Manager, Correctional Service Canada – Studies FASD assessment tools in federal institutions

Research Officer, Inuit communities – The organization is devoted to studying issues as it pertains to Inuit communities. She studies FASD specifically and creates workshops and material that is culturally relevant.

Appendix B - Letter of Information

Supervisor: Professor Dawn Moore
Carleton University
Tel: 613-520-2600 ext 3823

Researcher: Erin Donohue
Carleton University
Master of Legal Studies Program
Tel: 613-282-3619

Department of Law
C473 Loeb
1125 Colonel By Drive, Ottawa, ON
K1S 5B6

Research Ethics Committee Coordinator
511A Tory Carleton University
Tel: 613-520-2517

Dear Sir/Madame:

The purpose of this research project will be to explore the relationship between adults with Fetal Alcohol Spectrum Disorder (FASD) and the criminal justice system. This research is undertaken to fulfill the thesis requirement of the Master of Legal Studies Program at Carleton University.

In order to explore how FASD individuals are being perceived by the various disciplines and what impact this has on their lives, I will interview researchers from the Department of Justice, Correctional Services Canada and the Public Health Agency of Canada. In addition, I will interview program coordinators from Aboriginal organizations and non-governmental organizations in fields related to FASD. Finally, I will interview advocates for FASD individuals, in their professional capacity

I would like to request an hour of your time to ask you questions about your professional experiences, involvement and knowledge of the practices and procedures of dealing with individuals with FASD and issues related to their interaction with the criminal justice system.

If time is critical I would be happy to conduct the interview by telephone. If you would prefer to have the questions sent to you by fax I would be happy to accommodate you.

If we are able to meet for a face to face interview it would be at a time convenient for you. I would also like your permission to take detailed and accurate notes of our meeting.

You may decline answering any questions and can withdraw your agreement to participate in the interview at any time and have the data withdrawn. Should you decide to withdraw you may decide at that point if I may use any portion of your interview or request to have the notes destroyed immediately.

You will not directly benefit from this research. Your risks from participating in this research are minimal. You may ask for any comments to be erased at any point during the interview. This work will be made public and thus accessible to your co-workers and employers. This research will begin to address the current crisis of adults with FASD in the criminal justice system.

Interview notes, and consent forms will be kept in a locked filing cabinet in my home. Interview notes will be stored electronically. The documents will be stored on a memory stick to ensure security. Only I and my supervisor Dr. Dawn Moore will have access to these materials. The data will be destroyed ten years (2017) after the research is completed using paper shredders for information on paper and electronically deleting files stored electronically.

This research will be disseminated through conference papers, workshops, classroom presentations and possibly peer reviewed journal articles. The interviews will be used for the purposes of this project alone and will not be used again after this project is completed.

This project has been reviewed and received ethics clearance through the Carleton University Research Ethics Committee and if you have any questions or concerns regarding your involvement you may contact the ethics committee.

The chair's information is as follows:
Prof. Antonio Gualtieri, Chair
Carleton University Research Ethics Committee
Carleton University
1125 Colonel By Drive
Ottawa, Ontario K1S 5B6
Tel: 613-520-2517
E-mail: ethics@carleton.ca

Erin Donohue

Professor Dawn Moore

Appendix C - Informed Consent Form

Supervisor: Professor Dawn Moore
Carleton University
Tel: 613-520-2600 ext 3823

Researcher: Erin Donohue
Carleton University
Master of Legal Studies Student
Tel: 613-282-3619

The purpose of this research project will be to explore the relationship between adults with Fetal Alcohol Spectrum Disorder (FASD) and the criminal justice system. This research is undertaken to fulfill the thesis requirement of the Master of Legal Studies Program at Carleton University.

I _____, agree to participate in this research project.

- I agree that my participation in this research project is voluntary and will involve answering questions relating to my professional knowledge and/or working capacity with accused individuals with fetal alcohol spectrum disorder.
- I agree to meet with the researcher once, in person or by telephone, to answer questions about this topic.
- The interview will take an hour.
- I understand that I am being interviewed in my professional capacity and therefore face minimal risk.
- ____ I do agree to notes being taken.
- I may terminate the interview at any time. Should I exercise my right to withdraw I will decide at that time if the information I have provided to that point may be used or request that it be destroyed.
- I am also informed that the work will be published and thus accessible to the general public, my co-workers and employers.
- I understand that my Consent form will be kept in a locked filing cabinet in Erin Donohue's home and only she and her supervisor, Professor Dawn Moore will have access to the forms, interview material and that interview transcripts and notes will be stored electronically. I understand that although Erin Donohue's computer will have the necessary security hardware she cannot guarantee that the information I provide will be secure.
- The data will be destroyed ten years (2017) after the research is completed using paper shredders for information on paper and electronically deleting files stored electronically.

I understand that I may contact Professor Antonio Gualtieri, Chair of the Ethics Committee, with any ethics concerns or complaints.

Carleton University
Tel: 613-520-2517

Signature of Participant

Date:

Signature of Researcher

Date: