Fetal alcohol spectrum disorder
diagnosis and intervention:
An investigation of professional practice in New Zealand

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Abstract

Fetal alcohol spectrum disorder (FASD) is an umbrella term used to describe a range of neurodevelopmental and physical impairments associated with prenatal alcohol exposure. It is a brain-based disability which manifests in behavioural symptoms and cognitive deficits that adversely impact on the affected individual and their family. While FASD has been acknowledged as a disorder since the 1970s, it remains poorly understood in the New Zealand context, and does not attract much support from health and allied health services. Meanwhile, the normalization of alcohol in New Zealand culture affects the ways in which FASD is approached and perceived by medical specialists and lay people alike.

This thesis investigates the ways in which professionals within health, allied health and social service systems in New Zealand encounter, approach and manage FASD and cases of suspected FASD. It examines the circumstances surrounding diagnosis of and intervention for FASD in New Zealand, and the factors that inform professional practice in these two fields. It questions how FASD fits within specific professional practice contexts, how social and cultural forces influence the actions of professionals, and what barriers may exist in FASD-related practice. It aims to provide a nuanced analysis of how FASD is currently handled, and suggests potential strategies for achieving more effective service provision for FASD.

The research presented in this thesis is theoretically and methodologically grounded in applied medical anthropology, involving extensive participant-observation fieldwork in health and allied health training contexts in New Zealand and internationally. Over thirty in-depth semi-structured interviews were carried out with health, allied health and social service professionals in New Zealand. This data has been subjected to a thematic analysis that informs the scope of the research discussion, and provides the basis for my conclusions. Based on this data, my research suggests that professionals do indeed come into contact with cases of prenatal alcohol exposure in their work, and that many have developed innovative strategies for assisting individuals with confirmed or suspected FASD, but continue to face systemic and social barriers to achieving best practice in this area.
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Terminology, definitions and acronyms

This thesis presents a number of terms that are understood differently in different professional practice contexts, as well as acronyms that are specific to FASD and particular services. It is rendered in Australian English, except for words that appear in titles or direct quotations from sources in which Australian English is not used. For the purposes of clarity, I provide the following definitions:

**Fetus/foetus**
the words ‘fetal’ and ‘fetus’ in this document are spelt according to the original Latin, in preference to the etymologically inaccurate ‘foetal’ and ‘foetus’ (see Liggins Institute 2004, p. 7).

**Social service/services**
I use the designation ‘social service’ in this thesis to refer to any and all public and private services catering to the wellbeing of individuals in society. This includes services that might otherwise be termed ‘community services’, and services directed towards a particular demographic, such as youth services.

**Intervention**
For the purposes of this thesis, ‘intervention’ includes any and all formal or informal methods of providing support, advice or assistance to individuals with FASD and their families. FASD interventions employed in practice draw on disparate methods and ideologies that reflect the complexity of the condition and the varied perspectives and skills of professionals who engage with it. This can include pharmacological and clinical interventions which target specific neuropsychological or physical aspects of the condition, while other allied health and social service interventions commonly include environmental accommodations, the provision of FASD education, information, advocacy and support to individuals affected with FASD and their families.
**Client, patient, consumer, customer, case**

Different services refer to their service users differently and what may be considered appropriate in a medical setting might be considered inappropriate outside this context. Rather than seeking to establish a single term to cover all circumstances, I have deliberately used the above variants interchangeably to describe individuals or families that professionals engage with in their practice. The use of varied terms reflects the multidisciplinary approach of this research, and I am aware that the professionals represented within this thesis draw from different traditions and epistemological standpoints that influence how they conceptualize and name those with whom they work.

**‘Diagnosticians’ and ‘interventionists’**

I use these two terms as collective nouns to refer to the participants in my research who have multiple professional backgrounds, but who fall into one or the other of these two categories based on the nature of their work at the time of their involvement in my research. ‘Diagnosticians’ includes anyone involved in any aspect of FASD diagnosis, and ‘interventionists’ describes those providing intervention services for individuals with FASD or suspected FASD.

**Acronyms used in this thesis**

- **ADD**  Attention deficit disorder
- **ADHD**  Attention deficit hyperactivity disorder
- **ALAC**  Alcohol Advisory Council of New Zealand
- **ARBD**  Alcohol-related birth defects
- **ARND**  Alcohol-related neurodevelopmental disorder
- **CNS**  Central nervous system
- **DHB**  District Health Board. Funded by the Ministry of Health, DHBs are responsible for the provision of publically funded health and disability support services within their region.
- **DAP**  Developmental Assessment Programme
- **DSM**  Diagnostic Statistical Manual of Mental Disorders
- **FAE**  Fetal alcohol effects
- **FAS**  Fetal alcohol syndrome
Technical terms used in this thesis

**Dysmorphology**
Dysmorphology is the study of congenital malformations (ie. birth defects), particularly those that are manifested anatomically.

**Executive functioning**
The term executive functioning refers to how individuals regulate and control complex cognitive processes. People use executive functioning in organizing, planning, remembering details and managing their space and time.

**Teratogen**
A teratogen is a substance that can cause damage to the fetus when ingested during pregnancy, resulting in fetal abnormalities and/or birth defects which can be manifested externally or internally. Commonly known teratogens include thalidomide, lithium and alcohol.
Chapter 1: Introduction

Fetal alcohol spectrum disorder (FASD) is a relatively unknown condition affecting an unknown number of New Zealanders. It has garnered increasing attention in recent years as government and non-government agencies alike have begun to respond to the growing pool of evidence suggesting that the prenatal effects of alcohol might be more harmful than previously acknowledged. However, because of the socially and culturally entrenched position of alcohol consumption in New Zealand (and indeed most Western nations) and a range of other factors including the emergent nature of the research into FASD, the reception and acknowledgement of FASD as a health issue is a source of extensive disagreement and disjuncture. This thesis engages with the topic of FASD by exploring the professional practice of health, allied health and social service professionals whose practice brings them into contact with potential cases of FASD, and who have undergone training related to FASD. It seeks to investigate the circumstances surrounding FASD diagnosis and intervention in New Zealand, and to discover what factors inform professional practice in this field, in the absence of clear and consistent practice guidelines.

FASD is a health issue that fits within medical, mental health, and disability fields and its conceptualization is influenced by broader social constructs of alcohol consumption as a normalized part of cultural life. It is not a specific diagnosis, but an umbrella term to describe the spectrum of adverse effects that can occur as a result of prenatal exposure to alcohol (Chudley 2011, p. 109). The term FASD came into common usage following the work in this field by Ann Streissguth and Kieran O’Malley (2000).

Alcohol is a teratogen: a substance that can “disrupt typical development in offspring as a result of gestational exposure and can cause birth defects” (Streissguth 2004, p. 56). When alcohol is consumed during pregnancy it crosses the placental and blood brain barriers and results in blood alcohol concentration in the fetus proportionate to that of the mother (Nava-Ocampo et al. 2004). Whilst there is research to suggest paternal alcohol consumption can result in teratogenic
effects on sperm (Abel 2004, Lillian et al. 2009), FASD is generally considered to be a direct consequence of maternal alcohol consumption during pregnancy.

**Helen’s story**

To convey my perspective on how FASD is handled in New Zealand health and allied health service provision, it is appropriate to start with a case study of this under reported and relatively ignored disorder (suitably anonymized, and taken from recollections of my own practice as a social worker). The case study concerns a young South Island girl called Helen, who was ten years old when I met her in my role as a child and adolescent counsellor at a specialist counselling service in Dunedin.¹ She had recently been placed in the care of her biological father’s family, and her new caregivers were concerned about her behaviour – her aggression, her lying, her apparent inability to take responsibility for her actions – and they had decided to seek counselling. This was not the first time that Helen had engaged with our service. She had previously received counselling at the age of eight as part of a family counselling program under a referral from child protection services, who had placed her in the care of her grandparents at that stage. Indeed, Helen had engaged with a wide range of other social and community services in Dunedin throughout her short life, but her only long-term relationship with any of these was with the child protection service, which had been monitoring her since the age of two. At ten years old, despite her challenging behaviour, she had no educational or behaviour management plan, had never had any formal psychological or cognitive testing, and was not receiving treatment related to any medical diagnosis.

Like any new client, my relationship with Helen began with an initial assessment. Drawing on Helen’s own responses, on her caregivers’ comments, a case history, and by piecing together information from other services, this assessment revealed a history of abuse and neglect, frequent short term memory lapses, speech and language difficulties, low mood, impulsive and aggressive behaviour, attention and

¹ Helen’s story became the subject for my poster presentation at the 4th International Conference on Fetal Alcohol Spectrum Disorder in Vancouver in 2011. The poster is included here in Appendix A.
learning difficulties, poor planning, low self esteem, and a range of other factors relating to impaired executive functioning. Helen appeared to meet criteria for a number of diagnoses: ADHD, Oppositional Defiance Disorder (ODD), Conduct Disorder, possibly impaired intellectual functioning and possibly Reactive Attachment Disorder.

During the course of my initial assessment of Helen, a public health nurse working with the family raised Fetal alcohol syndrome as a possible contributing factor to Helen’s behavioural problems. At that point, I had little knowledge of FAS or FASD, however, after a little bit of background research, I became more interested. In many ways Helen was not dissimilar to other children I had worked with who had complex needs but her apparent short term memory problems, which had lead to her being labelled as a compulsive liar, and her severe learning difficulties at school, combined with impaired executive functioning raised ‘red flags’ for me as a practitioner. In order to get a better understanding of Helen’s history I tracked down her birth mother through the family and invited her to meet with me.

Helen’s birth mother was quite keen to meet with me and was concerned about Helen’s functioning. During my meeting with her I took a detailed history of Helen’s development, but before I had the chance to ask questions about the pregnancy and alcohol and other drug use, Helen’s birth mother raised FASD with me. She asked me “Do you think she has that fetal alcohol condition?”. Helen’s mother revealed high levels of alcohol consumption during her pregnancy, including daily drinking and episodes of binge drinking prior to discovering she was pregnant at around three months gestation, and she believed that FASD could be a factor in Helen’s behaviour. I therefore began to include mention of FASD in my referrals for Helen, and highlighted the confirmed high levels of maternal alcohol consumption during pregnancy. I also suggested to her caregivers that it might be a worthwhile thing to raise when meeting with their paediatrician; in the end Helen’s birth mother attended and raised herself.

The outcome of my initial assessment was for Helen to undertake a more in-depth assessment including psychometric testing, and for her to continue receiving
support from our service. I worked with Helen and her family on and off from 2006 to 2009, with periods spent waiting for assessments and trying to find an appropriate agency that would be able to meet her particular needs. It was becoming increasingly apparent that our centre, which provided children with a one-hour counselling session per week, did not appear to provide an appropriate fit for Helen’s complex needs. Despite this, my manager agreed for me to continue to work with the family until an appropriate alternative could be found.

In New Zealand, a diagnosis is essential not only to inform appropriate intervention but also in order to access a range of services, as well as funding for resources. As Helen did not have any kind of diagnosis when I began working with her, she was not eligible for any of the intensive support services that she desperately needed. My interventions for Helen therefore revolved around those strategies that were within my ability as a social work counsellor to provide. This included advocating for her with other professionals, working with her caregivers on the task of developing realistic behavioural expectations, developing plans to ensure her safety, fostering and reinforcing positive interactions between Helen and her family, and working with Helen to identify a number of things she was good at, with the aim of improving her sense of self worth. All the while, I continued investigating FASD and became more interested in facilitating an FASD assessment for her. Helen’s challenging behaviours continued without much change.

During this three-year period, Helen also engaged with a range of other generalist and mandatory services. Observations volunteered by her parents, carers, teachers, health and social service providers pointed to a range of behaviours associated with FASD, which mirrored my own suspicions. However, in the absence of a definite diagnosis, there was little chance of securing support for FASD-related interventions. A diagnosis for ADHD was, however, forthcoming. While many services were happy to work with Helen on interventions related to ADHD, they were reluctant to work on strategies related to FASD as there was no specific diagnosis for this.
In Helen’s case, some professionals put in place behaviour modification programs related to ADHD without taking her considerably limited cognitive and adaptive functioning levels into account. When these interventions did not work, Helen was labelled as defiant and troublesome. As a result, many professionals felt ill equipped to provide a service that met Helen’s complex needs and she was ‘handballed’ around to different services. This lack of continuity contributed to her (and her family’s) emotional instability. More specific services for intellectual disability were not available to Helen because a diagnosis for ADHD was in place to ‘explain’ her behaviour and, with an IQ of 70, she was considered to have ‘borderline’ intellectual functioning and thus was not eligible for intensive support. Helen’s parents became increasingly frustrated with the health system, as they felt that the service providers were not listening to them, frustrated with service providers who appeared to be making no progress with Helen and often frustrated at Helen. The good work they were doing to understand Helen’s needs and build a stronger relationship with her were often overshadowed by feelings of helplessness that sometimes resulted in disengagement which impacted even further on Helen.

During her sessions with me, Helen’s sense of self worth increased as she began to gain a greater understanding of the things she needed help with, as well as her strengths. Outside of our sessions, however, where her needs were often not understood and rarely supported, her situation steadily declined. She was eventually taken back into care by child protective services because her caregivers felt frustrated and unable to deal with her challenging behaviours with limited support, and because she posed a risk to herself and others. She had a number of changes in Child Protection social workers, many of whom did not understand her needs. She had multiple short-term placements with carers who had experience working with children with high and complex needs, but they all broke down, and she was eventually returned to the care of her grandparents from whom she had previously been removed. At the time of my last engagement with Helen, she had become involved in the juvenile justice system and had ceased to attend school. She was only fourteen years old.
Throughout my work with Helen, I became increasingly convinced of the need to have her assessed for FASD, rather than ADHD. It was my suspicion that an FASD diagnosis would have clarified many of the intervention-related issues faced by Helen and her family, and would have given them all a stronger basis from which to understand and approach her needs. My engagement with the literature surrounding FASD, especially in light of the ineffectiveness of ADHD interventions for Helen, led me to believe that FASD could have been a contributor to Helen’s behavioural problems, but systemic and professional culture barriers prevented me from achieving access to a diagnosis for her. Systemic barriers included the fact that there simply was no South Island diagnostic service for FASD, and most health and community service professionals I encountered had little or no awareness of FASD as a possible diagnosis anyway. Even if diagnosis were possible, there were no services in Dunedin equipped to provide FASD-specific intervention. The professional culture barriers were more insidious, and related largely to health professionals’ preconceptions about alcohol and pregnancy. A hospital-based paediatrician with enormous influence in the health system simply refused to believe that FASD existed, viewing it as simply part of a trend towards over-diagnosis of an increasingly diverse range of behavioural disorders in children. In addition, a mental health service psychiatrist claimed that such a diagnosis only creates stigma for the mother and claimed that there were no interventions for FASD thus a diagnosis was pointless. Such attitudes fly in the face of scientific evidence, but are all too common where FASD is concerned.

Ultimately, it is impossible to substantiate whether or not an assessment for FASD might have led to better health and wellbeing outcomes for Helen. However, the frustrating thing for me as a professional, and the family who were fully supportive of an FASD assessment, was that structural and cultural barriers in the health system prevented us from testing it out. Following my engagement with Helen and her family, I began to consider my other clients at the time and reflect on my prior work experience with children in the field of mental health, and identified a number of cases where I now suspected FASD may have had a role in the child’s presentation. My experience with Helen therefore became a catalyst for embarking upon this research, with the aim of investigating how FASD is handled in the New
Zealand health and allied health systems, and proposing strategies for fostering greater engagement with FASD amongst health and allied health professionals.

The case of Helen is a typical example of the confusion, inefficiency and ineffective support that can affect an individual, their family, and others engaged with them in a professional or personal capacity when it is suspected that FASD may be a factor. This was my experience as a child and adolescent counsellor, and, as I would learn when I began to investigate it more deeply, it was an experience shared by many others in my field and in other fields of health, allied health and social service provision.

**Research question**

International medical research leaves no doubt that FASD exists, and that it potentially affects a far wider range of people in a wider range of circumstances than generally believed. This thesis is written from a position that accepts that FASD exists, but that it can be difficult to define, and that professional knowledge of FASD is uneven at best. To return then to the opening paragraphs, this thesis is primarily concerned with how health and allied health workers in New Zealand approach and manage FASD or suspected cases of FASD, and what steps are currently being taken to improve outcomes for their clients. In other words, this research asks what are the circumstances of FASD diagnosis and intervention in New Zealand, and what factors inform professional practice in this field?

A number of sub-questions scaffold this inquiry: How does FASD fit within specific professional or disciplinary contexts? What barriers and difficulties do professionals encounter when dealing with FASD? What is the experience of professionals who have engaged in FASD training? What role do moral and social factors play in the construction of FASD and how do these intersect with medical, allied health and social service practice considerations? How do professionals’ personal perceptions and experiences of FASD influence their practice? Furthermore, what elements of international FASD practice are significant to the New Zealand context? Why are health professionals seemingly so reluctant to engage with FASD and finally, in the absence of FASD specific policy, funding and
standard practice applications, what do New Zealand health professionals do when they are presented with suspected or confirmed FASD? These are the questions that this research sets out to answer.

Underlying these questions is the implication that attitudes, opinions and experiences influence professional practice, especially in the case of a disorder that is poorly understood, difficult to define, and infused with moral social discourses. By the end of the research it became obvious that where FASD is concerned, personal experience is not only a factor in the style or performance of one’s professional practice, but also an influential force impacting upon decision making. This is especially important for FASD in New Zealand because there is no existing practice context for it, so professionals are in the process of developing their own positions and practice contexts. Their choices impact not only on the health and wellbeing of their clients, but also contribute to a broader social and moral construct of FASD that implicates the individual, their birth mother, and the family and social life that surrounds them.

This thesis is grounded in my own professional experience and is therefore subject to certain limitations of scope, but also rich in the detail and professional insight that results from the investigation of a topic that encompasses one’s own practice. This starting point is also a sensible one for a topic like FASD, as there are few (if any) alternative starting points that could offer greater insight. New Zealand has no consistent national policy or current strategic plan to address FASD. There are no official nationally consistent definitions or diagnostic criteria, and few financial resources for prevention and service provision for FASD. Information, training and support available to service providers to assist them with providing care to these clients is limited or non-existent. In some cases, professionals do not even have an awareness of FASD as a possible diagnosis. Despite this, health, allied health and human services professionals continue to come into contact with clients who present with FASD symptoms or documented prenatal alcohol exposure and must provide intervention. It is likely that this situation replicates the inefficiency, service duplication and ineffective services for FASD that I experienced with Helen, across the New Zealand system. This lack of legitimacy and uncertainty regarding
the diagnosis of FASD along side professional concerns about frequent examples of ‘suspected’ or ‘likely’ FASD will surface repeatedly in the data that this dissertation presents.

**Research framework**

My investigation of what health and allied health professionals do, alongside what they think, is a product of an interdisciplinary research background framed within applied medical anthropology (cf. Trotter 2011, Helman 2007). This reflects my own research trajectory and professional experience. I trained as a social worker in Australia before working in a wide range of social service and health provision contexts, finally becoming a child and adolescent counsellor in the field of Mental Health in New Zealand after nearly a decade of professional practice. My engagement with medical anthropology began only after this professional trajectory, and some years beyond my own undergraduate theory and methods training. I have therefore been able to strategically combine what I see as the most effective aspects of both anthropological and social work theory and practice in designing my own approach to the issue of FASD as a type of bricolage, in the Lévi-Straussian sense (Ginsburg 1992, p. 361) that is consistent with the multidisciplinary and interdisciplinary expectations of applied medical anthropology as a research field (Trotter 2011, p. 52).

My research process revolved around empirical, ethnographic data gathering, borne out of direct engagement with health, allied health and social service professionals who became involved in a range of FASD training initiatives between 2009 and 2012. My participant-observation in these training sessions enabled me to observe first hand their extant knowledge concerning FASD and their reactions to the information provided in the training. While previous New Zealand studies of FASD have taken a similar approach (cf. Salmon 2010, 2005), my research focuses not just what practitioners experience, know, think, and believe, but also how this translates into action in their work with FASD. This approach, together with an elaboration of the theories mentioned above, is expanded upon in Chapter two.
There were two groups of professionals involved in my research, one from the North Island and one from the South Island. The North Island group, referred to in this thesis as ‘diagnosticians’ consisted of health and allied health workers from District Health Board-funded services and included paediatricians, psychiatrists, clinical psychologists, one neuropsychologist, and one speech and language therapist. The South Island group, referred to in this thesis as ‘interventionists’ or ‘intervention workers’ contained allied health and social service professionals from a broad range of services including Government agencies such as Plunket, Child Youth and Family and the Public Health Nursing Service, and a range of community-based family support services, mental health services, and youth support services. This group included social workers, nurses, public health nurses, mental health nurses, family support workers, youth workers, drug and alcohol counsellors, occupational therapists, and child and adolescent counsellors.

The research framework weaves together the experiences of these diverse participants, together with my own, in a descriptive account that reflects a deliberate, post-positivist approach to foregrounding description in the presentation of my research. As the field of FASD practice is small and emergent, it is difficult to provide details on research participants’ experiences (not to mention gender, ethnicity, etc.) without revealing their identities. Thus, while a more critically reflexive approach would be welcome, it is not pursued here. Furthermore, my deliberately descriptive account reflects an applied research sensibility, as it intends to make the research accessible so that it will resonate with those most affected by it.

**Scope and limitations**

Despite its uncertain and often self-contradictory public profile, FASD has attracted a great deal of attention in a wide range of scholarly fields, and it is beyond the scope of this dissertation to engage with all of them. This project, for example, makes quite minimal engagement with the extensive scientific and medical literature available for FASD internationally (cf. Sulik et al. 2007, Mooney & Napper 2005, Kobor & Weinberg 2011, O’Leary-Moore et al. 2011). With FASD-related experimental studies now running into the tens of thousands of entries in
journal article databases, and largely outside the scope of my research expertise, it was not possible to incorporate this data into a study otherwise concerned with professional practice, opinions and perceptions.

Studies concerned with statistical data, socioeconomic impact, FASD prevalence and other worthy endeavours (cf. Popova et al. 2011, May et al. 2007) lie outside of the scope of this research, though they have been useful in helping me to attain some degree of fluency in understanding the extent of FASD research across a range of research fields. Similarly, the issue of FASD prevention (cf. Floyd et al. 2009, Poole 2011) is so vast as to constitute an independent field of enquiry, as it is an area that largely lies outside the professional experience of the health and allied-health professionals consulted in this research. For these reasons, it has been excluded from the scope of this dissertation, though there are occasional references to prevention throughout.

Finally, and most importantly, it is worth emphasizing that this thesis is specifically concerned with the experiences of health, allied health and social service professionals, and is not intended to encompass the experiences of individuals affected by FASD and their families. While other studies of health professionals’ engagement with FASD exist (cf. Blair 1997), this thesis is the first to examine and compare the experiences and views of professionals in the fields of both FASD diagnosis and intervention in New Zealand. The experiences of individuals with FASD is a domain of significant scholarly engagement in anthropology and allied fields, and biographical accounts of people with FASD (often written by a parent, about a child) have appeared in numerous contexts (cf. Doriss 1990, Kleinfeld & Wescott 2001, Kulp 2010). These discourses also lie outside of the scope of my research. It is also the case that, in New Zealand, some extant sources have already engaged with these biographical narratives (cf. Symes 2004) and it is not my intention to reprise this work, but rather to contribute a new perspective that has yet to be comprehensively investigated in the New Zealand context.
Dissertation outline

The structure of this dissertation follows a logical progression from contextual and theoretical discussions surrounding FASD, through to describing international practice models and contexts for FASD diagnosis and intervention, and then embarking on a close-up examination of the factors impacting FASD diagnosis and intervention in New Zealand. The dissertation then assembles the findings from engagement with diagnosis and intervention into a discussion chapter that articulates the extent to which issues and approaches are shared across and between these two areas, before proceeding to the conclusion.

Following this initial introductory chapter, Chapter two provides a description of the research method for this project and how this sits within the field of applied medical anthropology. Chapter three provides a literature summary of FASD as a medical construct, and introduces some of the research that has been influential in supporting my general knowledge of FASD. Chapter four complements this with a discussion of FASD in theoretical context, examining the key social, cultural and moral tensions that surround FASD, particularly with regard to the position of women and women’s agency and rights vis-à-vis pregnancy and modern medicine. This chapter reveals a number of the epistemic tensions that make FASD a difficult condition for diagnosis and intervention, but also suggests a Kuhnian construct of ‘paradigm shifts’ (Kuhn 2012) as an explanation for how these tensions may be resolved in health and allied health practice.

Chapter five transfers the research gaze to current international practice models for FASD diagnosis and intervention, paying particular attention to research projects and professional services from Australia, Canada and the USA – countries that each present public health issues with some characteristics in common with New Zealand. Chapter six then describes the engagement of New Zealand health and allied health professionals with one of these Canadian services through the 2011 Alcohol Healthwatch pilot project for diagnosis.

Chapters seven, eight and nine present the data derived from thirty-four extensive interviews, scaffolded by knowledge gained through participant-observation in
FASD training events. Crucially, I foreground the ‘voice’ of my research participants in these chapters by including extensive quotations from the interviews, so that the participants are represented in their own words. While I have lightly edited these quotations to remove many vocables (‘ums’ and ‘ahs’) and repeated words, I have endeavoured to preserve each participant’s manner of speech. Chapter seven describes the opinions and perceptions of the research participants with regard to alcohol consumption and FASD. Chapter eight reveals the challenges and strategies employed by diagnosticians in undertaking their work, and Chapter nine does the same for intervention workers. Chapter ten presents the discussions arising from this data, and places these findings in the context of the international research discussed in the preceding chapters. The implications and significance of these findings are reflected upon in the conclusion (Chapter eleven) to the dissertation.
Chapter 2: Approaching FASD

This chapter presents my approach and the methods underpinning my approach to research. The research method outlined here is the driving force from which all other elements of this project have been derived. It is a product of pragmatic decisions about how to commence and sustain my scholarly engagement with this research field, and has provided the basis for filtering and selecting appropriate literature sources on FASD and for constructing a theoretical framework for understanding the condition within the New Zealand health and allied health practice context. The explanation of method provided here therefore necessarily precedes these other chapters. This chapter also clarifies how my work sits within applied medical anthropology, and outlines the applied process underpinning my engagement with health and allied health professionals, from which the primary data for the thesis was derived.

This chapter has three main sections beginning with a description of anthropological practice, placing the research clearly within the domain of applied medical anthropology. It then moves on to consider the dominant social research methods that have been applied to FASD research topics similar to my own, and then systematically outlines the steps I took in constructing and carrying out my own research. The conclusion to this chapter demonstrates the contribution that this method has made to the construction of other aspects of the thesis.

The anthropological context

The parameters of this research – an ethnographic study in a health system context – invite its disciplinary positioning within the field of medical anthropology. Medicine and medicinal practices have been a prominent element of anthropological research since the establishment of the field, and while medical anthropology has been recognized as a discrete disciplinary strand since at least the 1960s, it remains consistent with general anthropological theories and methods in seeking empirical knowledge about human behaviour, society and culture (Hahn & Inhorn, 2009, p. 8–9, also Eagleton 2000, Monaghan & Just 2000, Ginsburg 1992).
The focus on culture is of particular importance in the context of this project, as FASD is affected by workplace cultures and culture at large, manifested in loosely defined constructs such as ‘drinking culture’. As Helman notes, the field of medical anthropology is interested in culture from a number of perspectives: from the comparative understanding of health and medicine across different cultures, through to the ‘culture’ of health service provision, and cultural aspects or constructs of disease (2007, p. 2–3). These interests are not unique to medical anthropology, but permeate all anthropological disciplines. What makes them important to medical anthropology, especially as conceived from a Western, Anglophone perspective, is that they serve as a reminder that, despite their almost complete institutionalization in clinics and hospitals, the domains of medicine and health are affected by social and cultural forces.

Medical anthropology has one other unique characteristic that is of particular relevance to this study: it seeks to build a bridge between cultural and biological constructs of disease, health and wellbeing (Romanucci-Ross, Moerman & Tancredi 1991, p. x): "A medical event is both biological and cultural, and since investigators are usually aligned with one aspect or the other of such an event, the simultaneity of the two aspects needs to be acknowledged" (Romanucci-Ross, Moerman & Tancredi 1991, p. 421). Andrea Wiley and John Allen describe this juncture as a ‘biocultural approach’:

This perspective considers the social, ecological, and biological aspects of health issues, and how these interact within and across populations. It is a uniquely anthropological and holistic view of health, incorporating these different aspects of the human experience. (2009, p. 5–6)

While much medical anthropology is interested in comparative constructs of disease, health and wellbeing across cultures, the cultural context for my research is rather narrower in that it concerns Western-trained professionals’ understandings of a particular health concern in one national context – a context that I also share. As such, it aligns somewhat with the trend towards ‘insider’
anthropology, identified in the early 1980s as anthropology ‘at home’ (cf. Jackson 1987), and is to some extent conversant with the theoretical notion of auto- anthropology (Strathern 1987), in which my own ‘insider’ position is both acknowledged and foregrounded. Indeed, this positionality led me to consolidate my research as a work of applied medical anthropology.

**Applied medical anthropology**
The field of applied medical anthropology is defined by Robert Trotter as follows:

> Applied medical anthropology is a natural extension of basic anthropology theory and methods into a practical exploration of the relationships between culture, society, health, healing, and the definition of distress and disease, with the ultimate goal of deliberately improving health, healing, medicine, and the overall well being of individuals, communities, cultures, and societies. (Trotter, 2011, p. 49)

Others take this definition further, claiming medicine itself as a kind of applied anthropology (Romanucci-Ross, Moerman & Tancredi 1991, p. x). Most medical anthropology textbooks pay some degree of attention to applied medical anthropology, with Wiley & Allen, for example, referring to applied anthropologists’ capacities as advocates and lobbyists for policy change, as well as acting as cultural intermediaries or as hired hands for specific action-oriented projects (2009, p. 31).

Theoretically, applied medical anthropology follows established trends in anthropology, with the added impetus of seeking practical (non-theoretical) outcomes from research. Trotter (2011) provides an excellent explanation of the three dominant theoretical frames in anthropology – atheoretical research, grounded theory, and theory-framed research – all of which are influenced by the ethnographic process (2011, p. 51-52). My own research overlaps with the first two of these. As applied research first and foremost, it is somewhat atheoretical in that the aim of my project is not to test theory but to generate a useful description of the circumstances surrounding FASD in New Zealand health systems; offering an
insider perspective in the hope that this will result in a catalyst for change. However, my ethnographic research process resulted in the emergence of certain theoretical tropes, particularly those relating to the valorisation of evidence-based practice and the moralization of maternal alcohol consumption, which strongly affect the field and which can not be ignored. To this end, an entire chapter of this thesis has been devoted to the theorization of FASD and prenatal alcohol consumption in New Zealand.

Alternatively, to borrow Norman Blakie's ‘four research strategies’ (2006, p. 91–101), my research could be described as having both inductive and abductive qualities. It is inductive in so far as the main purpose of my investigation is to provide a generalized understanding of how FASD is managed in New Zealand health and allied health service contexts. However, it is also abductive in that it converts individuals’ own descriptions and understandings into a generalized technical account of how FASD is handled within these service systems (cf. Blakie 2006, p. 101).

Importantly, Trotter acknowledges that applied medical anthropology is also inherently interdisciplinary: “this empirical and eclectic approach often produces crucial new links between different theoretical perspectives” (Trotter 2011, p. 49). This perspective resonates with my own experience in aligning my prior social work training with an anthropological research framework.

**FASD and health professionals in extant research**

The investigation of health professionals’ experiences and perceptions is particularly appropriate to a study of FASD because practitioners are often bereft of other types of resources and are forced to rely on their experience and professional judgment when encountering FASD. Extant research in this domain has largely been carried out in social research frameworks making use of three key strategies: surveys, interviews and ethnographic participant-observation engagement. These methods have revealed certain trends internationally that reinforce the perception that, where FASD is concerned, professionals are bereft of support. As Tough, Clarke & Hicks have observed: “Surveys in Canada and the
United States have found inconsistencies in diagnosis, treatment and management of children with FASD due to gaps in physician knowledge and attitudes regarding FASD” (Tough, Clarke & Hicks 2003, p. 1).

It is widely argued that professional opinions and experiences influence their professional practice, as Diekman et al. assert: “Studies have shown that physicians’ knowledge, attitudes and beliefs about a health problem such as alcohol abuse can either predispose or deter them from screening, identifying and managing the problem” (Diekman et al. 2000, cited in Tough, Clarke & Hicks, 2003, p.1). Where FASD is concerned, researchers from many of the professional fields that intersect with FASD, including nursing, psychology, social services and paediatric medicine, have established frameworks for investigating practitioners’ knowledge and attitudes (Mengel et al. 2006, Payne et al. 2005, Wedding et al. 2007, Caley 2006, Cox, Clairmont & Cox 2008, Tough, Clarke & Hicks 2003). All of these studies revealed that professionals either thought they were not sufficiently familiar with FASD to be able to recognize it, or that they had such a limited knowledge of FASD diagnostic criteria that this was likely to impact on their ability to work with FASD in practice. Wedding et. al. raise the issue of training, noting “...inadequate training and serious knowledge deficiencies in the areas of prevention, diagnosis and treatment of FAS” (2007, p. 212) amongst their participants. Meanwhile, both Caley (2006) and Payne (2005) referred to practitioners’ lack of knowledge as a particular concern. These studies have, however, all depended on impersonal qualitative surveys as the data collection tool, leaving little scope for deeper case-based analysis of the problems that they have identified.

Much of this research has explored the knowledge and attitudes of health professionals who specifically engage with pregnant women in their practice, and is therefore focused on health promotion, prevention and harm reduction (cf. Wouldes 2009, p. 12–16). However, there are also studies that consider the knowledge and attitudes of professionals who are likely to engage with cases of FASD in practice. This research is largely located within Canada, the USA and
Australia and has taken place in a timeframe stretching from the mid-1990s through to the present time.

The subjects of these research projects have included a range of different professionals such as paediatricians (Payne et al. 2011), physicians (Mengel et al. 2006), psychologists (Wedding et al. 2007), school nurses (Caley 2006), psychiatrists (Tough, Clarke & Hicks 2003), human service professionals (Caley et al. 2008), and criminal justice professionals (Cox, Clairmont & Cox 2008). Additional groups of health professionals who have been studied include Aboriginal health workers, allied health professionals, community nurses, general practitioners and obstetricians (cf. Payne et al. 2005, Payne et al. 2011). By and large, these research projects have been approached in a similar manner, using survey-based methods to accumulate data. A similar model appears to have been used across these studies and is designed to reveal the extent of knowledge of professionals regarding FASD, as well as gaps in their knowledge. Participants were asked to either self identify gaps in their knowledge or were tested by the researchers with predetermined questions that focus in on what the researchers perceive as the important areas of knowledge. These surveys take an instrumentalist approach, and give the impression that they were designed with some sort of knowledge or skill improvement exercise in mind. Within the research reports, the authors often position themselves as experts able to suggest solutions to overcome the knowledge gaps that their research has revealed.

In the case of research by Payne et al. (2005), surveys were used to gain information about health professionals’ knowledge, attitudes and practice with regards to prenatal alcohol exposure and FASD in 2002 in Western Australia. Of the 1,143 professionals who engaged in the project, they found that only two per cent felt very prepared to deal with FAS and most wanted further information and training on FASD and resources for themselves and their clients (Payne et al. 2005).

Following on from this research, in 2007 researchers developed educational resources for health professionals on FASD and the prevention of prenatal alcohol
exposure and distributed the resources to 3,348 health professionals in Western Australia (Payne et al. 2011). Six months later they surveyed 1,483 of the health professionals in order to determine the impact that the educational resources had on the workers’ knowledge, attitudes and practice. The research found that following the distribution of educational resources, professionals were more likely to advise women to abstain from alcohol consumption during pregnancy and were more likely to diagnose or refer children for a FAS diagnostic assessment. There were also fewer requests for FASD-specific training and resources from this second research group, leading the researchers to conclude that it is likely that the resources they had developed fulfilled the need in this area for many of the professionals. Overall, by drawing a comparison between the 2002 and 2007 research, the researchers concluded that the health professionals in Western Australia had an increased knowledge of FASD and had changed their attitude and practice regarding FASD and prenatal alcohol exposure as a result of increased access to educational resources. This research, which extended to the evaluative testing of the ‘before and after’ effects of actual instances of training or information provision has resonances with my own research, as I also focus on the effects of training on the knowledge and professional practice of allied and health professionals. However, Payne et. al. (2007) concentrate more on evaluating the effectiveness of their own interventions than upon the dynamic practices of their research subjects.

The findings of all of the research projects that seek to examine the knowledge, attitudes and experiences of professionals with regard to FASD are similar, reflecting both the consistency of the research model and the consistency of the challenges of FASD in a range of professional fields. While there were variations in the type of knowledge professionals possessed, which can be attributed to their varied professions and types of engagement with FASD, overall the research projects concluded that their participants had a ‘general’ or ‘limited’ knowledge of FASD or relevant aspects of FASD or significant knowledge ‘deficits’ (Mengel 2006, p. 1, Payne 2005, p. 563). This was the case for Cox et al. (2008) in their study, which examined the knowledge and attitudes of criminal justice professionals from New Brunswick, Quebec, Nova Scotia, Prince Edward Island and Nunavut,
Canada. This study found that, despite their perception that FASD was a ‘pervasive phenomenon’ in their practice, professionals indicated that they were not equipped with appropriate knowledge of FASD, and that this impacted on their preparedness to deal with FASD in a professional context (Cox et al. 2008, p. 309). Meanwhile, Mengel and colleagues (Mengel et al. 2006), who studied the knowledge and attitudes regarding FASD and prenatal alcohol exposure (PAE) of physicians from the Midwest of America, noted that “Significant knowledge deficits exist in the area of prevention, diagnosis and treatment and significant barriers make completion of these tasks difficult in practice” (Mengel 2006, p. 1). All of these sources concluded that professionals’ knowledge regarding FASD was either ‘insufficient’ or that professionals would benefit from further information, training or education on FASD.

Most extant research projects into professional perceptions of FASD cited inadequate clinical training or education regarding FASD. In Mengel’s words, “Inadequate clinical training in medical school, residency and continuing education venues may be a prime reason why these deficits occurred” (Mengel 2006, p. 1). Researchers have recommended that FASD education be integrated into clinical training (Payne et al. 2011) or have noted that professionals required or requested access to further training on FASD (Caley et al. 2008, p. 122, Cox et al. 2008, p. 310). Other factors that impacted on professional practice with FASD which the research reports identified included: a lack of accessible research on FASD (Cox et al. 2008, p. 309), a lack of practice guidelines (Cox et al. 2008, p. 309, Tough et al. 2003), a lack of access to diagnostic and intervention services for referral (Cox et al. 2008, p. 310), time constraints of professionals (Tough et al. 2003) and limited experience with clients likely to be effected by FASD (Tough et al. 2003). Despite these limitations, many of the studies indicated that professionals thought FASD was very relevant or significant to their practice (Cox et al. 2008, p. 309l, Tough et al. 2003, Payne et al. 2005).

**Attitudes towards FASD**

Whilst many of these studies claim to explore the attitudes of professionals, there was little discussion of this in any of the reports. Indeed, unlike my own study,
there was no broader analysis of the sociological and moral context within which FASD sits and how this may impact on professionals’ response to FASD in the reports. Of all the reports, the one that reported attitudes to the greatest extent was the 2008 study by Cox et al. on the knowledge and attitudes of criminal justice professionals in relation to FASD. However, this discussion’s scope was limited to the researcher’s own predetermined questions, to which participants were invited to respond on a four-point scale (from ‘highly agree’ to ‘highly disagree’) and provided little scope for canvassing the participants own organic and unprompted opinion.

The questions in this study covered two narrow areas: first, the study asked participants about the relevance of FASD in the legal sector, and sought to ascertain the extent of their direct knowledge of FASD. Second, the study included questions about whether FASD was of particular relevance to certain minorities in society, such as youth or unspecified ethnic minorities. On both of these fronts, the participants declared little agreement, leading the researchers to conclude that ‘the FASD phenomenon is not limited to youth and those in minority families’ (Cox et al. 2008, p. 309) in the view of legal professionals. The purpose of such lines of questioning is unclear, as the researchers did not really explain why they were asking the judges and lawyers about youth and ethnic minorities, though this may relate to the researchers’ perceptions about the prevalence of clients from these two groups within the justice system.

The other discussion about attitudes related to professional perceptions of whether a diagnosis would make a difference for the child, such as Tough’s study where psychiatrists “indicated that many doctors do not make a diagnosis due to a belief that it will not make a difference for the child” (Tough et al. 2003, p.5). In a similar vein, the study by Payne et al. (2005) found a reluctance to diagnose FASD and concluded that this may have been reflective of the participants’ diagnostic uncertainty, although they speculated that “it may also reflect the concern expressed by over half of the sample that the child and family could be stigmatized if the diagnosis was made” (Payne et al. 2005, p. 563).
Overall the strength of these reports is that they offer reliable data concerning the extent of knowledge that different groups of practitioners in different parts of the world have about FASD: the outcome being that it is disturbingly little. However, these studies do not explore the underlying context of the work of the participants, nor do they give their participants an opportunity to articulate in depth and at length their own experiences and strategies for engagement with FASD. My own research has, however, undertaken such an analytical approach.

**The New Zealand context**

A similar approach to engaging with professionals was employed by Trecia Wouldes (2009) in her report concerning what professionals know and do about maternal alcohol consumption and other drug use in New Zealand. While basing much of her findings on data derived from questionnaires, she scaffolded this with information derived from interviews as well. Wouldes interviewed 241 health professionals, mostly midwives (68%) but also obstetricians, general practitioners and practice nurses to identify their practice approach to alcohol and drug use when dealing with women of childbearing age. She also investigated their knowledge and opinions about drug and alcohol use during pregnancy and questioned them about what they need in order to address the needs of their patients who report using alcohol, tobacco and other drugs (Wwouldes 2009, p. viii). The advantage of this approach is that instead of just identifying the extent or gaps in professionals’ knowledge, she was also able to convey a more detailed understanding of the context in which this knowledge exists. This was reflected, for example, in discussions that position alcohol in relation to other drugs (2009, p. 38) and in her ability to capture health professionals’ opinions rather than just the extent of their knowledge (2009, p. 43–47). This research thereby demonstrated the value of supporting a survey approach with more in depth interviews.

Contrasting with all of these examples both in terms of approach and outcome, a doctoral dissertation by Margaret Symes (2004) provides a counterpoint by approaching FASD in a manner that prioritizes the voices of those directly affected by FASD. This thesis, along with that of Loren Blair (1997), which I discuss below, was one of the earliest examples of FASD research in New Zealand.
The study by Symes (2004) is an example of the impetus for deeply engaged ethnography and what this approach can contribute to our understanding of the impacts of FASD. Symes became aware of FASD whilst living in Canada in the 1980s and on return to New Zealand found a lack of knowledge and awareness of the condition. Her ensuing research was situated within the field of medical anthropology and examined “the lack of acknowledgement [of FASD] or action on the part of the New Zealand government” (p. i) aiming to answer four questions: What exactly is FASD and do we have a problem here? Was the resistance in acknowledging FASD within New Zealand due only to personal attitudes surrounding alcohol consumption or have political and economic factors influenced this situation? How difficult was it to obtain a diagnosis of FASD in New Zealand and what were the barriers? What issues and problems were commonly experienced by FASD caregivers in relation to their FASD charge? In answering these questions, Symes’ privileged the perspectives of individuals and families affected by FASD including an autoethnographic account of a grandparent of a child with FASD in one of her chapters – a narrative that reveals in some detail the challenges faced by the individual in their encounters with a health system that is ill-equipped for responding to FASD. She also documents ethnographically the experiences of a range of families affected by FASD in their daily lives.

Some years prior to Symes, Loren Blair undertook a Masters research project examining the views and experiences of professionals regarding FAS (fetal alcohol syndrome) in New Zealand (Blair 1997). To my knowledge this was the first qualitative research undertaken in New Zealand on FAS. This research involved open-ended interviews with eight professionals regarding FAS (at the time the term FASD was not in usage) including two medical professionals, five educational professionals and one social services professional. Blair’s work identified themes derived from the responses to questions and conversations within her interviews. As the bulk of her participants were from the field of education, much of the data related to this field, however her data also revealed a number of similar themes to my research. For example, her research identified significant gaps in professional
knowledge regarding FAS and in the service system contexts within which they operated (1997, p. 51).

The generalizability of Blair’s data is, however, limited because of the small number of participants involved. Whilst the varied perspectives of professionals across the three areas provided interesting and often contrasting data as well as many common themes, the limited number of medical professionals and the solo social service professional hampered Blair’s attempts to analyse the differences in data between the three types of professionals (Blair 1997, p. 73). Blair sought to engage professionals in her research who had some knowledge or experience with FASD. Her method for recruiting professionals involved sending letters to various medical, educational and social service organizations explaining the project and inviting professionals to engage in the research. The final outcomes of her project included some evidence of professionals’ limited knowledge of FASD and this issue, of how to engage professionals in research about a topic which they are likely to know little about, was also a large consideration in my own project. Both Blair’s work and feedback from other researchers in the field helped to inform my own method of identification and engagement with research participants.

Jennifer Salmon’s extensive research (2010, 2008, 2005) is similarly grounded in intimate engagement with birth mothers and later, individuals affected by FASD, providing nuanced understandings of what it means to live with FASD. Her Masters research (2005) resulted in a journal article (2008) and a book which outlined the experiences of birth mothers to children with FASD (2007). In 2010 she completed her doctoral thesis, which examined the daily challenges of individuals with FASD in New Zealand. Both pieces of research drew on qualitative methods including semi-structured interviews to give voice to this group.

The women in Salmon’s studies identified a range of gaps in both public policy and professional practice that, if addressed, would go some way to improving the experiences of birth mothers and individuals with FASD in New Zealand and, to some extent, my research is intended to address the professional practice deficits identified by Salmon. Despite the range of barriers to addressing FASD; the women
identified connecting, sharing experiences and strategies with other parents as their major source of help.

Salmon's research is well known in New Zealand FASD circles for the manner in which it gave voice to birth mothers and individuals affected by FASD in New Zealand. Her work highlighted the experiences and challenges that both groups face living and managing FASD and in doing so points to underlying problems within New Zealand’s health, education and service systems, which fails to address FASD in policy and practice. Salmon points to professionals’ views, opinions and their limited understanding, knowledge and practice experience as key barriers to individuals and families getting the help and support they need in New Zealand. My research seeks to extend this by providing research that gives voice to professionals’ views, knowledge and experience regarding FASD in the area of diagnosis and intervention given the conundrum that these professionals must engage with FASD within a context where New Zealand is yet to address FASD in policy and across service systems.

**Research design**

The first, fundamental step in capturing the lived experiences of health allied health and social service professionals in this research was to settle on a research process that would facilitate this style of data collection. To this end, my research is located in and organized through a series of participant-observation processes, and informed by a considerable amount of ‘insider’ information. Participant-observation ethnography is central to contemporary anthropology, and is perhaps the most typical characteristic of any research conducted anthropologically. It positions the researcher herself as the main data-gathering instrument (Monaghan & Just, 2000, p. 26–27), and recognizes the interactive and dynamic nature of the data sources – the people with whom she works. As Monaghan & Just emphasize, “...if you want to understand what anthropology is, look at what anthropologists do... ethnography is based on the apparently simple idea that in order to understand what people are up to, it is best to observe them by interacting with them intimately and over an extended period (2000, p. 13). ‘Participant-observation’ emphasizes the participatory aspect of the observation process.
Participating in the actions and activities of a community removes the distance that simple observation might engender, and ensures a more nuanced understanding of the culture under investigation. This technique has a long history in anthropology:

The origins of participant observation as the hallmark method of anthropology began at the end of the last century as an attempt to compensate for the variable reliability of descriptions of non-Western peoples. Not content to rely on travellers’ tales, missionary accounts, and official colonial reports... the founders of modern professional anthropology insisted on the first-hand collection of ethnographic data by trained observers. It was their hope that training would suffice to compensate for the prejudices of the observer. (Monaghan & Just 2000, p. 27)

Such training has variously involved elements such as local language acquisition or developing aptitude in the generation of skills or materials of potential value to the research participants (pedagogical resources, cultural heritage resources, etc). In my own case, the 'language' of the research participants was one that I already spoke: a professional language associated with public health and health and social intervention, and my ability to participate in the field was enhanced by my extant status as a member of this professional community. Beyond just interviewing my research participants, I was able to actively participate in their training processes and some of their professional processes, where I was already qualified to do so.

The research design for this project, like many ethnographic studies, was a constantly emerging and evolving process of discovery, enquiry and rediscovery, however it did fall into three key phases of investigation: participant-observation ethnography, interviews, and follow-up ethnographic fieldwork with initial participants. It also involved engaging with others, external to the interview process, who were able to provide contextual information on the interview findings. These phases are described below.
Establishing appropriate participants for this research was the primary challenge for the research design. My own professional experience suggested that other health and allied-health professionals’ knowledge bases for FASD were limited (similar to my own) and that it may prove difficult to identify any professionals with FASD experience. Furthermore, ignorance of FASD was widespread amongst health professionals, with many senior practitioners in Dunedin (my base as both professional counsellor and PhD candidate) publicly adopting positions of scepticism regarding FASD. Indeed, initial enquiries with other social researchers who had investigated FASD revealed that they had met with substantial difficulty for precisely these two reasons: general ignorance of FASD on the one hand, and denial of its possible significance on the other.

**Phase 1: Participant-observation ethnography**

My starting point for this research was my own workplace, the context in which I had encountered FASD for the first time. While operating as a broad-based child and youth counselling service, the director of the workplace was a drug and alcohol specialist, and much of the centre’s work ultimately revolved around drug and alcohol issues. There was, therefore, an enhanced general awareness of a range of drug and alcohol related health issues amongst the staff, including a basic awareness of FASD. One of the ways that this was manifested was in the director’s periodic engagement of a specialist drug and alcohol trainer from Canada to deliver workshops and training in Dunedin. This trainer’s workshops included an overview of the cause and presentation of FASD as well as discussions on working with FASD in diverse social and community contexts.

I first attended one of these training sessions in 2008, and this became a catalyst for the recruitment of my own research participants. In the absence of an extant regional network of FASD specialists, a sporadic training event such as this one provided the best opportunity for accessing colleagues through their concentrated focus on the issue. I therefore began to recruit participants for interviews while also participating in FASD training events around New Zealand over a two-year period in 2009 and 2010. Attending and participating in these FASD training
initiatives also allowed me to establish the extent of awareness and interest in FASD amongst health and allied health professionals in the region.

A second important benefit of participation in professional training initiatives was that it gave me a platform from which to establish direct contact with those few organizations (mostly based in the North Island) that did have direct FASD expertise, and which were often involved as organizers in these training projects themselves. While these organizations had public engagement as part of their remit, and were therefore very open to unsolicited approaches from researchers. Furthermore, having an actual engagement objective seemed to facilitate my ability to forge a research relationship with these bodies and the key individuals within them.

In addition to facilitating FASD training, the organizations Fetal Alcohol Support Trust (Hamilton) and Alcohol Healthwatch (Auckland) were also closely networked with international FASD experts, and had been regular participants in international forums such as the International Conference on Fetal Alcohol Spectrum Disorder, held biennially in and around Vancouver, Canada. Thus, with a view to enhancing my own understanding of FASD in the international context, I undertook to attend and observe proceedings at the 2009 conference, which had the added benefit of bringing me closer to the other New Zealanders who were in attendance, as well as getting to know their international contacts. All of this coincided with the development of the pilot project for FASD diagnosis by Alcohol Healthwatch: a highly significant training initiative which will be discussed at length in Chapter six of this thesis. Through these engagements, I established both a national and international frame of reference for my research, and a consistent method for recruiting interview participants.

This snowballing process of engagement with national and international experts in the field of FASD also had a generative influence on the scope of my research subject. Based on my initial experiences in trying to get an FASD assessment done for one Dunedin-based client, I was attuned to the fact that both diagnosis and intervention are implicated in providing effective services in this area. However, in
the absence of specialized local diagnosticians, and taking into account the general lack of engagement with FASD within regional diagnostic services, I came to the pragmatic decision of focusing instead on intervention work as the main context for this ethnography. This remained the case until early 2010 when, as a result of my increasingly close relationship with the activities of Alcohol Healthwatch, I was permitted to join their project as a participant-observer in the training process and in return I provided an external review of the project upon its completion. This involvement brought me into direct contact with all of the diagnosticians who were working on improving diagnostic capacity for FASD in New Zealand, and made it possible for me to include diagnosis as a focus area within my research. The final result was a research design in which both diagnosis and intervention were equally represented. The first stage of the research for this project therefore proceeded in site-specific and time-bound fieldwork segments throughout New Zealand over the course of eighteen months between January 2009 and July 2011. This included two FASD intervention workshops with local and international facilitators and the whole Alcohol Healthwatch pilot project, which involved meetings in Auckland and Vancouver.

The first FASD workshop encompassed in the timeframe of my research was organized by Dunedin’s Mirror Counselling Service, and took place at the Mirror Youth Day Programme facility at Waitati Marae in August 2009. This workshop was run by Janelle McMillan, First Nations drug and alcohol worker from Canada who had run similar workshops for Mirror Counselling Service in the past. On this occasion, the workshop was co-facilitated by Alcohol Healthwatch, and was open to participation for all community services workers in the Dunedin area. Over the course of two days, McMillan provided a comprehensive overview of FASD and its causes, the challenges for individuals and families affected, and some of the strategies that professionals can follow in handling it. McMillan's presentation was particularly evocative as she is a parent of a child with FASD, and her presentations drew from the intimate personal experience. Forty allied-health sector workers attended this training, and sixteen of them agreed to participate in follow-up interviews for the purposes of my research.
The second FASD workshop was a fetal alcohol awareness seminar organized in Christchurch by Footsteps – a community-based social service NGO working with children in care – in August 2010. This workshop was led and facilitated by two North Island-based professionals with extensive expertise in FASD: Christine Rogan from Alcohol Healthwatch, and Valerie McGinn, a private neuropsychologist specializing in FASD diagnosis. They were joined in their presentations by a mother of a child with FASD, giving the workshop a somewhat personal touch. This workshop was organized as an information sharing exercise for Footsteps staff, other community-based allied health professionals, and foster carers in the Christchurch area. Around fifty professionals and parents attended this workshop, with eight agreeing to participate in my research through follow-up interviews.

The third training exercise encompassed within my fieldwork was the pilot project for FASD diagnosis initiated in 2011 by Alcohol Healthwatch in collaboration with a number of North Island District Health Boards. This training commenced in Auckland in October 2010 and continued on to Canada in March 2011, where participants attended the Vancouver conference and then undertook the three-day diagnosis training provided by the Asante Centre. Various debriefing sessions followed, with the project concluding in an Auckland meeting in July that year. For this project, Alcohol Healthwatch facilitated the training of eleven key health professionals in three teams, seven of whom (four psychologists, one speech and language therapist, one paediatrician and one psychiatrist) participated in the Canada-based component. My own participation in this third training initiative was particularly fruitful as I benefited from the opportunity to undertake the Asante Centre training and, while in Canada, had the opportunity to meet with professionals behind some of the programs for FASD that are considered to be leading international practice at present, including the Asante Centre itself and the Canadian Key Worker Program in British Colombia. Both of these programs are subsequently discussed in this thesis in Chapter five in relation to various international models for FASD diagnosis and intervention.
Phase 2: Interviews

A second stage of my ethnography, beyond participant-observation in training exercises, was the accumulation of interview data. As indicated above, a total of 35 individual interviews were conducted between 2010 and 2011, subsequent to each training event, with a view to establishing broad-based perceptions of knowledge regarding FASD in the health, allied health and social service sectors. The interviews were undertaken in three geographical locations, Dunedin, Christchurch and Auckland. Most (twenty-eight) of the interviews were undertaken in person in a place identified as suitable by the participant. Most often, this was the participant’s workplace, but interviews were also undertaken in participant’s homes, in cafes, hotels, and an airport. The rest of the interviews where undertaken over the phone (five) or over Skype (two). All of my interaction with participants in this research was subject to the approval of the University of Otago Human Ethics Committee, which approved my research ethics application (protocol approval no. 10/157) in 2010.

It must be acknowledged here that in between the time of the Christchurch FASD training and the commencement of my fieldwork interviews, a series of serious earthquakes hit Christchurch, which had a devastating effect on the city and its people. The earthquake damage, and the lengthy recovery, affected the workload of the Christchurch participants in this research, most of whom worked in social and community service contexts. They had to not only deal with the impact of the quake on a personal level but also respond to the needs of the community in very challenging working conditions. For many of the participants, the buildings that they worked in had been destroyed in the earthquake or permanently evacuated because they were considered unsafe. Most of the participants were working in alternative buildings not designed for their work needs, or working from home and within the community, meeting their clients in parks and cafes. Because of the earthquake a few participants who had initially indicated a willingness to engage in the research were understandably unable to continue to remain involved. However, despite these challenges, a dozen participants made space in their own personal time or pressured work time to meet with me, making their own arrangements to come to the hotel I was staying at to meet, as there was nowhere
safe or appropriate for me to travel to meet with them. All indicated that they considered FASD to be a significant issue in New Zealand, which motivated them to participate despite these challenges.

I approached all of my interviews in a semi-structured manner, as this presented the most effective means of gathering information on this topic. Too much structure would have failed to capture many of the nuances that individual professionals brought to the discussion; too little would have likely resulted in responses that strayed away from the FASD focus and into broader professional practice issues and problems. While I did use a guide list of questions (see Appendix B for details), I found that, in most cases, interviewees covered these in their responses without much prompting (if any). While both the diagnosis and intervention groups were guided by the same set of questions, the interviews had a dual role for the diagnostian participants, who were also providing feedback for me to include in an evaluative report that I was concurrently writing for Alcohol Healthwatch, relating to their pilot project for FASD diagnosis. Each of the interviews lasted from one to two hours in duration, with some running into more than 15,000 words in transcription. Once transcribed as text, I coded the interview data using the constant comparative method (Denzin & Lincoln 2005, p. 378), and developed a thematic analysis of key concepts and constructs that populate chapters eight, nine and ten of this thesis.

**Phase 3: Follow-up fieldwork**

The third stage of my fieldwork was a reflexive process in which I sought feedback on my research findings from national and international FASD workers and experts. My collaboration with the New Zealand professionals trained in the Alcohol Healthwatch pilot project led to ongoing engagement with Christine Rogan, who became a reference point for a number of questions. My attendance at subsequent formal and informal meetings by those involved in the pilot project was crucial to contextualizing the contributions that they had made in my interviews. My presentations at the 2011 and 2013 FASD conferences in Canada gave me the opportunity to compare my own experiences and understandings with international benchmarks (see Appendix A for a poster presentation
example), and also gave me an opportunity to gather feedback from international professionals (in Canada, USA and Australia) whose work or work programs are discussed in this thesis. These professionals welcomed my questions and, as many were aware that progress around addressing FASD in New Zealand was well behind the developments in their own countries, they invited me to be involved in their meetings and social gatherings. Through this process, I benefitted from a great deal of informal learning that would not have been possible in the New Zealand context alone. I also established extensive networks with professionals and researchers from a range of fields as well as organizations for families and families and individuals themselves.

A further fact-checking opportunity arose in November 2011, when FASD intervention expert Diane Malbin was invited to Hobart (Australia) by NOFASARD, (National Organization for Fetal Alcohol Syndrome and Related Disorders) to provide an intensive FASD training program. Diane Malbin, is an FASD specialist based in Portland, USA, who has taken the results of research into brain function and developed a framework for the logical application of this research to the FASD intervention context. Her approach is regarded as being extremely effective, and she is often sought as a consultant for training and intervention program development worldwide. This Hobart training, which ran over two days, included an overview of Malbin’s influential theoretical framework for understanding FASD, and for applying a ‘brain based approach’ to fetal alcohol neurobehavioral conditions. This framework is discussed at numerous points in this thesis, and is a key influence on my own approach to the topic of FASD intervention.

The Hobart training drew together a broad range for professionals including paediatricians, psychologists, speech and language therapists, and social workers, as well as parents and caregivers of children with FASD, from across Australia. Thus the training also provided a unique opportunity to gain a greater understanding of FASD related work across Australia. I met with Diane Malbin again in 2012 at a training session in Brisbane (organized by the University of Queensland Collaboration for Alcohol Related Developmental Disorders), which provided the opportunity to extend my knowledge of the Key Worker program
(which is discussed in Chapter five) and to ask her about her experiences as an FASD trainer, social work practitioner and mother to children with FASD. Subsequent to these meetings, once my dissertation manuscript had reached draft stage, I distributed it to my interviewees and research collaborators for feedback.

Conclusion
The benefit of this three-phase research design was that it allowed me to generate both breadth and depth in my data collection. This rich qualitative process provided me with a comprehensive overview of the experiences of all of the active FASD diagnosis and intervention workers in New Zealand between 2009 and 2012. In the interviews, the subject of inquiry, while loosely determined, was not fully preconceived, and interviews were allowed to unfold according to the perceptions, experiences and preferences of the interviewees. Despite this flexibility, the overall experiences that they related were surprisingly similar and interviewees from different workplace contexts frequently repeated, albeit unknowingly, comments made by their counterparts elsewhere. A consequence of this process, however, was that some topics pertinent to FASD remained outside the scope of the research. The most important of these is the topic of prevention – a part of the social service cycle that goes hand in hand with diagnosis and intervention. None of the interviewees in this project were actively involved in FASD prevention strategies, and while many mentioned prevention as an important step in service provision, it was not something with which they were directly involved.

Most importantly, the research method ultimately provided the framework for the structuring of the dissertation itself. The decision to include a chapter devoted to theory, for example, is a reaction to the ways in which the research participants problematized their engagement with FASD, and therefore needed to be presented and unpacked before the presentation of the interview data. Similarly, the decision to split the research data into five separate domains – international models, diagnosis training, perceptions, diagnosis and intervention – reflects the manner in which these five areas appeared and reappeared across different phases of the research process.
Chapter 3: FASD in scholarly context – an overview

This chapter draws on pertinent literature to provide an overview of FASD, how it affects people, how it is understood, and how it has been examined in the New Zealand context. This overview is intended as a foundation to support some of the more complex themes and discussions that emerged from my research and which are extrapolated in Chapters five through to nine of this thesis. This literature review is organized in such a way as to foreground a working understanding of FASD itself, with the choices of which material to include being made pragmatically with regard to their international relevance, degree of acceptability as key references for clinicians, and the quality and rigour of their contents. In this sense, the review is not exhaustive because (as previously noted) in experimental science alone, publications concerning FASD run into tens of thousands of items, and it is beyond the scope of this thesis to engage in a meaningful way with a literature base of this magnitude. Rather, this chapter provides a practical understanding of FASD that will help the reader to contextualize the challenges and solutions for managing FASD in professional health and allied health contexts.

The first part of this chapter follows on from the brief description of FASD provided in the introduction, with some notes on the development of literature regarding prenatal alcohol exposure, through to the consolidation of FASD in Anglophone Western diagnostic terminology. This is followed by a description of the condition and an overview of its main characteristics and effects. An important point in considering the effects of FASD is the delineation of primary, secondary (and tertiary) disabilities, and how these designations relate to the position of the disorder in social context. Within this discussion, it becomes apparent that FASD is most commonly described through a deficit discourse that focuses on problems associated with the disorder, and it is at this point that I turn away from the scholarly literature to consider the discursive contributions of authors (usually parents of children with FASD) who eschew this deficit discourse in favour of a more uplifting and less dire narrative. The final portion of this chapter details, in broad terms, the extent of New Zealand research into FASD, and concludes by offering a sense of how my own research contribution might fit in relation to these
existing studies and discourses, particularly in relation to the practice-based context that is the focus of this thesis.

**Prenatal alcohol exposure in Western scholarship**

Fetal alcohol syndrome was established as a medical condition in 1973 (Jones & Smith 1973), however numerous works of FASD scholarship reveal a much longer history of awareness of the potential adverse effects of prenatal alcohol exposure, stretching back over millennia. Tanya Nguyen et al. (2011) point to the Carthaginian custom of forbidding alcohol consumption by bridal couples on their wedding night (p. 2), and Calhoun & Warren (2007, p. 168) make reference to Old Testament biblical references concerning drinking and pregnancy to suggest a long awareness of potential problems. Other historical reference points include a mention in Robert Berton’s 1621 text *The Anatomy of Melancholy* attributed (possibly apocryphally) to Aristotle (Nguyen et al. 2011, p. 2), eighteenth century observations of children of alcoholic mothers in Britain (Calhoun & Warren, 2007, p. 169), and observations published in 1899 by a prison doctor tending to the children of imprisoned pregnant alcoholic women (Nguyen et al. 2011, p. 2). Diane Malbin (2011, p. 6–7) details a further series of medical investigations of alcohol and pregnancy in Western Europe and the USA between 1901 and 1965, all conducted sporadically and with contradictory findings.

It was not until 1968 that an observation-based report entitled ‘Outcome of Children of Alcoholic Mothers’ (Lemoine et al. 1968), established a link between alcohol consumption by mothers and the ill effects of this consumption on their children. This study, which is acknowledged broadly in extant literature, was a turning point in the recognition of alcohol’s teratogenic effects, but did not extend into providing diagnostic criteria or a definition of the disorders caused by alcohol. Furthermore, as a French-language publication, it had limited distribution in Anglophone contexts.

A crucial turning point for the definition of FAS as a medical condition in Anglophone biomedical research literature was the publication of research by Jones & Smith in 1973, which provided a name and diagnostic advice for the
condition they were investigating (Jones & Smith 1973). Following their work with Christy Ulleland, a paediatric resident who had noted that a number of infants who had been born to mothers with alcohol addiction demonstrated a failure to thrive, Smith, a paediatric dysmorphologist, and his student Jones identified a range of physical features common to children whose mothers were identified as alcoholics. Following numerous case studies, they came to the conclusion that alcohol was a teratogen (Golden 2005, p. 3). The pair published their first article ‘Pattern of Malformation in Offspring of Chronic Alcoholic Mothers’ and five months later published a second article, ‘Recognition of the fetal alcohol syndrome in early infancy’, in which they introduced the term fetal alcohol syndrome (or FAS). The case studies they referenced provided consistent documentation for FAS, and their work became a reference point for further research in the 1970s (including that of Erb & Andresen 1978, Clarren & Smith 1978, and Tenbrinck & Buchin 1975).

Since the documentation of FAS, developments in animal model research and human studies have revealed that prenatal exposure to alcohol can result in a spectrum of possible effects. As a result of this, over the years there have been changes in terminology to reflect the broadening understanding of the condition and its definitions. A number of years after the diagnostic criteria for FAS were established, the term “fetal alcohol effects” came into common usage to describe the presentation of clinical conditions in which there was a history of prenatal alcohol exposure, but where the individual did not meet the specific criteria for a diagnosis of FAS. In 1996, the US based Institute of Medicine (IOM) introduced the term alcohol related neurodevelopmental disorder (ARND) to replace FAE, which was often considered too ambiguous. As well as this, the IOM proposed additional terms relating to the diagnosis: fetal alcohol syndrome (FAS) with confirmed maternal alcohol exposure; fetal alcohol syndrome (FAS) without confirmed maternal alcohol exposure; partial fetal alcohol syndrome (PFAS) with confirmed maternal alcohol exposure, partial fetal alcohol syndrome (PFAS) without confirmed maternal alcohol exposure; alcohol-related birth defects (ARBD); and alcohol related neurodevelopmental disorder (ARND). Since then, various other terms specific to different diagnostic processes have come into use (these are discussed in detail in Chapter five). Despite some disagreements in specific
diagnostic terminology, FASD is now accepted broadly in the field as an umbrella term (however not as a diagnosis itself) encompassing the spectrum of effects of prenatal alcohol exposure (Malbin 2011, p. 7).

This brief description of terminological disjuncture reflects some of the complexities of a condition whose characteristics are so varied and often difficult to identify, as Kristina Uban et al. observe: “Alcohol is known to act on or modulate many different target molecules, multiple mechanisms, activated at different stages of development or at different dose thresholds of exposure, probably contribut[ing] to the diverse phenotypes seen in FASD” (2011, p. 74). In the next section, I comment on the extent and range of this variety.

Alcohol and the fetus

As established earlier, the biomechanical reason that FASD exists is that alcohol is a teratogenic substance that can pass through the placenta from mother to fetus (Paintner et al. 2012). There is evidence to suggest that it can take up to three hours for alcohol to be eliminated from the amniotic fluid following the equivalent of a single drink (Burd et al. 2007). One reason for this is that the fetus ingests the alcohol and excretes it into the amniotic fluid and then ingests it again resulting in a prolonged period of exposure during which the alcohol can directly act on developing fetal cells (Uban et al. 2011, p. 73). There are a number of ways that the teratogenic effect of alcohol can impact the development of the nervous system. Paintner, Williams & Burd (2012) describe six main processes: cell damage or cell death; disrupted cell to cell interactions; interference with growth-factor signalling; altered regulation of gene expression; impaired or disregulated cell acquisition; and disrupted cell energetics. These can result in decreased cells, abnormalities in cell migration, and structural and functional abnormalities in the brain as well as organ system damage (Paintner, Williams & Burd 2012, p. 262) As well as the direct effect of alcohol on the fetus, alcohol can also alter the function of the placenta by causing the blood vessels to constrict and narrow which in turn reduces the supply of nutrients and oxygen from the mother (Commonwealth of Australia 2012, p. 16). Exposure to teratogens can result in malformations, functional deficits, growth deficiencies and death. Whilst not all teratogens have
the ability to cause all four of these outcomes, alcohol does (Streissguth 2004, p. 56).

While alcohol can potentially affect any part of the developing fetus, the brain is the part of the body that is most susceptible to damage, and potentially the site of the most serious permanent adverse effects. This is partly due to the fact that the brain and central nervous system are in a constant state of development throughout the gestation period (Paintner et al. 2012). Thousands of animal model studies have demonstrated the direct and indirect impacts of alcohol on the developing brain, which can cause structural abnormalities and functional deficits (as a starting point, see O’Leary-Moore et al. 2011). Studies on children with prenatal alcohol exposure using magnetic resonance imaging (MRI) and functional imaging techniques, such as electroencephalography (EEG), positron emission tomography (PET), and single photon emission computed tomography (SPECT) have compared results with those not affected and found significant differences in brain structure and function (cf. Lebel et al. 2008).

Alcohol can work directly on the structure of the brain, resulting in physical changes such as decreased numbers of mature neurons and structural damage to areas of the brain. As Uban et al. observe, “the hippocampus, amygdala and cerebellum show particular sensitivity to the inhibition of protein synthesis by alcohol, resulting in decreased numbers of mature neurons” (Uban et al. 2011, p. 75). Meanwhile, “prenatal exposure to alcohol can result in a disorganized cortical architecture, which ultimately influences the pattern of communication in and across regions involved in higher cognitive function” (Uban et al. 2011, p. 75).

Alcohol can cause cell death in numerous ways, causing different parts of the fetus to develop abnormally: “Defects caused by prenatal exposure to alcohol have been identified in virtually every part of the body, including the brain, face, eyes, ears, heart, kidneys and bones. Significantly, toxic by-products of alcohol metabolism may become concentrated in the brain” (Commonwealth of Australia 2012, p. 17).

Another set of factors in the FASD context is the role played by genetics, epigenetics and environmental factors that might affect the health of the fetus as
not all of those exposed to alcohol in utero have FASD, and those who are affected can present with varied phenotypes, severity and outcomes. This points to a number of other factors that may mitigate or exacerbate alcohol’s effects. As well as these direct and indirect mechanisms stress, nutrition, multiple drug use and maternal age are also of relevance (May 2011, p. 18). As noted in a recent report: “Alcohol sets in motion different processes at different sites in the developing fetus. Consequently the effects of alcohol on the developing fetus can be wide ranging” (Commonwealth of Australia 2012, p. 17). Internationally, since the 1970s, there has been a large amount of animal model research that has demonstrated the teratogenic effect of alcohol on fetal growth and development and provided insights into the direct mechanisms that act on the fetus, and indirect mechanisms which are influenced and mediated by individual and environmental conditions (Uban et al. 2011, p. 74).

**Dose and timing**

A third consideration in evaluating the effects of alcohol is the question of dosage and timing. The timing of alcohol exposure has a huge effect on the outcome. Simply put, alcohol acts on whatever was developing at the time the alcohol was consumed. This is an important point in the field of FASD because it explains why the physical impact of alcohol varies from person to person: “Of particular interests to both researchers and clinicians, there appear to be fairly large differences in the susceptibility of different brain regions to alcohol depending on the dose and timing of exposure” (Uban et al. 2011, p. 75).

Even now it not known how much alcohol is necessary to produce the symptoms of FASD. There is a large amount of research that considers this issue with mixed and opposing outcomes, as Wouldes notes:

One prevalent view proposed that even small amounts of alcohol during pregnancy may cause ‘fetal alcohol effects’ or result in some form of FASD. The main basis for this proposition is twofold: first research has been unable to establish the level or dose at which alcohol consumption is likely to cause FAS. Second, the varied neurological effects on infants and children
that has been reported in the extant literature investigating antenatal exposure to alcohol has been interpreted to mean even small to moderate doses of alcohol can cause FASD. (Woundes 2009, p. 7)

Whilst the teratogenic effect of alcohol is considered to be dose related, there is conflicting research regarding the safety of pre-natal alcohol consumption. It is accepted within the field that there is no known safe amount of alcohol or safe time to consume alcohol during the period of pregnancy. Binge drinking is specifically discouraged (Commonwealth of Australia 2012, p. 37). Whilst alcohol can adversely impact the development of the fetus from two weeks post conception to term (Chudley 2011) there are critical periods of development in which the fetus is at greater risk, for example, “exposure between the fourth and ninth weeks is the critical period for malformations of the brain and other cranial structures” (Elliot et al. 2008, p. iii).

**Characteristics of FASD**

As previously stated, FASD is an umbrella term that encompasses a range of diagnoses characterized by physical and/or central nervous system abnormalities caused by prenatal alcohol exposure. FAS, which represents the severe end of the spectrum, is the most commonly known of these diagnoses, partly because it was the diagnosis first described by Smith and Jones (1973), and also because FAS presents visible physical features including distinct facial dysmorphism. Despite the specificity of the physical features associated with FAS, FASD is often described as an ‘invisible’ or ‘unseen disability’ (Paley 2009) because for the rest of the spectrum of affects, the prenatal damage primarily occurs to the brain and thus is not visible but rather presents as a range of cognitive and functional deficits often characterized by behavioural symptoms. Research suggests that the damage to the brain caused by alcohol is irreversible and thus FASD is considered a lifelong disability (Andrew 2011, p. 136).

The two common factors in all diagnoses on the FASD spectrum are prenatal exposure to alcohol and evidence of organic central nervous system dysfunction, or CNS dysfunction, which is defined by the IOM as “a complex pattern of
behavioural or cognitive abnormalities inconsistent with the developmental level and not explained by a genetic predisposition, family background or environment alone” (Andrew 2009, p. 6). In Canada, diagnostic categories under the spectrum include fetal alcohol syndrome, partial fetal alcohol syndrome and alcohol related neurodevelopmental disorder (Chudley et al. 2005, p. S4–S5). My descriptions of the spectrum follow the Canadian nomenclature here, because the Canadian diagnostic toolkit is the approach most commonly used in New Zealand.

A diagnosis of FAS requires deficits or abnormalities in three areas: facial dysmorphology, pre and postnatal growth deficits, and Central Nervous System (CNS) dysfunction. Confirmation of prenatal alcohol exposure is preferred in all cases of FASD but is not essential for a diagnosis of FAS because of the distinct physical features that otherwise mark the syndrome. These physical features include short palpebral fissures (small eye openings), a flattened or absent philtrum (the ridge between the nose and upper lip) and a thin upper lip. In order for a diagnosis of FAS to be confirmed, prenatal and postnatal growth deficits including height and weight measures must be at or below the tenth percentile and there must be some evidence of central nervous system problems (including structural, neurological and functional deficits). FAS can include a range of other physical malformations and birth defects, however these do not constitute part of the diagnostic criteria, as many of them are not specific to FAS but they are noted at the time of diagnosis. In some cases, individuals presenting with only some of the physical features required for an FAS diagnosis may be diagnosed with Partial FAS (PFAS) instead (Chudley et al. 2005).

While FAS and PFAS are the most specific of the FASD conditions, they represent only a small fraction of the total diagnoses on the spectrum. The most common diagnosis (generally speaking), accounting for the remainder of cases, is that of Alcohol Related Neurodevelopmental Disorder (ARND). In cases of ARND, individuals present with none of the physical features of FAS but with evidence of significant CNS damage and confirmed prenatal alcohol exposure. While ARND is often considered less severe than FAS or PFAS due to the absence of physical
features and growth deficiency, recent studies have shown similar levels of CNS dysfunction to that of FAS and PFAS.

**Understanding the characteristics of FASD and CNS dysfunction**

The dysfunctions associated with CNS damage reflect structural, functional and/or cognitive impairments result in a wide range of learning and behavioural symptoms. It is common within FASD literature for FASD to be described using these general traits and symptoms. Non-clinical reference sources that discuss the characteristics of CNS damage generally provide, with slight variations, the following sort of descriptions of the presentations of FASD at different ages.²

Infants with FASD are often described as having feeding difficulties, sleep disturbances, irritability, reduced attention, poor visual focus (visual tracking), hyper-arousal, and sensitivity to light. For preschool children, this is manifested in short attention spans, hyperactivity (often classified as ADHD), challenges with fine and gross motor skills, speech delay, and increased reactions to stress. Older children and adolescents are often described as having academic problems, difficulty planning, organizing, predicting, prioritizing, and setting goals, as well as memory problems resulting in making the same mistakes over and over. They have difficulty understanding abstract concepts such as time and money, difficulty reading common visual and social cues, problems with confabulation, slow mental processing, and might appear to understand instructions or directives when they really don’t. They become easily fatigued and have problems with impulsivity, hyperactivity, poor self-regulation, poor judgment, immaturity or ‘dismaturity’, problems understanding boundaries, and poor understanding of danger and risk.

Descriptions of these characteristics in adolescents and adults also commonly draw on a range of secondary disabilities such as substance abuse, trouble with the law, high risk of teen pregnancy, mental health problems and employment problems, which I will discuss later in this chapter. Many of these challenges relate

² The North American National Institute on Alcohol Abuse and Alcoholism provides comprehensive descriptions of these effects at: http://pubs.niaaa.nih.gov/publications.
to poor executive functioning, which is common among people affected by FASD, and many of the behavioural issues exhibited by children and adolescents with FASD correlate to executive functioning deficits (Kalberg & Buckley 2007, p. 280). Poor executive functioning has an impact on adaptive functioning, as noted by Novick Brown et al.: “Adaptive and social functioning relies on underlying executive skills, which control the processing and integration of information and, ultimately, self-regulation” (2012, p. 770–771). Therefore, individuals with FASD often exhibit poor adaptive functioning as well. While poor adaptive functioning is often correlated with mental retardation, this is not necessarily the case for FASD, where even individuals with low to average range IQ can still exhibit the level of adaptive functioning that would otherwise be correlated with a much lower IQ (Novick Brown et al. 2012, p. 779).

These issues provide insight into the possible challenges or symptoms of individuals with FASD but are neither comprehensive, nor systematic and may not apply to any and all cases. As FASD operates on a spectrum, presentations can vary. Given this, a fair degree of work in FASD research has gone into developing tools for evaluating CNS dysfunction. One tool widely employed internationally to describe the range of CNS damage associated with FASD is the mnemonic ALARM developed by Julianne Conry and Diane Fast. ALARM stands for Adaptive functioning, Language, Attention, Reasoning and Memory (Burd et al. 2010, p. 571) which are terms used in neuropsychological assessments aimed at evaluating the extent of CNS dysfunction. The benefit of this acronym is that it is easy to remember, however it does not cover all of the key brain domains assessed and affected in cases of FASD.
Figure 1: Ten Domains of Neurological Function (from Lang 2006, p. 4)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Achievement</td>
<td>Assess skills in core academic areas – reading, math, and written language. A primary focus includes comparison of the child’s academic skills to their own intellectual potential and to their peers’ abilities</td>
</tr>
<tr>
<td>Adaption</td>
<td>Refers to the degree to which a person is able to meet the challenges of daily living when compared to others their age</td>
</tr>
<tr>
<td>Attention</td>
<td>Refers to the processing capacity for selective, focused, sustained and flexible attention, as seen, for example in behavior of concentration, hyperactivity and impulsivity</td>
</tr>
<tr>
<td>Cognition</td>
<td>Refers to the general level of thinking ability. An important facet of assessment in this domain is comparison of verbal and non-verbal thinking abilities</td>
</tr>
<tr>
<td>Executive functioning</td>
<td>Encompasses the capacity for goal-directed behavior; including self-regulation, initiation, working memory, planning, organizing and self-monitoring</td>
</tr>
<tr>
<td>Language</td>
<td>Encompasses all aspects of expressive and receptive language. It includes the ability to integrate the specific language skills such as grammar and sentence structure and the use of words to convey meaning</td>
</tr>
<tr>
<td>Memory</td>
<td>Encompasses the capacity to consolidate, store and retrieve information for short and long term application</td>
</tr>
<tr>
<td>Motor</td>
<td>Encompasses general abilities to use and coordinate large and small muscles. Gross motor skills including walking, running, hopping and climbing. Fine motor skills including hand writing and eating. Eye hand coordination refers to the ability to coordinate vision with movement</td>
</tr>
<tr>
<td>Sensory/soft neurological</td>
<td>Refers to an individual’s ability to process and make sense of incoming sensory information from the surrounding environment. Soft neurological signs are indicators of an immature nervous system. Those signs can be seen in an individual’s motor control, balance, rhythm, strength, motor planning and sequencing</td>
</tr>
<tr>
<td>Social communication</td>
<td>Refers to the ability to communicate appropriately and effectively in a variety of social situations with both peers and adults, including the ability to relay verbal information coherently and cohesively</td>
</tr>
</tbody>
</table>

Lang (2006), in contrast, provides a more comprehensive summary of the specific brain domains that may be impacted in cases of FASD. This approach was developed to both clarify the CNS parameters critical to a successful diagnosis, and to provide a framework for understanding, discussing and relating FASD diagnosis and intervention in ways that are accessible to both professionals and families. Lang states that assessments of the CNS “review structural, neurological and brain function in an overall way and are key to understanding the long-term implications of FASD for a client” (2006, p. 2), and proposes ten specific brain domains:
achievement, adaptation, attention, cognition, executive functioning, language, memory, motor, sensory/soft neurological, and social communication.

Individuals with FASD may have impairments in a number of these domains but not necessarily all of them. However, in order to meet the diagnostic requirements for CNS dysfunction using the Canadian adaptation (Chudley 2005) of the University of Washington 4-Digit Diagnostic Code (Astley 2004), they must have significant impairments (defined as two standard deviations below the norm) in at least three domains. These ten domains provide a mechanism for clear discussion between professionals, and between professionals and families, about the functioning of the individual, including their strengths and challenges. Assessments of these domains help to identify, address and accommodate the primary disabilities of FASD.

**Primary and secondary disabilities**

A useful way of understanding FASD is to delineate between primary and secondary disabilities. Primary disabilities are characteristics that reflect brain dysfunction caused by PAE, and align with the categories listed above (in Figure 1). For example, poor short-term memory is a ‘memory’ dysfunction that may manifest in forgetting events, such as medical appointments, and thus not turning up for them. Other examples, within the domain of executive functioning, such as poor planning and organizing skills may manifest in an inability to identify and complete the tasks needed to get ready for school. All disabilities that directly relate to brain function are primary disabilities.

Secondary disability is a term that was introduced by Ann Streissguth et al. (1996) in a longitudinal study of children and adults with FAS and FAE. It refers to behaviours, conditions or situations that the individual was not born with, but which arise due to the adverse interaction between primary disabilities and social and environmental factors. Streissguth and colleagues reported on a range of secondary disabilities and risk factors for adverse life outcomes of individuals diagnosed with FAS and FAE from their longitudinal study. This study of 415 participants found that 90% had mental health problems, 50% had been in trouble
with the law, 50% had been confined for mental health problems, alcohol and drug problems or as the result of crime, 60% had a disrupted school experience indicated as being either suspended, expelled or dropped out of school, 50% manifested inappropriate sexual behaviour, 30% had alcohol and/or drug problems, 80% were dependent on support for daily living and 80% had employment problems (Streissguth 1996).

It is commonly understood that secondary disabilities present in the absence of appropriate support and accommodations for the primary disabilities and are often the result of chronic failure and frustration (Malbin 2011, p. 30). Streissguth’s study identified a range of protective factors against secondary disabilities including: living in a nurturing and stable home, being diagnosed before the age of six years; having a diagnosis of FAS rather than the other affects of alcohol exposure (primarily because those with FAS commonly have greater access to services), receiving disability services and never having experienced violence (Streissguth 1996). Further research by Streissguth indicated that the likelihood of avoiding adverse life outcomes increased when individuals receive a diagnosis at an early age and live in a stable nurturing environment (Streissguth et al. 1997, p. 35).

Diane Malbin builds on Ann Streissguth’s concept of primary and secondary disabilities, and breaks this down further to include primary disabilities, secondary defensive behavioural characteristics and tertiary characteristics. Similarly to Streissguth, ‘primary behaviours’ reflect brain function and include “learning thinking, physical responses to the environment and other behavioural symptoms associated with differences in brain structure and function” (Malbin 2011, p. 30). Secondary defensive behavioural characteristics are behaviours that develop over time as a result of chronic failure and frustration, which “reflect a poor fit between the needs of the person and his or her environment. These are preventable and resolvable” (Malbin 2011, p. 30). Tertiary characteristics are described by Malbin as “the net effect of chronic failure and frustration” (Malbin 2011, p. 30), and are ultimately reflected in individuals’ engagement with mental health and justice system services, often with adverse consequences.
Malbin maintains that secondary defensive behaviours, which can result in tertiary characteristics, often stem from inappropriate interventions and accommodations and that these can not only can be damaging to those with FASD and their families but can mask the individual’s fundamental strengths and abilities (2011, p. 89). She therefore counsels professionals and caregivers to critically reflect on any underlying assumption and expectations that they may have. The table provided in Figure 2 gives examples of how inappropriate expectations and values can impact negatively and gives examples of accommodations built on strengths (2011, p. 62).

Malbin emphasizes the importance of applying appropriate interventions for FASD that are underpinned by a theoretical understanding of FASD grounded in research. What Streissguth and Malbin’s work reveals is that, whilst secondary (or, for Malbin, ‘tertiary’) disabilities are common in cases of FASD, they are not predictive outcomes of the condition. Rather, they reflect a lack of appropriate service provision or support and are thus theoretically preventable and solvable.

One downside to this framework of primary and secondary disability is its tendency to frame FASD in terms of a deficit discourse where children are negatively compared against the norm (Chasnoff 2010). However, on the positive

<table>
<thead>
<tr>
<th>Primary symptoms</th>
<th>‘Fit’ with values and expectations</th>
<th>Interpretation of behaviours: Feelings:</th>
<th>Intervention</th>
<th>Secondary behaviours</th>
<th>Accommodations built on strengths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Slow auditory pace; goes blank.</td>
<td>Think fast, pay attention, stay on task.</td>
<td>S/he is ignoring me, being resistant: personalized, angry, frustrated</td>
<td>Talk fast, Therapy, Punish.</td>
<td>Anxiety, frustration, shut down.</td>
<td>Slow down, give time, adjust workload.</td>
</tr>
<tr>
<td>Dysmaturity: developmentally younger than their age (ie.16 year old more like a 10 year old).</td>
<td>Act your age, be responsible, be appropriate.</td>
<td>S/he is socially inappropriate, acting like a baby: frustrated, irritated, angry.</td>
<td>Teach age-based skills, punish ‘inappropriate’ behaviors,</td>
<td>Lonely, isolation, depression.</td>
<td>Think younger, establish developmentally appropriate expectations.</td>
</tr>
</tbody>
</table>
side, families of individuals with FASD including, parents, birth mothers, foster parents, adoptive parents and the individuals themselves have been active contributors to the collective knowledge of FASD and agitators for the development of services and education campaigns within their communities.³ It is also interesting to note that many professionals and researchers in the field of FASD are themselves parents or family members of an individual with FASD. While the literature representing the perspective of families and individuals highlights the struggles they face dealing with both FASD and health and allied health service systems, this group also make an important contribution to highlighting the positive aspects and success of individuals with FASD.

For example, Myles Himmelreicher explains the importance of communicating the strengths and resourcefulness of those with FASD through relaying his personal story of living with FASD, where the identification and development of his own strengths has lead to his career as a mentor and public speaker:

Five years ago in 2004 I started going to conferences and sharing what it was like for me growing up with a disability. As I travelled around attending conferences on FASD, I couldn't help but notice that much of the information shared seemed to be negative... ...I decided that when I would do my presentations I would share not only the loss and hardships but also the triumphs and successes I have had in my life. I wanted people to leave my presentations smiling. (Himmelreicher 2011, p. 413)

While perspectives such as Himmelreicher’s are largely absent in academic literature, there are a few recent case examples that consider the positive elements of FASD, such as the North American study by Brown et al. (2008) that examined the rewards of parenting a child with FASD, or social worker Prue Walker’s advocacy of a strengths-based approach (Walker 2008). Walker lists a string of attributes – including being loving, affectionate, gentle towards younger children, hard working, curious, creative, cooperative, interested in animals and activities like gardening – that she associates with FASD children. This commentary has

³ See, for example: http://www.nofas.org; http://www.rffada.org.
influenced the inclusion of strengths or positive traits of individuals affected with FASD reports, such as the Australian government inquiry into FASD (2012, p. 45).

**FASD research in the New Zealand context**

Much of the research on FASD in New Zealand has been limited to university sector research including a number of PhD and Masters theses, and quite a few important project, such as prevalence studies, remain to be undertaken. It is not known how many people are affected by FASD in New Zealand, however Alcohol Healthwatch suggest that, given both anecdotal evidence of FASD in New Zealand, and international research on prevalence from countries with similar (often lower) levels of alcohol consumption, the numbers are likely to be significant (Alcohol Healthwatch 2007, p. 6) On this basis, the most commonly quoted prevalence rate for FASD is between 1–3% in the general population and 5–9% in communities that face significant disadvantages and where alcoholism can be a larger issue. Because in New Zealand FASD is not routinely screened for in infancy even if alcohol exposure is known, data is not collected to record incidence when diagnosis is made and there have been no prevalence studies of FASD. The only research that touches on the incidence of FASD and that could be sourced at the time of writing was some early work in 1995 by two Auckland paediatricians (Leversha & Marks 1995). This research surveyed paediatricians about FASD, revealing few instances of paediatric engagement with FASD-affected individuals, but as Marks stated in a later article, the low numbers were likely to have been a reflection of under recognition of FASD rather than a real difference in incidence (1996). Further to this, Marks asserted that most affected children were more likely to be known to the primary health professionals and providers than paediatricians (Marks 1996, p. 10).

**Major studies**

Government agencies have played a leading role in examining alcohol as a public health issue, including some discussion of FASD in reports and policy documents, and it is clear that the New Zealand Ministry of Health (MOH) considers alcohol consumption in pregnancy to be a major health concern. In 2008, the MOH
Population Health Directorate commissioned the University of Canterbury’s Health Services Assessment Collaboration (HSAC) to undertake a review of the evidence relating to strategies for reducing the burden of FASD (Elliot et al. 2008). This major review considered literature related to FASD prevention and prenatal screening, postnatal screening and diagnosis, and relied largely on scientific sources, to the exclusion of a range of alternative sources of information.

In regard to FASD management, this review placed the aim of management within a deficit discourse which “aims to minimize both primary and secondary disabilities” (Elliot et al. 2008, p. xv). It identified that individuals with FASD benefit from a broad management plan, requiring the multiple support of clinical staff, caregivers and teachers. It also noted that affected individuals need access to a range of services, and that older children need practical interventions, “…such as improving skills of daily living, specific job skills and money management” (Elliot et al. 2008, p. xvi). The report identified three sets of guidelines (Alcohol Healthwatch New Zealand, British Medical Association, American CDC) and two review articles (Green 2007, Kalberg & Buckley 2007) that emphasized the importance of early intervention and effective management strategies to minimize the effect of primary disabilities and prevent secondary disabilities. However, the report concluded that “there was insufficient evidence in the literature to recommend any specific management strategies” (Elliot et al. 2008, p. xvi). This conclusion seemed to place FASD in the ‘too hard’ basket and resulted in no further government-level action on FASD. Disappointingly, the narrow focus on scientific literature excluded other sources that might have provided more grounds for action.

The New Zealand MOH has also provided some funding to independent body Alcohol Healthwatch, which is the body responsible for most of the action taken on FASD in New Zealand. Indeed, one of the most comprehensive reports on the state of FASD within New Zealand is a 2007 briefing paper on FASD by Alcohol Healthwatch. The paper suggests that FASD is likely to be a significant health issue in New Zealand and cites anecdotal evidence as well as drawing parallels between international research on FASD prevalence and current New Zealand research on
the alcohol consumption of women. The report states that the financial costs of failing to prevent FASD is significant and that new cases of FASD could be conservatively costing New Zealand $3.5 million annually in medical, social services and education, not counting the costs of secondary disabilities that are likely to be prevalent given a local context where diagnostic and intervention services for FASD are scarce (Alcohol Healthwatch 2007, p. 22)

A concern raised in this briefing paper is that New Zealand is currently facing a ‘catch 22’ situation with FASD where “a lack of evidence of the prevalence and incidence of FASD in New Zealand has been cited as the reason why health policy and programs have not been developed to prevent and/or treat FASD in this country. [However] Without trained professionals to diagnose FASD the prevalence cannot be accurately assessed” (Alcohol Healthwatch 2007, p. 6).

The Alcohol Healthwatch briefing paper points to the lack of policy and planning regarding FASD in New Zealand and highlights a number of gaps within health, social services and disability services. This includes inadequate provision of diagnostic and intervention services, a lack of support avenues for families and barriers to the access of current services which may be relevant to those with FASD but which they are not eligible for. The report draws on extant research on FASD in New Zealand to highlight the negative impact of these gaps on families and argues that alongside the emotional, health and practical costs to individuals’ families, these gaps are likely to increase to the financial costs of FASD due to the duplication of ineffective but costly services and increase the likelihood of costly secondary disabilities (Alcohol Healthwatch 2007, p. 6). To this end, the paper argues that:

There is a proven cost effective benefit from investing in FASD prevention and early intervention at the individual and at the population level. Any preliminary cost involved with establishing better systems will be more than offset by the preventative and protective factors associated with awareness, diagnosis and interventions that help to prevent secondary disabilities and trans generational FASD. (Alcohol Healthwatch 2007, p. 8)
The briefing paper outlines a number of recommended actions to meet the needs of FASD in New Zealand and address gaps in service provision. Amongst these include recommendations around prevention of FASD. Alcohol Healthwatch, whose primary role is situated in the field of prevention puts forward a number of suggestions targeted at different levels of prevention. Primary prevention initiatives cited included projects such as evidence-based awareness campaigns, alcohol and pregnancy information dissemination and the provision of the MOH guidelines on alcohol consumption during pregnancy by health providers. It also recommended screening for women around alcohol use using appropriate tools and referral to a drug and alcohol service if needed. Secondary prevention measures included routine screening of pregnant women for alcohol and other drug use by lead maternity carers and ensuring that alcohol and drug services had adequate knowledge and resourcing to assess and provide services for women. Tertiary prevention strategies included the incorporation of evaluated and successful Maternal–Child programs into existing DHB’s and recognition “that not all women who abuse alcohol during pregnancy will fit diagnostic criteria for alcohol use disorder but that they require intervention to reduce the risk of FASD in current and subsequent pregnancies” (Alcohol Healthwatch 2007, p. 10).

However whilst the report asserts these initiatives as essential, it also emphasizes that prevention must be “carried out in an ethical manner” (Alcohol Healthwatch 2007, p. 10) which includes appropriate multi-systemic service provision to meet the needs of referrals. It conceptualizes FASD prevention on a continuum which ethically must also include access to appropriate diagnosis and intervention services, arguing that “there is sufficient international evidence, effective models and strategic policy for New Zealand to develop its own specific policy guidelines and cost effective action plan” and that “FASD must become a government priority” (Alcohol Healthwatch 2007, p. 8).

**Women, alcohol and pregnancy**

A key area in this literature is the topic of women’s alcohol consumption, which has been documented in New Zealand research literature over the past two
decades or so (cf. Counsel et al. 1994, Watson & McDonald 1999, Habgood et al. 2001, Parackal et al. 2006, Ho & Jacquemard 2009). Habgood et al. (2001) noted a trend towards increasing levels of alcohol consumption amongst women, especially young women, and most of the other studies indicate generally high levels of alcohol consumption compared to other similar countries. A study by Mathew et al. (2001) indicated that a majority of teen pregnancies in New Zealand involve some level of alcohol consumption, and alcohol is assumed to be a widespread factor in many adult pregnancies as well (cf. Ho & Jacquemard 2009). Other research reveals that around a quarter of women of childbearing age reported consuming alcohol during pregnancy (McLeod 2002, Watson & McDonald 1999, Mathew S. et al. 2001).

Within this overall picture of consumption, binge drinking (defined here as at least four standard drinks in a sitting) is of particular relevance to FASD because of the accentuated adverse effects that instances of high alcohol consumption can have on the developing fetus. In their 2006 study, Parackal et al. revealed that around one fifth of the women who responded to their national survey reported binge drinking during pregnancy, mostly before realizing that they were pregnant. This combination of high levels of alcohol consumption, combined with the likely contribution of alcohol to instances of unplanned pregnancy, is a cause of concern in New Zealand.

Other studies have dealt with particular aspects of this topic. For example, Keriata Stuart’s research (2009) approached Māori women’s alcohol use in pregnancy as a specific topic. This research was located within a social context shaped by gender role expectations and knowledge about alcohol and pregnancy (2009, p. 3), which considered the impact of colonization on Māori attitudes and responses to alcohol.

Alternatively, a 2009 project concerning warning labels on alcohol containers revealed that the “Introduction of a warning label on alcohol containers in New Zealand may be effective in increasing awareness of the risks associated with alcohol consumption in pregnancy amongst at risk drinkers” (Parackal, Parackal & Harraway 2010, p. 302). Another research project, which surveyed non-pregnant
women aged 16–40, found that over half of the women rated warning labels on alcohol containers highly as a source of information regarding alcohol consumption during pregnancy. Further, that younger women (under 30) were more likely to rate this method of information highly, which is significant given findings from other New Zealand research that found that women under the age of twenty-five were more likely to drink heavily during pregnancy (Watson & McDonald 1999). The researchers cautioned that warning labels on alcohol containers constituted but one part of the information-raising process and that prevention of alcohol-exposed pregnancies also required other complimentary approaches targeting behavioural change.

**Birth mothers and individuals with FASD**

The research that has been conducted with birth mothers and individuals affected by FASD reveals a more intimate side of the discourse, and provides some perspective on how research and policy decisions actually play out for the people they affect. Jenny Salmon’s work with birth mothers (2008), for example, revealed that they faced a range of challenges parenting children with FASD. Many of these challenges were attributed to, or negatively impacted by, professionals’ understanding of FASD, as well as a lack of support and recognition of FASD within the health, allied health, social service, education and justice sectors.

Salmon’s research identified a number of key themes that influence the perception of birth mothers. The first, that ‘FASD is the mother’s fault’, revealed that the mothers in the study overwhelmingly felt responsible for their child’s disability, though this did not mean that all experienced guilt. Many talked about consuming alcohol prior to knowing they were pregnant with a few linking ineffective birth control with binge drinking. All talked about their lack of knowledge of the FASD and the potential harmful effects of prenatal alcohol consumption.

A second theme, ‘Medical and Health Professionals Abandon the Mothers” (Salmon 2008, p. e201), revealed that mothers felt unsupported by professionals who were not able to explain the presentation of the child or provide services to meet their needs. In some cases they felt actively discriminated against by professionals who
“tended to view them judgmentally and with a somewhat negative attitude” (Salmon 2008, p. e201). Salmon’s research reported that mothers seek diagnosis for their children (Salmon 2008, p. e202), however all of the women in her study found it very difficult to gain a diagnosis for their child and felt they were constantly fighting the system, creating much frustration. When mothers did gain a diagnosis they often felt relieved “because as well as knowing what was actually wrong with the child, it also made sense of confusing behaviours they had observed and had thought were the consequences of their own poor mothering skills” (Salmon 2008, p. e202). Despite the challenges related to gaining acknowledgement and support from professionals, the research highlighted that mothers developed their own ways to ‘cope’. This included understanding and making accommodations for their children, developing practical tools to assist their child (such as wall-hanging charts to aid memory and keep structure), and advocating for their child with professionals.

Mothers in this research felt particularly unsupported by the education system, claiming that programs, facilities and teachers were unable to meet their child’s needs which created stress and frustration and as a result of this their children had “suffered a disrupted school experience” (Salmon 2008, p. e203). Similar to experiences with professionals in other systems, mothers felt like they were not listened to, or “viewed negatively and without empathy by school teachers” (Salmon 2008, p. e203), and were perceived to be a burden on the education system. The mothers reported that teachers knew little about FASD, their children were given schoolwork that they could not complete, were excluded from classrooms because their frustrations lead to challenging behaviours, and as a consequence their children were labelled as "lazy, naughty, spoilt and dumb” (Salmon 2008, p. e203) instead of getting the support they needed. Children also faced social challenges within school settings because they found it difficult to make and maintain friendships and often made friends with younger children.

Extant research into the experiences of individuals affected by FASD by Jenny Salmon and Stephen Buetow (2012) paints a grim picture of their life experiences in New Zealand. It is unclear whether the strengths and achievements of the
individuals in this research are absent because they did not reflect on them, were not asked about them, or whether the research sought to express a deficit discourse which aimed to highlight the challenges of FASD without identifying the success and strengths of the individuals. Whatever the reason, their research revealed significant problems for those living with FASD, including problems fitting in at school or in the workplace (2012, p. 44), a range of memory and mental health issues (2012, p. 45), experiences of social exclusion, and 'run-ins' with the legal system.

According to Salmon and Buetow, many of the reactions to these experiences related to “experiences of failure, marginalization, oppression and violence” (2012, p. 45) and impacted negatively on the participant’s lives including their family, education, employment, social relationships and had in some cases resulted in or contributed to the loss of custody of their children. Within the area of mental health, Salmon also noted that drug and alcohol use presented a problem for many participants and attributed alcohol to being both the “cause and consequence of mental ill-health” (2012, p. 45). Most of the participants in Salmon’s research reported that they had been in trouble with the law with many voicing their dislike for authority.

Overall, participants reported feeling “under-supported by the social/health systems” (Salmon & Buetow 2012, p. 41) and attributed a number of their negative experiences and challenges to a lack of support and recognition of FASD amongst health and Social Service professionals. Salmon & Buetow report that overall the participants “struggled to survive and maintain a decent quality of life within a society where they have felt misunderstood, stigmatized, oppressed and different or defiant” (Salmon & Buetow 2012, p. 48).

This research points to some of the ways in which the concerns raised in the research findings could begin to be addressed. Suggestions from participants include supporting people in the workplace and home, and employment options that meet their needs, such as “quiet environments and slow-paced work with people trained and knowledgeable in FASD” (Salmon & Buetow 2012, p. 47). Other
suggestions from Salmon & Buetow include the development of policy and fostering increased awareness of FASD by professionals. They conclude that “understanding what individuals with FASD struggle with and what they look like from a clinical perspective is essential in helping clinicians diagnose and treat them and alleviate some of their more debilitating behaviour” (Salmon & Buetow 2012, p. 48).

**Knowledge, attitudes and perceptions**

Research into the knowledge, attitudes and practice of health professionals with regard to alcohol use in pregnancy and FASD stem as far back as 1995 when Leversha & Marks (1995) undertook the first survey regarding knowledge, attitudes and practice around alcohol and pregnancy with paediatricians and obstetricians. This study, which drew from the results of a questionnaire that was distributed randomly to practitioners throughout New Zealand, found that while doctors in New Zealand believed alcohol to be an important health issue their attitudes did not reflect their reported clinical practice. The study found that only half of the participants routinely asked and advised their patients about the risks of alcohol consumption in pregnancy in the first antenatal contact despite their overall agreement that they had some responsibility for conveying information regarding alcohol use in pregnancy. And further, that professionals provided inconsistent and varied recommendations to patients regarding alcohol use during pregnancy with only just under half recommending abstinence. One reason for this was that the doctors felt ill prepared to impart this information. Doctors also felt that the awareness of the risks of alcohol consumption during pregnancy amongst the general public was poor. Leversha & Marks (1995) concluded that confusion is caused amongst professionals and the general public alike because of inconsistent advice about alcohol use in pregnancy. They called for improved education regarding alcohol use in pregnancy both in the general public and within the medical profession and for clear guidelines with a consistent message on alcohol consumption and pregnancy to be developed and delivered nationally (Leversha & Marks 1995).
More recent New Zealand studies have found that health professionals have generally inconsistent practices in how they respond to or address alcohol consumption. For some, it is a non-issue, while for others it is something they might only bring up in obvious cases of alcoholism and alcohol addiction. Wouldes’ 2009 survey, for example, revealed that only seven per cent of health professionals used any form of standard questionnaire to pick up on alcohol use in their clients, and less than a quarter of them were able to fully identify the four main criteria for FAS diagnosis. A majority of the respondents signalled a desire for greater training on the risks of prenatal alcohol exposure, but even more of them saw training for other drug use as being more important (Wouldes 2009). The information available to health practitioners on prenatal alcohol consumption is also inconsistent, as revealed in an international study in which only a quarter of obstetric training textbooks recommended no alcohol intake for pregnant mothers (Sarkar 2002). Thus, even information derived from professional and scholarly sources has the potential to conflict with the New Zealand Ministry of Health’s own guidelines, which recommend zero alcohol intake.

FASD and the law
FASD is increasingly being documented in broader discussions of alcohol-related risk and harm in New Zealand, particularly in relation to law and justice. For example, a 2009 Law Commission review identified FASD as a specific issue in New Zealand (New Zealand Law Commission 2009, p. 82). Juvenile justice has been a field of particular engagement with FASD, spearheaded by the interest and intellectual investment of individual magistrates, especially New Zealand’s principal youth court judge, Judge Beecroft, and Auckland General/Family and Youth Court judge, Judge Fitzgerald. In 2011, Dunedin judge Stephen O’Driscoll, wrote an article for the New Zealand Law Journal in which he outlined FASD and its relevance within the New Zealand criminal justice system (O’Driscoll 2011). In this article, he points to a number of reasons why individuals with FASD are likely to come to attention of the court, and observes that the characteristics of FASD are frequently present amongst youth defendants. O’Driscoll considers youth court principles and sentencing decisions that may be relevant to FASD, and laments that “FASD is a serious and debilitating disorder yet it has received little recognition in
the youth justice and criminal justice system in New Zealand” (2011, p. 120). He attributes this to a lack of understanding and knowledge of FASD within the health and legal community, including a lack of funding for diagnostic and support services. In his conclusion, O’Driscoll highlights growing knowledge and interest of FASD within the Justice community internationally, arguing that New Zealand must keep up to date with developments in FASD diagnosis and treatment (2011, p. 120). The issue is gaining traction in this arena, with at least one further FASD-related article in 2012 (Wishart 2012).

Meanwhile, a recent Honours thesis in Law (Thom 2012) draws on international literature to explain the implications of FASD within the New Zealand criminal justice system. In this thesis, Thom postulates that “Individuals with FASD are over-represented yet under-detected in justice populations and New Zealand offers no specialized programmes to cater to their unique needs” (2012, p. i). This is despite what Thom terms ‘the fated relationship’ between FASD and the criminal justice system. Thom asserts that cognitive, social and behavioural impairments can place individuals with FASD at heightened risk of coming in contact with the justice system, and that this, coupled with a lack of understanding and recognition of FASD in the field, can result in misunderstandings such as misinterpreting neurological deficits as bad behaviour, non compliance, and aggression. She also identifies areas of concern for those involved in the justice field dealing with FASD including suggestibility and the risk of false confessions and questions how FASD fits within discussions and conclusions related to fitness to stand trial.

Thom’s dissertation provides a further example of how the knowledge and practice of professionals from varied sectors intersects when it comes to FASD. Amongst her recommendations regarding FASD in the New Zealand Justice system is the importance of improving diagnostic capacity for FASD. She argues that this must be nationwide and points to the success of a pilot project for diagnosis (which itself constituted a major part of the fieldwork of my thesis) as an example of a program that has helped build capacity for diagnosis in New Zealand. Her other recommendations relate to education and awareness, which includes FASD training for those in the field of Justice, and identification, which includes
prevalence studies of FASD within both the Justice and general population, as well as screening and improving diagnostic capacity as mentioned above. She recommends changes in the approach of justice professionals toward individuals with FASD, including recommendations for appropriate police interviews and strategies within the courtroom, as well as sentencing considerations for defendants with FASD. Finally, she draws on international examples of services within the justice system to advocate for specialized programs or initiatives, which include “wrap-around services, whereby an individual’s family works together with various government and community-based agencies to provide support and act as an “external brain” (Thom 2012, p. 54).

Conclusion
Back in 1996, in one of the first articles on FASD in New Zealand, Rosemary Marks, a paediatrician from Auckland, wrote:

This is not just an issue of educating women. Women whose partners, family and friends are supportive of their abstinence will be much more likely to remain abstinent than those who are constantly pressured to drink. Our whole community needs to know about FAS and to support women to avoid alcohol in pregnancy. (Marks 1996, p.13)

Concerns around creating stigma for women with affected children is one of several ongoing concerns in the field of FASD and in the general health community. This sentiment is not new as Marks (1996) noted that though it is important that women are able to make informed choices about alcohol use in pregnancy, health professionals have found it difficult to advise women not to drink alcohol during pregnancy because of concern for making women anxious about their drinking. However she argued that, “Women who have drunk during pregnancy are extraordinarily anxious five years down the track when they have a child with a developmental problem. Quite rightly they ask ‘Why didn’t somebody tell me that I should stop drinking alcohol when I was pregnant?’” (Marks 1996, p. 12).
This important concern is, however, just one piece of the puzzle. To date, there has been no research in New Zealand regarding the development of intervention or management of FASD, despite the repeated acknowledgement, from Marks in 1996 onward, of the need for a multi-systemic, multidisciplinary approach to FASD.

Furthermore, the research that does exist tends to articulate a deficit discourse concerning FASD, framing the disorder almost entirely in terms of the problems it causes and the problems that lead to its appearance in the first place. As Chasnoff has noted:

One great deterrent to progress is that even the most sophisticated of modern studies continue to be conducted from a deficit perspective. Research studies of children affected by prenatal exposure to alcohol and illicit drugs tend to determine, first, how exposed children differ from the rest of us, only to define those differences as the cause of any problems we find in the children. Programs are set up to correct the differences. However, this kind of deficit approach allows us to ignore factors that are not under the lens of investigation such as poverty, homelessness, and poor access to health care. A narrow focus on 'differences' also provides government agencies with an excuse to neglect serious attempts towards more long-term comprehensive solutions. (Chasnoff, 2010, p. 13)

Such discourses do little for the needs of people trying to cope, often in less than ideal circumstances, with the ramifications of FASD. However, as the law and justice literature reveals, there are people working within these systems who are becoming increasingly cognizant of FASD as a contributing factor to law and order problems. Likewise, researchers and professionals from a number of health and social service contexts are beginning to achieve some traction in getting their services to take FASD more seriously – a process assisted enormously by the activities of organizations such as Alcohol Healthwatch.

Overall, the extant literature on FASD is characterized by two factors. On the one hand, there is historical and persistent inconsistency in the nature of advice
available about FASD, and this impacts on how the disorder is understood, appreciated and managed in health and social service systems. On the other hand, however, there are increasing numbers of researchers willing to question and problematize systemic reactions to FASD, and they have achieved some headway in doing so.
Chapter 4: Conceiving FASD

The purpose of this chapter is to provide a theoretical context for understanding the conceptual complexities of FASD. It does so by setting up a model that presents the two main conceptual positions of FASD – as a biomedical condition, and as a social condition. The biomedical-social dyad is a longstanding trope of applied medical anthropology, and this chapter attempts an FASD-specific rendering of how this duality affects practice in this particular field. It is the disjuncture or slippage between social and medical responses to FASD that most often contributes to confusion or uncertainty about how to approach the condition, and therefore impacts upon the work of those who are engaged in this field. Resolving these issues requires synergy between both fields of discourse, and Thomas Kuhn’s (2012) construct of the paradigm shift is employed here to express how this might occur. My own professional position (as a social worker and counsellor) is relevant to this discussion in so far as it reveals the starting point for my framework. This said, the theoretical framework is also influenced by the experiences, comments and reflections of professionals from medical and social practice domains who participated in this research and whose stories and insights I cover in the following three chapters.

In the first section, the positionality of health and allied health professionals is considered in relation to the dominant theoretical positions underpinning current practice, particularly the trend towards evidence-based practice (EBP) and its alternatives. I examine the role of evidence-based practice as a potentially positive force in clarifying aspects of FASD and removing some of the mystery and stigma that surrounds the condition, however in doing so I also point out that the EBP movement has its own ideologies and while offering opportunity for better-informed treatment techniques, it has a tendency to devalue individually tailored treatments. I then consider alternative theoretical frameworks for working with FASD, some of which stem from my own prior training in social work. I end this section of the discussion by suggesting that the complexity of the ‘clinical encounter’, in which a range of professionals across multiple health, social, and education sectors are implicated, needs to be sensitive to the strengths that
cooperative work brings and employ approaches from a range of theoretical and practical stances, including EBP, but also those that draw from practice knowledge and professional experience.

In the second section, the discussion surrounding the subjectivity of the individual has gendered resonances, as this discussion frequently revolves around women in relation to notions of risk, control, stigma and blame. The construct of risk is theorized in terms of the individualization of medical intervention and the conceptualization of pregnant embodiment. I have anchored the discussion in this section around the two bodies of work that comprehensively approach the issue of female subjectivity: firstly, sociologist Deborah Lupton’s work (especially 2012, 1999) which considers notions of pregnancy and risk and, secondly, Elizabeth Armstrong’s controversial book, Conceiving Risk Bearing Responsibility (2003), concerning the construction of FASD as a medical and social issue. Lupton critiques pregnancy and its construction from a sociological standpoint, and Armstrong specifically critiques the construction of FASD. Both authors raise important considerations for understanding FASD that are rarely clearly articulated in discussions within practice or clinical contexts, with the exception of the influential work of Diane Malbin (2011) and Dorothy Badry (2009), whom I draw on later in this chapter, and in some literature in the field of FASD prevention (cf. Greaves & Poole 2004). To better contextualise this discussion, I also refer to New Zealand academic Peter Beatson's (2004) conceptualization of disability and its social, biomedical, political and identity meanings as they apply to the FASD context.

These two sections are then related to a Kuhnian discourse of scientific revolution, in which the construct of ‘paradigm shift’ is presented as an integral part of scientific progress, and the chapter concludes by positing that the field of FASD research is itself undergoing such a shift, or perhaps even multiple simultaneous shifts, as it becomes a more consolidated area of study. This discussion ultimately serves as a theoretical underscore for the ethnographic data presented later in the thesis, in which shifting and occasionally contradictory stances and experiences are articulated and problematized.
Part 1: FASD and public health

Like most public health concerns, FASD engages professionals across sectors and systems, and is therefore subject to different understandings through divergent approaches to and priorities within professional practice. This is the case in all of the (predominantly) Anglophone countries in which FASD is acknowledged, despite the differences in health care provision from country to country. While these differences should not be ignored, approaches to FASD have been fairly consistent from country to country, with similar barriers in each system, and it is therefore instructive to draw on references from a range of different contexts in order to understand the contextualization of FASD in public health.

Internationally, FASD is mainly researched within medical and clinical frameworks, and professionals from medical and allied health sectors have often advocated for an evidence-based practice approach to the condition because of the generally accepted reliability of EBP in medical research. This is also reflected in FASD literature reviews by health researchers (cf. Elliot et al. 2008, Premji et al 2006), where an evidence-based approach is often espoused, and where much is made of the lack of research into interventions for FASD. However, EBP is not the only approach to working with FASD, and research and practices that draw from paradigms alternative to EBP are commonly employed in practice in the field of FASD based on my own observations of treatment settings in three countries (New Zealand, Canada and Australia) and have occasionally been articulated in the literature. This tension between EBP and other approaches is a factor in the conceptualization of FASD.

The following section seeks to define EBP and some of its perceived benefits to the field of FASD whilst also considering its limitations and critiques. It demonstrates that while clinical research based in quantitative, positivist paradigms provides useful information for consideration, alternative research and theoretical frameworks (such as those employed in my own field of social work) also offer useful ways of considering and engaging with FASD. It also demonstrates that the polarization of epistemological frameworks provides barriers to understanding
and engaging with FASD effectively. In the conclusion of the thesis, I argue that these barriers must be overcome in order to engage with FASD appropriately using a multidisciplinary approach.

**Evidence-based practice**

Evidence-based medicine, or evidence-based practice (EBP), is an approach that has gained increasing support in the biomedical sciences over the last fifteen years and is considered by many as essential to appropriate and justified clinical practice (Parsonson 2012, p. 98). Where FAS is concerned, EBP has some application in so far as clinical measures for some aspects of FASD diagnosis do indeed exist, however, this is not the case for all of the disorders on the spectrum. While there is significant scientific evidence to demonstrate the teratogenic effect of alcohol on the fetus, a key concern voiced by some professionals in the field of FASD is that ‘good quality’ data to support evidence-based clinical practice in FASD is lacking, especially in the area of intervention (Bertrand et al. 2009, Bohjanen et al. 2009, Premji et al. 2006). As Jacquelyn Bertrand notes, for example, the absence of evidence-based information concerning both the condition and its management leads some clinicians to refuse FASD diagnosis (Bertrand et al. 2009 p. 987). Where FASD is concerned, an EBP approach therefore has clear detriments that may, in many cases, outweigh its benefits.

Evidence-based medicine seeks to apply clinical research evidence to decision making in clinical practice. In doing so, it favours measures that are scientifically grounded and recent. It is based within a positivist paradigm that espouses objectivity, and which values quantitative research methods such as clinical randomized control trials, double blinded and cohort studies, and single case experimentation (Webb 2006). It is generally considered that these measures provide the most reliable information for the optimum management of patients (Sackett et al. 1996). According to Sackett (et al.) evidence-based medicine is grounded in five related ideas: the availability of scientific evidence, a focus on the clinical problem over work habits or protocols, the integration of biostatistical and epidemiological evidence into clinical thinking, the practical application of

These ideas revolve around the goal of improving the quality of medical care through the standardization of practice, which has “typically been implemented through clinical guidelines, protocols, or best practices, all of which are used to standardize not individualize patient care” (Hasnain-Wynia 2006, p. 1). The claimed benefits of EBP are regarded by its advocates as falling into five key areas. According to its advocates, EBP provides a common, systematic basis for clinicians’ objective experiences, has efficiency dividends and decreases ineffective clinical practices, provides more reliable information for patients, and provides a firm foundation for the development of health care policies (Hasnain-Wynia 2006, p. 2). The widespread current acceptance of EBP across health and allied health fields means that what is considered by many in the field as ‘good’ management for FASD is often limited by what can and cannot be measured. This creates problems for FASD intervention strategies in the New Zealand context, as there is simply not enough evidence available to be able to apply EBP to FASD intervention.

Critiques of EBP

While it is generally accepted that EBP can provide important information for supporting and improving professional practice, there is a growing body of research and literature that highlights the drawbacks of EBP. Criticisms are frequently based on four main limitations: the non-consideration of individual health practitioners’ expertise and intuition; EBP’s debatable claims to objectivity; EBP’s contribution to social decontextualization of complex clinical and social problems; and EBP’s capacity to overshadow viable alternatives. I now consider each of these criticisms in more detail.

First, the perceived objectivity of EBP does not accord with the fact that clinical decision making requires individual expertise, and that this is often encountered in highly trained and skilled individuals, not the systems or structures that they inhabit. Indeed, many writers on professional medical practice describe good clinical practice as an art, or an attribute at least requiring some degree of
intuition, professional judgement or artistry. Jan Fook (1996), for example, stresses the role of intuition in clinical practice, acknowledging the ability of intuitive practitioners to make connections between a patient’s experiences where such connections might not otherwise be apparent, which “reaffirms the artistry of professional practice involved in the ability to make judgements to act in situations which are often unpredictable, complex, changing and uncontrollable” (Fook 1996, p. 4).

Even where EBP is advocated in research, it is sometimes accompanied by acknowledgements of the intangibilities of medical practice. As Felicity Goodyear-Smith notes, while EBP helps inform best practice in general, it does not cater to the specific needs, beliefs, conditions or expectations of individual clients, therefore “general practice will always be an inexact science as well as an art, and quality of care also relies on excellent communication skills and truly informed decision-making” (Goodyear-Smith 2012, p. 91). Even highly quantified processes such as medical diagnosis are at some level subject to the individual practitioners’ interpretation and clinical judgement.

Second, one of the perceived benefits of EBP in the case of FASD is an underlying assumption that EBP is objective and neutral and that this goes some way to removing some of the more stigmatizing constructions of FASD. However, scholars who draw on alternative theories and practices (such as critical theory) question the perceived objectivity of EBP and value-free research, suggesting that this is more perception than reality (Blair and Robertson 2005, p. 270). Third, an emerging critique of EBP is that it is not client-centred, and therefore lacks consideration of broader issues that inform practice. EBP assumes that practice is decontextualized from these broader issues (Webb 2001, p. 76), which is problematic given the complexity of many individual and family presentations. Webb, a social worker, argues that EBP provides an unsatisfactory, deterministic version of the client’s situation, based on contrived, controlled environments and optimal behaviours or reactions. He instead advocates a heuristic model for decision making which is indeterminate and reflexive, arguing that social workers
..."engage in reflexive understanding and not a determinate or certainty based decision-making process based on objective evidence" (Webb 2001, p. 57).

As Blair and Robertson suggest, EBP is problematic because of the way it separates proof from understanding, raising epistemological concerns about the ways in which the perceived objectivity of evidence can overshadow the complexities and discontinuities of lived experience (2005, p. 270). Meanwhile, medical professional Tricia Greenhalgh argues that best practice is not just a matter of following rules and guidelines, but also a matter of being able to decide which of these rules is most relevant to the specific practice context – a factor she claims to be under-acknowledged in EBP discourses (Greenhalgh 2012, p. 95–96).

Fourth, as a dominant epistemological standpoint from which to view FASD, EBP has a tendency to devalue alternative ideologies, especially qualitative types of research and critically reflexive and reflective practices based on practice-based evidence, and to regard these types of practices and knowledge as inferior. Blair and Robertson argue that intuition is downgraded as an element of practice simply by individuals aspiring to do ‘good’ practice based on ‘hard’ evidence (Blair and Robertson 2005, p. 270). Greenhalgh posits that medical professionals need to learn from other disciplines to overcome these challenges in order to release medicine from “a paradigm that has gone beyond its terms of reference and is beginning to do damage” (Greenhalgh 2012, p. 97). As Blair and Robertson observe, this ascendance of EBP “perpetuates a dominant discourse concerning methods of inquiry and the nature of knowledge, which serves to separate rather than unite theory and practice” (Blair and Robertson 2005, p.270).

**Complementary practices and critical practice alternatives to EBP**

While EBP provides important information for clinicians working with FASD to consider, there are a range of alternative research paradigms, practice methods and ideologies that make an important contribution to understanding the complex diagnosis of FASD, which is situated in and impacted by the individual, family, social, cultural, moral contexts as well as the biomedical context. This is especially true of many of the practices derived from social work, a discipline that has
traditionally rejected EBP in favour of theoretical frameworks grounded in criticaleflexive and reflective practice. In considering individual situations and the social,
moral and systemic frameworks within which they sit, social workers draw from
‘evidence’ derived from both quantitative and qualitative research to inform their
practice, but this constitutes but one part of their decision making and engagement
process.

The foundation of critical practice is that it values knowledge from diverse sources
and encompasses “critical social theory, quantitative and qualitative research, tacit
knowledge, critical reflective practice, social justice values and consumer based
knowledge” (Pease 2009, p. 195). Thus critical practice considers a range of
approaches to a particular problem, critically reviewing examining and reflecting
on varied perspectives and options before deciding on the best practice and
“reviewing different perspectives and options before deciding on ‘best practice”
‘critical’ is used here to refer to open-minded, reflective approaches that take
account of different perspectives, experiences and assumptions” (Glaister 2008, p.
8).

Critical theory employs judgment and reasoning in the attempt to improve practice
by allowing greater reflexivity for individual problem posing and problem solving
(Blair and Robertson 2005, p.270). As Glaister attests, “What is required
increasingly is a capacity to handle uncertainty and change, as well as being able to
operate in accordance with professional skills and knowledge” (Glaister 2008, p.
8). Glaister describes three essential components of critical practice: critical
analysis, critical action and critical reflexivity. In her description, ‘critical analysis’
entails acceptance of multiple possible perspectives on an issue and the evaluation
of the knowledge leading to these perspectives, whereas ‘critical action’ entails the
addressing of structural disadvantage and power inequalities in service provision.
Critical reflexivity, meanwhile, requires that practitioners recognize the
assumptions and perspectives that they themselves bring to practice, in order to
effectively communicate and negotiate with clients (Glaister 2008, p.12). These
components also intersect with the socio-political and ideological constructs surrounding both practitioner and client (Glaister 2008, p. 17).

In the FASD context, there are three types of critical practice that are particularly applicable to work in this field: reflective practice, reflexive practice and evidence-informed practice. Reflective practice, for example, seeks to engage professionals with the context within which their practice is located and to consider all of the possible avenues of action or explanations of the issues they confront in their work. As Jan Fook asserts, competing perspectives can be involved in the interpretation of the practice situation, and these need to be understood (Fook 1996, p. 4). Reflective practice is especially important given the social context within which FASD sits as discussed above.

Fook describes reflective practice as a means to engage with a holistic mode of work, one that focuses not just on objectified problems or conditions but on wider-frame contextual issues. She asserts that a reflective approach is needed in order to recognize that realities are merely constructions, built out of the participants’ shared understanding of and mutual participation in the situation (Fook 1996, p. 5). Ultimately, Fook positions this approach in opposition to positivist practice paradigms, rejecting technical or scientific approaches because of how they seek to understand and control problems by separating and compartmentalizing them into segregated specialist areas (Fook 1996, p. 5). The reflective approach advocated by Fook therefore allows for a more holistic and complex understanding of complex social phenomena, blurring arbitrary boundaries and allowing for the possibility of multiple categories of understanding (Fook 1996, p. 5).

Reflexive practice, which is often confused with reflective practice, takes reflection a step further to the consideration the practitioner’s own self-awareness and how their personal views and experiences might impact on their practice (Blair and Robertson 2005, p. 270). Webb considers the scope of reflexive practice to also include the social system and the individual’s roles within it (Webb 2006, p. 36). This is of particular importance to the field of FASD because of the potential for
practitioners’ own experiences and views about alcohol consumption in society to impact on how we view and work with the issue in our professional lives.

The concept of 'evidence-informed practice' is in some respects a critical practice-oriented attempt to bridge the disjuncture between critical practice and EBP. Despite the common use of the critical theory in interventions, evidence-based practice concepts ultimately do influence practice in the allied health and social service fields. According to Webb this is largely because it appeals to management and policy makers who consider EBP as a measureable and thus easy way to evaluate service outputs (Webb 2006, p. 6-7). However, many social care agencies have preferred to use terms such as "research minded practice, evidence informed decision making or more vaguely evidence influenced practice" (Webb 2006, p. 15) in order to recognize that the use of research-based evidence is important, but that it constitutes just one part of the practice experience. Instead of EBP, Nevo & Slonim-Neho (2011) advocate for Evidence informed practice (EIP), where “Practitioners are encouraged to be knowledgeable about findings coming from all types of studies and to use them in their work in an integrative manner, taking into consideration clinical experience and judgments, client’s preferences and values and the context of intervention” (Nevo & Slonim-Neho 2011, p. 1193). They argue that this process brings the professional practice closer to the needs of the individual client, allowing for greater flexibility and creativity in treatment in order to meet the ongoing experiences and challenges faced by the individual and the practitioners alike (2011, p. 1194).

They also argue for an interpretative view of evidence that considers qualitative evidence alongside practice-based evidence and is therefore “less restricted by a hierarchy of evidence in which RCT’s [randomized controlled trials] are placed on top and qualitative inquiries are at the bottom” (Nevo & Slonim-Neho 2011, p. 1,193). Another way of framing this is to acknowledge that, rather than a hierarchy of evidence, what is needed is a wide knowledge base and broad clinical experience, which can be applied to practice in a sensitive way that is aware of the client’s experience (Nevo & Slonim-Neho 2011, p. 1195). Nevo & Slonim-Neho conclude by advocating for balanced approaches to professional practice, asking
for evidence to be viewed in balance with other factors, especially the contextual knowledge that can be gained from dialogical engagement with other practitioners (Nevo & Slonim-Neevo 2011, p. 1195).

While many of the epistemological standpoints discussed above seem to be at odds with each other, in order to engage effectively in the field of FASD, which requires a multidisciplinary multi-system approach, one must consider how to view and overcome the polarizing effects of these competing discourses. Blair and Robertson provide a useful framework for overcoming this polarization. By utilizing the terms proposed by Snowball (1999) of ‘hard complexities’ to describe the quantitative positivist approaches to practice and ‘soft complexities’ to describe the qualitative, interpretative and humanist approaches to practice, they provide a conceptual pathway for viewing ‘hard’ and ‘soft’ factors as component parts in the overall, holistic case, rather than as opposing or competing positions. They argue that this creates “…a repertoire for the discerning health care professional to draw upon with the accompanying caveat that each epistemological position is rooted in wider political discourses” (Blair and Robertson 2005, p. 275).

The dichotomy above is not unique to FASD, however the importance of considering and analysing these standpoints in the case of FASD is based in the complex individual, societal and practice framework where FASD sits. Ultimately, as Goodyear-Smith observes, “The overall message is that there are many forms of evidence that inform our practice” (Goodyear-Smith 2012, p. 91). Blair and Robertson (2005) suggest that critical interpretive practices such as reflective and reflexive practice (ie. ‘soft complexities’ or ‘soft data’) offer useful alternatives or complementary paradigms to EBP for engaging and understanding the field of occupational therapy where the value system is directed by a client-centred approach, focusing on enablement and empowerment. Glaister (2008) also supports this view, asserting that this allows for practice to be conceptualized as part of a generative process of theorizing and building evidence bases. As she states, this does not mean denying the important role of evidence in established thinking, but rather recognizing the evolutionary nature of professional practice:
“Professional practice is rooted in theories and keeping up with the latest research evidence will continue to be important. It is more like the adage, ‘the more you know, the more you know what you don’t know’” (Glaister 2008, p. 14). In other words, knowledge requires engagement with the unknown in order to evolve. This pragmatic stance is inherently beneficial to the field of FASD, where it is necessary for professionals from different disciplines with different ontological and epistemological standpoints to work together.

**Part 2: The social context for FASD**

While the bulk of extant FASD research is primarily framed within medical research contexts, FASD is a complex condition that cannot be considered in isolation from the sociocultural context in which it is entangled, and any social or cultural research into a topic such as FASD must address at some point the very uneven moral terrain over which a diagnosis such as FASD must travel. In other words, a consideration of what Blair and Robertson (2005, p.275) term the ‘wider political discourses’ that frame epistemological debates about EBM for FASD must include questions surrounding alcoholism, women’s lifestyles, children’s futures, families’ experiences and the construct of ‘good parenting’. These topics all contribute to moral claims-making about FASD internationally, and link the issue to other core elements of contemporary social discourse. These issues are particularly important to consider in New Zealand where awareness and approaches to FASD in professional and personal contexts are currently expanding and increasing.

In the FASD literature, FASD is constructed as a gendered social issue in which women (and, to a lesser extent, children) are frequently the subjects of theoretical discourses, and in which men are largely absent. These discourses tend to focus on notions of risk, on a continuum stretching from the individualization of FASD as a medical risk on the one hand, to the construction of FASD as social risk on the other. Any position on this continuum has gendered implications that problematize FASD. This is because risk in this context is presented as being related to the individual choices of women about alcohol consumption, the ways in which women’s choices (social, personal or otherwise) are controlled by others,
and the degree to which women’s choices can be considered to be supported by education, and the reliability of this information. However, as I argue below, this creeping individualization of risk is potentially misleading when it ignores the social and discursive contexts surrounding the individual.

**Risk and the individual**

The consideration of risk within health service contexts often revolves around attempts to educate and guide clients towards positive outcomes and mitigate negative outcomes, however this also entails elements of social control that deserve unpacking. According to Lupton, the period of pregnancy can be perceived as a time of great risk, for the fetus and for the mother. Increasingly women are expected to strictly monitor their bodies and control their lifestyles throughout pregnancy to ensure the best possible outcome for their fetus and decrease the risk associated with pregnancy (Lupton 2012, p. 330). (Examples of this increased personal monitoring includes caffeine intake, weight gain through pregnancy, the consumption of certain dairy and seafood, and the inhalation of garden compost). Perceptions as to what constitutes best care in pregnancy are often determined within medicalized contexts with an increasing shift to the neo-liberal medicalization of pregnancy in which pregnant women are expected to monitor their own adherence to the body techniques and self-management dictated at a distance by the medical or midwifery gaze. Women are thus surveilled and measured via scans, blood tests, etc., in order to minimize risk and maximize positive outcomes of pregnancy.

Lupton argues that, in recent times, “the fetus has become fetishized as a precious body to the exclusion of the pregnant woman’s needs and rights” (Lupton 2012, p. 1) and thus, pregnant women are under strong pressure to conform to normalized social and medical expectations of how to behave during pregnancy. Armstrong also considers this notion in her own US-based research with health professionals, and suggests that “doctors’ perceptions of risk and responsibility – both their own and [that of] their patients’ – varied according to their speciality” (Armstrong 2003, p. 154). In other words, the type of patient doctors feel responsible for influences their approach to their practice. Where a paediatrician might talk about
the ‘baby’, an obstetrician might refer to the ‘fetus’, and both might view the woman in different ways, depending on their perspective.

Who ‘we’ perceive to be our clients, how ‘we’ conceptualize FASD, and how ‘we’ act to prevent it, impacts on how we engage with it. According to Armstrong (2003, p. 215) FASD must be considered within a broader social-cultural paradigm:

Is the disorder we diagnose as fetal alcohol syndrome caused by exposure to alcohol in utero, or is it caused by poverty, social distress, and the deeply rooted inequity of American society? Simply identifying individual behavior as the primary vehicle of risk negates the fact that behavior is shaped by powerful currents – cultural, psychological, as well as biological processes – not all immediately within the control of the individual. Behaviors such as cigarette smoking are sociocultural phenomena, not merely individual, or necessarily rational. (Armstrong 2003, p. 215)

In this discourse, women are often presented as passive subjects lacking agency whether for lack of information, lack of education, or at the mercy of social norms about alcohol consumption in Western society. A counter source of agency, however, has been the advocacy of these same women such that many of the advances in FASD research, prevention, diagnosis and intervention have been the direct results of the actions of mothers of FASD-affected children. A further complication in the discourse of risk is that writing concerning the social construction of pregnancy and birth tends to be either mother-centred or fetus/infant-centred, but not both. Iris Marion Young has provided compelling descriptions of the complex and uneasy dyadic relationship between mother and fetus in her work (Young 1984), however little FASD research has considered mother and fetus as a unit. Armstrong has referred to this tendency as ‘maternal–fetal conflict’: “...predicated on the notion that the pregnant woman and the fetus are divisible; that as divisible and thus separate entities, they have individual as opposed to mutual interest, and that, furthermore, those individual interests may be in opposition to each other” (2003, p. 198). From Young’s perspective, however, the complexity of the fetal/mother dyad is that it is both conflicting and unifying
and that this relationship is extremely fluid, varying throughout pregnancy (Young 1984).

Much of the discourse surrounding women and risk also relates to the area of prevention because a prominent aspect of FASD in public discourse is that it is a condition that is (in theory at least) totally preventable. The argument is based on the logic that if pregnant women abstain from alcohol consumption, then FASD is an impossibility. However, this position fails to take into account the social complexities of alcohol as a normalized aspect of Western social life, and can have unintentional consequences in implying blame and producing stigma. I discuss these issues in more detail below.

**The individual in isolation**

As previously noted, both Lupton (1999) and Armstrong (2003) believe that there has been an increasing individualization in the perception of risk. Whilst on one hand women are given increasing choices in their pregnancy thanks to the development of technology (for example, discovering the gender of the fetus), Armstrong argues that technology has, on the other hand, made it “conceptually possible to think of the pregnant woman and the fetus as separate entities, thus setting the stage for the emergence of maternal–fetal conflict” (Armstrong 2003, p. 196). Increasingly, technology allows the fetus to be perceived as a patient in its own right. If women deviate from the suggested medical recommendations to minimize risk and this results in negative outcomes, they may therefore be seen as impacting on the health and wellbeing of another entity and transgressing their ‘reproductive citizenship’ responsibilities.

The concept of ‘reproductive citizenship’ was proposed by Ruth Lister (1998) in an article dealing with a range of different types of marginalized citizenship. For women, Lister argues that “their ability to act as citizens in the public sphere continues to be constrained by their responsibilities in the private, with

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4 See, for example, the advice given by the American Pregnancy Association: http://americanpregnancy.org/pregnancycomplications/fetalalcohol.html; or even this extract form the official magazine of the American Academy of Pediatrics: http://aapnews.aappublications.org/content/32/3/26.extract.
implications too for the rights they enjoy as citizens (1998, p. 7). The reproductive act figures within this paradigm because of the manner in which childbearing is idealized in society as a kind of civic duty for women. Bryan Turner (2001) provides further useful comment on this construct, and Lupton applies the concept to the realm of FASD as follows:

The concept of ‘reproductive citizenship’... denotes this emphasis on self-regulation in the context of a neoliberal political environment in which individuals are required to take personal responsibility for their actions, and in the case of pregnant women or mothers, for the health and well being of their children. (Lupton 2012, p. 336)

Thus, the trend towards individualization in medical treatment for pregnancy can lead to confusion in social outcomes, as Lupton asserts, pregnancy blurs corporeal boundaries as it is difficult to determine where the maternal body ends and the fetal body begins (Lupton 2012, p. 333).

In response to this, Prout (2000) offers a social construction of embodiment, viewing bodies as 'hybrid entities' constituted and reconstituted via social interactions. The strength of this approach to embodiment is its acknowledgement not only that bodies are inter-embodied, or experienced through interactions with other human bodies, but are also constructed and experienced via encounters and relationships with non-human actors such as material objects, including medical technologies.

Over the past half-century, biomedical technologies have become increasingly prominent in the monitoring of pregnancies (Lupton 2012, p. 334). While fetal imaging is currently not used during pregnancy to diagnose for FASD, its use in science has had a significant impact on the medical understanding of the condition. Lupton argues that these visualizing technologies have led to a disruption of “traditional concepts of ‘inside’ and ‘outside’ the pregnant women’s body” (Lupton 2012, p. 334) resulting in the fetus being "represented as a social actor in its own right" (2012, p. 334). Armstrong extends this idea to argue that: “What we are
witnessing is not only the ascendance of a paradigm of maternal–fetal conflict but also an extension of childhood as a social and biological state, an extension backward into the womb.” (Armstrong 2003, p. 21). These comments reflect a wider body of discourse on the increasing visuality of the thesis due to the uptake of ultrasound imaging for pregnancy initiated by Hartouni (1997) and Stabile (1998) in the 1990s in which they argued that the capacity to represent the fetus as single object unobscured by the flesh and body of the woman whose womb contained the fetus was of fundamental importance in the prioritizing of fetal ‘rights’ by the US anti-abortion lobby.

A key concern in the conceptualization of maternal–fetal conflict and individualizing the cause of FASD to the mother is that it can lead to practices in the field that are punitive rather than preventative, and punish women rather than support and assist them and their families. In justifying this, Armstrong (2003) notes that maternal–fetal conflict has been a foundation for criminal prosecutions historically and that it also influences thinking about prenatal alcohol consumption: “we conceive of harm occurring solely to the “innocent” fetus, perpetuated by a mother who is ignorant, selfish or remiss” (2003, p. 198) effectively equating prenatal alcohol consumption to a form of child abuse. This opens the door to the consideration of punitive consequences, such as incarceration, rather than focusing on social service provision. The problem that this leads to, as Dorothy Badry notes, is that women may not report alcohol consumption or other illicit substance use out of fear of criminal persecution (Badry 2009, p. 49).

The end result of all this is that individualization can lead to ineffective health and wellbeing outcomes for people with FASD and their families, and can indeed cause greater harm, especially if mothers are at risk of prosecution for contravening their ‘reproductive citizenship’ while indulging in behaviours that are otherwise condoned and celebrated by Western society. Not only does this create unequal impact for women, it also creates a barrier to considering collective social responsibility for the aetiology of FASD, with the potential for public attention to be diverted away from investigations of social inequity and instead directed
towards a trope of individual responsibility, a blaming process that “privileges private morality over public justice” (Armstrong 2003, p. 188).

The individual in context
The discourses of individualization, risk and responsibility entered into by Armstrong, Lupton and their contemporaries revolve around issues that are effectively related to prevention, or lack of prevention, warning, transgression and consequence. Nevertheless, these issues are highly relevant to diagnosis and intervention because of the ways in which they inform the views and actions of professionals in these fields. They do, however, lack an important connecting factor, which is the critical understanding of the discursive contextualization of individuals affected by FASD, and their families.

Three particular areas in which a critique of prevailing discourses can be perceived are those relating to symbolism and language, imagery, and the construction of disability. A commonality of these three areas, in relation to FASD, is the deficit discourse that pervades them (briefly discussed at the conclusion of the preceding chapter). One reason for the perseverance of this deficit discourse is that, in studies of children affected by illicit substances, ‘differences’ are framed as the causes of children’s problems (Chasnoff 2010, p. 12). Another possible reason is that, in the attempt to attract funding, resources and support for families and individuals with FASD, researchers, professionals and in some cases families have emphasized the negative side of the outcomes of prenatal exposure to alcohol and the adverse outcomes that result in a lack of investment in health and services to support those with FASD. Third, the conceptualization of FASD as a medical condition needing treatment can have the unintended effect of emphasizing deficits, which in turn minimizes consideration of the individual as a whole, including their strengths and positive attributes. It can also lack consideration of the social context that scaffolds their experiences in the world and the perceptions of others.

A deficit-based perspective impacts upon the manner in which professionals engage with FASD and the programs developed to address it. It also has a
significant impact with regard to how affected individuals view themselves and others view them. Chasnoff argues that, when children with FASD are conceptualized in terms of their deficits, interventions tend to revolve around the attempts to ‘correct’ their differences (Chasnoff 2010, p. 12). This contributes to the individualization of FASD because it ignores or downplays other factors, such as poverty, in the overall picture. A focus on deficits or ‘difference’ redirects government services towards individualized services, and away from considering the broader social and moral and political context within which services need to operate.

Visual imagery plays a role in this discourse. Where image is concerned, common icons of FASD-related print media include the fetus in a glass or bottle, or images of the torso of a pregnant woman with a glass or bottle in her hand (sometimes also accompanied by a cigarette). Variations of this image adorn book covers, posters, pamphlets, beverage labels and so on. It is assumed that this visual construction of FASD and the risks of alcohol consumption during pregnancy act as a deterrent to consuming alcohol during pregnancy, though research suggests that this may not actually be the case (cf. Elliot et al. 2008, p.8–9, 53). Less consideration is provided as to how these images may impact women who have already consumed alcohol during pregnancy, who feel unable to stop consuming alcohol during pregnancy, who have had a child with FASD, or how they may impact those who have a diagnosis on the spectrum, or even on public perceptions of birth parents and children.

Similar criticisms can be made about the widespread ideological discourse (mentioned earlier in this chapter) that FASD is completely preventable: that if only women abstained from drinking alcohol during pregnancy that FASD would not occur. As Badry notes:

Fetal alcohol spectrum disorder, in contemporary Western society, has become overtly represented as a moralized disability. As such, the evolution of a prevailing discourse, grounded in the bio-medical definition of FASD, that suggests if only women refrain, by choice, from alcohol use during
pregnancy, then FASD will cease to exist. Discourse on prevention suggests if pregnant women do not refrain from alcohol, then these mothers-to-be must be held responsible – ethically, socially, morally, medically, politically – for any alcohol-related difficulties the child experiences. (Badry 2009, p. 49)

Terminology is a further crucial factor in ameliorating the stigma and blame associated with individualization, and the deficit discourse that surrounds this. For example, describing individuals with FASD as ‘victims’, or birth mothers as ‘abusers’ of alcohol reinforces a negative perspective that has the potential to subliminally permeate professional practice. However, as Badry advocates, the deliberate selection of more neutral, less emotionally loaded or even positive terminologies can pay dividends in the domain of intervention. For example, stigma and blame can be reduced by substituting ‘prenatal alcohol exposure’ or ‘alcohol exposure in utero’ for ‘prenatal substance abuse’, with the added benefit of not positioning the mother in opposition to the service system (Badry 2009, p. 48).

The power of semantics is not lost on parent contributors to FASD literature internationally. Book titles such as Fantastic Antoine Succeeds (cf. Kleinfeld & Wescott 2001) exemplify the deliberate advocacy of a positive perspective.

Another example of reframing deficits is provided in Peter Beatson’s discussion of disability. Beatson defines disability as: “A disadvantage experienced by a person as the result of the interaction between ...[an] impairment on one hand and physical barriers, institutional structures, social policies and cultural attitudes on another” (Beatson 2004, p. 41). Beatson’s work is particularly useful because he makes clear the difference between impairment, as “a simple objective biological phenomenon” and disability as “a complex social and cultural” phenomenon (2004, p. 34).

According to Beatson, there are four dimensions of disability. First, disability is often (but not always) based on a medical condition. Second disability always includes impairment which he defines as constituting a sort of loss or abnormality that inhibits the individual’s ability to participate normally and actively in society
(Beatson 2004, p. 23). Third, disability is the disadvantage that individuals with impairments experience as a result of interactions with their sociocultural environment. And finally disability is a characteristic of identity similar to other characteristics such as gender, ethnicity, or social class. Beatson highlights that whilst disability is based on the presence of impairment and commonly associated with social and structural inequality and disadvantage “it is not in itself a cause for negative self image” (2004, p. 41). Indeed, he argues, some may take pride in this characteristic and others may consider it as a ‘matter of fact’.

By employing this construct it is easy to consider FASD as a disability. FASD is considered a medical condition. Individuals with FASD have brain-based impairments, often alongside other physical and psychological impairments that affect their ability engage and participate in social and community life. They also live within a sociocultural context that lacks understanding of their impairment, often problematizes them and maintains barriers that impact on their ability participate positively in community life.

By identifying impairment as but one part of disability, Beatson shifts the discourse away from the conceptualization of disability as an individualized issue related to functional deficits, to one that considers the individual as a whole, and how the sociocultural framework within which we all operate minimizes and/or maximizes individual’s opportunities to be active participants in social and cultural life. This is important because:

If we regard disability solely as a bodily or psychological loss or abnormality, we will be led to devote all our time, energy, ingenuity and resources on impaired individuals themselves... [and in this way] disability becomes something to be fixed. (Beatson 2004, p. 35)

Contextualizing the individual’s experience allows us to consider how the social construction of disability can create and contribute to the disadvantage of those with impairments. Beatson asserts that the experience of life with a disability can be impacted by the sociocultural context as much as the impairment, arguing that:
The negative features of disability may stem from disabling physical barriers, institutional structures, social policies and community attitudes. If these were altered or removed, impairment would still remain but many of the negative features of disability would evaporate. (Beatson 2004, p. 35)

By considering disability in a context that encompasses the dimensions espoused by Beatson we can begin to understand the disability aspects of living with FASD in a more nuanced manner and develop ways to minimize disadvantage and increase opportunities for positive engagement in community life.

In arguing this, I am not stating that consideration of the sociocultural context is absent from the field of FASD, but just acknowledging a tendency in the field for birth mothers and children to be considered from an individualized perspective. This means that the question of how the individual fits, or does not, fit within expectations created by the sociocultural context within which we live, is privileged over any consideration of how the sociocultural context ‘makes up’ or frames our perceptions of the individual and limits their ability to participate in community in the first place. Indeed, as Beatson (2004, p. x) observes, a functional deficit definition of disability assumes “…an impairment that can be clearly and unambiguously located in the body or mind of the individual. It does not recognize that the root of the problem may lie not in the biological organism but in cultural definitions of normality and deviance”. This perpetuates “the tendency to blame disability on individual deficits rather than on the social and cultural environment which aggravates and at the limit actually causes them” (ibid, p. 39). It is on the basis of the preceding discussion that I would argue that an analysis of FASD that places it in a context which considers social, moral and political factors alongside impairment and individual circumstances is required in order to minimize issues of stigma and blame that engender prejudice.

**Part 3: From disjuncture to paradigm shift**

FASD is both an accepted and contested medical and social condition, with an associated array of discourses for each of these domains, ranging from individual
to collective responses to risk on the one hand, and EBP to critical practice on the other. As the discussion of ‘evidence-informed practice’ reveals, however, the greatest potential for resolving the disjuncture apparent in these axes of aetiology is where middle-ground positions are pursued that acknowledge both the social-medical duality of FASD and the potential benefits that can be derived from each side of the domain of practice. This constant conceptual repositioning can be understood in terms of Thomas Kuhn’s theoretical framework of scientific revolutions, in which he provides the useful concept of the ‘paradigm shift’ (Kuhn 2012).

Kuhn, a scientific philosopher, developed a theoretical framework for understanding/explaining the process and progress of scientific discoveries that challenged positivist perceptions of scientific discovery. Essentially, Kuhn theorized that advancement in science is not a simple linear process of discovering ‘the truth’ but instead is a messier and more complex process of the development of knowledge. He postulated that scientific knowledge is created through the discovery and development of new findings that challenge the status quo. These findings progress knowledge away from less adequate conceptions of the condition or idea, until enough evidence or pressure is presented to move the new ideas/conceptions forward past scepticism and resistance, to an acceptance of the new scientific achievement/discovery. Thus the history and development of scientific ideas is not just a catalogue of discovery but a complex and ever changing process of discovery, resistance and acceptance. Whilst Kuhn’s theoretical framework related to scientific discoveries, it can equally be applied to discoveries such as FASD (where research and practice application span science, medicine and social domains).

In order to understand Kuhn it is useful to explain his theory of ‘scientific revolutions’ in his own terms. Kuhn’s revolutionary sequence begins with ‘normal science’. Normal science is “research firmly based upon one or more past scientific achievements, achievements that some particular scientific community acknowledges for a time as supplying the foundation for its further practice” (Kuhn 2012, p. 10). Within normal science, scientists ‘puzzle solve’ to extend knowledge,
based on the facts and theories that have been established within a scientific paradigm (the contemporary meaning of ‘paradigm’ as a set of concepts, thought patterns or models, was derived from Kuhn). Kuhn describes a ‘paradigm’ as achievements that were “sufficiently unprecedented to attract an enduring group of adherents away from competing modes of scientific activity” but were simultaneously “sufficiently open-ended to leave all sorts of problems for the redefined group of practitioners to resolve” (Kuhn 2012, p. 10). A paradigm is the result of a previous scientific revolution and provides the basic framework for normal science’s problem solving to occur. Researchers who share paradigms are “committed to the same rules and standards for scientific practice” (Kuhn 2012, p. 11) and through their work extend the knowledge within the paradigm by “increasing the extent of the match between those facts [already articulated in the paradigm] and the paradigm’s predictions, and by further articulation of the paradigm itself” (Kuhn 2012, p. 24). According to Kuhn this is where most science takes place, and it is “predicated on the assumption that the scientific community knows what the world is like” (Kuhn 2012, p. 5).

However, every now and then, an unexpected discovery eventuates that does not fit within the confines of the paradigm. Kuhn terms these discoveries ‘anomalies’. According to Kuhn, normal science often “suppresses fundamental novelties because they are necessarily subversive of its basic commitments” (Kuhn 2012, p. 4), thus when anomalies arise they create tension within the bounds of normal science, resulting in a period of ‘crisis’. The new discovery is often perceived as controversial and thus often faces resistance. During this period “the profession can no longer evade anomalies that subvert the existing tradition of scientific practice - then begin the extraordinary investigations that lead the profession at last to a new set of commitments, a new basis for the practice of science” (Kuhn 2012, p. 6). “To be accepted as a paradigm, a theory must seem better than its competitors, but it need not, and in fact, never does, explain all the facts with which it can be confronted” (Kuhn 2012, p. 18). If this happens a scientific revolution results in which a new paradigm is created, which “implies a new and more rigid definition of the field. Those unwilling or unable to accommodate their work to it
must proceed in isolation or attach themselves to some other group” (Kuhn 2012, p. 18).

The process described by Kuhn in relation to the evolution of science maps very easily onto the field of FASD research. As a relatively recently identified field, and one with multiple facets that defy easy compartmentalization, FASD research is simultaneously establishing bases of operation and investigating new practice paradigms. Deconstructing and navigating the competing medical, moral, social and political discourses around FASD is no easy feat. In order to do so, one must also deconstruct and navigate competing discourses to develop ways to talk about, understand and address FASD that are helpful and useful to those affected, without demeaning of the complexity of the positions that they are in. Failing to consider the complex socio-political construction of FASD, could result in the stigmatization of women and those affected, however deconstructing such issues without a commitment to addressing them and improving professional practice can place FASD too easily in the ‘too hard’ basket.

**Conclusion**

In order to address FASD effectively, its multifaceted nature as both a social and medical concern must be taken into consideration at every level. It is imperative that FASD be considered as a health issue, just as much as its social context requires critical examination, and dealing with FASD professionally must involve multidisciplinary, cross-systems approaches. Within these professional approaches, one must consider a range of variables that are specific to FASD as well as those specific to the individual and the family. The paradigm shift required, therefore, is one that allows the highly individualized context of medical need to be incorporated as an element within the sociocultural context that defined that need. In the next three chapters I introduce the three varied arenas in which the press of a paradigm shift is being experienced.
Chapter 5: International models for FASD diagnosis and intervention

The process of developing diagnosis and intervention practices for FASD in New Zealand has necessarily involved extensive reference to and interaction with ‘best practice’ (or ‘promising practice’) models established internationally, usually in countries where there is a longer history of FASD awareness. This chapter discusses these international models, with the aim of establishing a clear background to the current diagnosis and intervention work that is the subject of this thesis. The chapter draws on international literature, information gleaned from interviews with research participants in New Zealand, interviews and other informal discussions with leading international FASD experts, and information gathered from my own participant-observation in training activities offered through some of the international services discussed herein. While this chapter draws on a range of international sources, much of the information presented comes from Canada; a country with well-established services for FASD, and the location in which I have conducted most of my participant-observation research outside of the New Zealand context.

This chapter is divided into two sections. The first section focuses on FASD diagnosis and will give the reader an overview of the development and complexity of FASD diagnosis practice internationally. As I am not a trained diagnostian, it is not appropriate for me to engage with the technicalities of diagnostic practice, but I do outline the diagnostic tools and guidelines that are most commonly used in FASD diagnosis and what some of the main critiques of them are. Within this, I explain what a multidisciplinary approach to FASD diagnosis involves and why it is desirable and considered best practice internationally. This discussion is illustrated by a key practice example of multidisciplinary team diagnosis practice as it is done at the Asante Centre for FAS in Canada. The second section provides an overview of the different types of intervention for FASD currently employed in practice or currently being investigated through research internationally, and suggests pathways forward to developing an intervention response to FASD in
New Zealand. It focuses on the work of American social worker Diane Malbin, who created an influential theoretical framework for engaging with FASD, and examines the application of this framework in the context of a successful intervention program, the Key Worker Program, also in Canada.

Part 1: International practice in FASD diagnosis
FASD presents a range of challenges for diagnosticians. As discussed previously, the manifestations of adverse outcomes of prenatal alcohol exposure may be determined by many factors, including the dose, timing and frequency of alcohol exposure, genetics, epigenetics, maternal diet, as well as environmental factors both pre and postnatal that are not specific to the alcohol exposure but may affect the presentation. In clinical practice there is no universal diagnostic tool or test for FASD (Andrew 2009) and, internationally, FASD diagnosis is complicated by the existence of different models of diagnostic criteria (Peadon et al. 2009). In the absence of an agreed set of diagnostic guidelines, diagnostic methods, reporting, and outcomes vary from country to country and even clinic to clinic. According to Susan Astley, the potential for diagnostic misclassification from a clinical perspective “leads to inappropriate patient care, increased risk for secondary disabilities and missed opportunities for primary prevention” (Astley, 2011, p. 3–4). The lack of consensus on diagnostic guidelines also has a negative impact on clinical data collection for FASD, which impacts upon the reporting of clinically diagnosed incidence and research concerning clinical features (Peadon 2009, Astley 2011). These issues, in turn, negatively impact the allocation of sufficient resourcing and funding for health, allied health education, social and community services and “preclude accurate assessment of primary prevention intervention efforts” (Astley 2011, p. 4).

There are currently five different sets of diagnostic guidelines for FASD diagnosis employed in clinics worldwide: The US Institute of Medicine (IOM) guidelines, the University of Washington (UW) four digit diagnostic code (Astley 2011), Eugene Hoyme's clarification of the 1996 IOM criteria (Hoyme et al. 2005), the US Centers for Disease Control (CDC) Referral and Diagnostic Guidelines and the Canadian
guidelines for FASD diagnosis. Whilst there are some similarities, each set of guidelines has variations in their criteria for diagnosis and in their nomenclature.

The Institute of Medicine guidelines
The American Institute of Medicine (IOM) guidelines for diagnosis, published in 1996, were the first set of diagnostic guidelines to be produced for FASD. They were the result of growing recognition of the seriousness of the issues surrounding FASD in the USA in the 1990s, resulting in the US congress mandating that the IOM of the National Academy of Sciences undertake a study of FAS and related effects. In 1996, the IOM published their report on FASD, which drew from research and discussions by a range of experts in the field on FASD epidemiology, diagnosis, prevention and treatment (Stratton, Howe & Battaglia 1996). As a part of this, the IOM evaluated the existing evidence and diagnostic criteria in order to develop “the best possible diagnostic guidelines reflective of current knowledge” (Astley 2011, p. 4). The IOM guidelines outline five diagnostic categories and their criteria, which range from FAS with confirmed maternal alcohol exposure through to alcohol-related neurodevelopmental disorder, depending on the severity of the condition and the level of evidence available.

<table>
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<tr>
<th>Category</th>
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<tr>
<td>1) FAS with confirmed maternal alcohol exposure</td>
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<td>2) FAS without confirmed maternal alcohol exposure</td>
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<tr>
<td>3) Partial FASD with confirmed maternal alcohol exposure</td>
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<tr>
<td>4) Alcohol-related birth defects</td>
</tr>
<tr>
<td>5) Alcohol-related neurodevelopmental disorder</td>
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Figure 3: The IOM Categories for FAS Diagnosis

The guidelines made a significant contribution to FASD diagnosis, however they were “intentionally broad and conceptual...rather than specific and operational” (Astley 2011, p. 4). While the IOM guidelines are not commonly used in practice today, all of the other guidelines have built on them in some way, aiming to develop FASD diagnosis in ways that were more applicable clinically.
Diagnostic guide for assessing fetal alcohol spectrum disorders: The 4-Digit Diagnostic Code

The 4-Digit Diagnostic Code was the first diagnostic guideline to build on the IOM’s work on FASD. It was developed by epidemiologist Susan Astley and paediatrician Sterling Clarren in consultation with experts from the University of Washington FASD diagnostic and Prevention Network (FAS DPN) in 1997, and has been updated three times, most recently in 2004 (Astley 2004). As well as drawing from the clinical expertise of those who developed it, the 4-Digit Diagnostic Code was based on clinical records of over 2,000 patients diagnosed through the FASD DPN network.

The 4-Digit Diagnostic Code is a comprehensive set of FASD diagnostic guidelines developed to standardize the diagnosis of FASD by providing specific, objective, quantitative scales to measure and report the expression of FASD diagnostic features across the spectrum. It aims to improve the precision and accuracy of the diagnosis in clinical practice with clearly defined diagnostic criteria across the spectrum (Astley 2004, p. 4). The key to the code is its 4-digit system of classification which rates the magnitude of expression of the four key diagnostic features of FASD: growth deficiency, the FASD facial phenotype, Central Nervous System function and prenatal alcohol exposure, on a four-point scale. A ‘one’ on the scale reflects a complete absence of the FASD feature and a ‘four’ reflects a strong presence of the FAS feature. Thus, individuals rated on the code as 1111 show no features of FASD whilst those with ratings of 4444 (severe growth deficiency, all three FAS facial features, neurological and structural evidence of CNS damage and confirmation of high levels of prenatal alcohol exposure) reflect the most severe expression of the disorder, fetal alcohol syndrome (Astley 2004, p. 4). All of the scale combinations in the 4-digit code have been observed by professionals in the Washington State FAS Diagnostic and Prevention Network.

As well as the four key diagnostic features, other pre and post natal risk factors are recorded and taken into account in deriving a diagnosis. An important area of difference between the 4-Digit Diagnostic Code and other diagnostic tools is that the code nomenclature separates evidence and exposure. That is, the code does not
use the terms ‘Alcohol related’ in any of its diagnosis. Astley argues that the terms Alcohol Related Neurodevelopmental Disorder and Alcohol Related Birth Defects used in other diagnostic tools draw a causal link between PAE and growth deficiency and CNS damage/dysfunction which is currently not able to be substantiated in research. She argues that growth deficiency and CNS damage are not exclusive to FASD, so unless the individual presents with the FAS or PFAS facial phenotype which is specific to FASD, one cannot conclude that the aetiology is PAE. Instead, the 4-Digit Diagnostic Code reports the diagnosis of disorders separately to the evidence of exposure to alcohol. The aim of including the term ‘alcohol exposed’ in the diagnosis is to alert clinicians that the individual was exposed to a teratogen and thus underlying brain damage may have a role to play in their presentation. This approach makes the 4-Digit Diagnostic Code quite complex, however, with twenty-two diagnostic categories in total (Astley 2004, p. 59).

Independent of the code as a whole, the 4-digit diagnostic has made two important contributions to the field of FASD diagnosis: first the four digit system of classification of the magnitude of expression of the four key features and, second, a pictorial lip/philtrum guide (see Hoyme et al. 2005, p. 42) that was developed to accurately and objectively assess the facial features of FAS. These tools were integrated into some of the other diagnostic guidelines or employed independently regardless of the guideline employed (Hoyme et al. 2005). While there are debates around whether the lip/philtrum guide can be universally adapted to diverse ethnic groups and disagreement on what constitutes dysfunction within each of the four digit rankings, overall both of these tools are viewed as a positive contribution to objective measurements of facial features and dysfunction and have been adopted in varying degrees in the other guidelines.

**CDC guidelines for fetal alcohol syndrome referral and diagnosis**

The *Fetal Alcohol Syndrome: Guidelines for referral and diagnosis* (CDC 2009, Bertrand et al. 2004) was developed for the American Centers for Disease Control (CDC), through their National Center on Birth Defects and Developmental Disabilities, following a congressional mandate in 2002. This act by US Congress reflected the extent to which FAS and FASD were being treated as serious health
concerns at the time, and funding was provided to help develop referral and diagnostic frameworks that would make health service engagement with FASD more systematic and sophisticated.

The framework developed by the CDC includes diagnostic criteria for FAS but not the rest of the spectrum. It also includes guides for differential diagnosis, age-specific intervention guides, guides for screening and for early intervention. The development of the guide led to greater awareness of the need for interdisciplinary communication on the health sectors, for expanding services to meet the needs of children and adults, and for increasing public awareness of FASD (Bertrand et al. 2009).

‘Hoyme’s guidelines’
A Practical Clinical Approach to Diagnosis of Fetal Alcohol Spectrum Disorders: Clarification of the 1996 Institute of Medicine Criteria is a set of diagnostic guidelines published in 2005 by Hoyme (et al.), developed to clarify the 1996 IOM criteria and to “facilitate their practical application in clinical paediatric practice” (Hoyme et al. 2005, p. 39). Colloquially referred to as ‘Hoyme’s guidelines’, Hoyme and colleagues evaluated 1,500 children as a part of various research projects in the USA and South Africa and identified 164 children with a potential FASD diagnosis. These cases, in addition to animal-based research and the authors’ clinical expertise, were combined to develop specific criteria that clarify the IOM’s FASD diagnostic categories. Possible diagnoses using this model defined in the guideline include: FAS with confirmed maternal alcohol exposure, FAS without confirmed alcohol exposure, Partial FASD with and without confirmed alcohol exposure, ARBD and ARND.

Hoyme’s guidelines emphasize that FASD must be a diagnosis of exclusion. He argues that FASD shares common characteristics with many genetic and malformation syndromes and that a thorough medical and genetic assessment must rule these out prior to a diagnosis on the fetal alcohol spectrum of disorders.
The ‘Canadian guidelines’ for FASD
The ‘Canadian guidelines for diagnosis’ for FASD (Chudley et al. 2005) were published in 2005 with the aim of reaching an agreement on a standard for FASD diagnosis in Canada. The guidelines were developed in consultation with leading experts in the field from Canada and the USA who reviewed and analysed alternative guidelines and approaches to FASD diagnosis. The result was an integration or ‘harmonization’ of two of the approaches, the IOM and the UW. The Canadian guidelines recommend the use of the IOM’s terminology to describe the spectrum of FASD diagnosis and the approach of the 4-Digit Diagnostic Code to “describe, assess and measure objectively alcohol exposure, growth, facial features and brain damage” (Chudley et al. 2005, p.12). However their criteria for the diagnostic categories differ from both the IOM’s and UW’s definitions in some areas, which according to some of the New Zealand participants in this research, results in a more ‘robust’ and/or ‘conservative’ diagnosis.

Australian engagement with international diagnostic guidelines
The current state of investigation and health sector engagement with FASD in Australia is of interest to New Zealand and other countries currently developing a response to FASD, as the Australian research approach has involved attempts to canvass a wide scope of information about FASD practices internationally through surveys, and to then construct an Australian model based on the findings of these surveys. This approach differs to that undertaken in New Zealand, where information has been gleaned more through direct interpersonal contact with international collaborators than broad-based surveying. For example, in 2009, Australian researchers Elizabeth Peadon, Elizabeth Elliot and colleagues undertook a systematic worldwide review of FASD specialist diagnostic clinics and found that the clinics had different approaches to FASD assessment and used varied diagnostic tools (Peadon et al. 2009). This study was the first of its kind, and was useful because it identified the ways in which diagnostic guidelines were employed internationally, FASD clinics’ varied assessment and referral processes, staffing and expertise, staff specialist FASD training, funding, services offered and patient make up. One limitation was that the study focused only on specialist diagnostic clinics, thus excluded clinics that might include FASD diagnosis in their
remit but not as their specialty, such as generalist paediatric services and child development clinics.

In this study, the researchers identified thirty-four FASD clinics mostly in the USA but also in Canada, the UK, Italy, Chile and South Africa, through literature database searches and subsequent contact with organizations involved with FASD internationally. Data was gained through a survey process in the form of a questionnaire. Of the thirty-four clinics surveyed, fourteen used the Washington 4-Digit Diagnostic Code (Astley 2004), eight used Hoyme’s 2005 revision of the 1996 IOM criteria, and one used the 1996 IOM’s criteria. Eleven clinics used a combination of diagnostic criteria or an adaption of one of the published guidelines (Peadon et al. 2009, p. 6). While Peadon and colleagues noted that none of clinics used the CDC 2004 guidelines, they did not mention the Canadian harmonization in their study. One possible reason for this may be that the study design restricted the researchers’ engagement with Canadian clinics resulting in a “poor response rate from Canadian clinics where there is a large amount of clinical activity” (Peadon et al. 2009, p. 7).

This study reported that diagnoses were delivered in a variety of settings including in the community, in large centres, which in some cases provided outreach to smaller centres and, in one case, in a telemedicine service (Peadon et al. 2009, p. 7). The research demonstrated that there is strong practice support for a multidisciplinary team approach to diagnosis with thirty-three of the thirty-four clinics employing such an approach. Multidisciplinary team makeup varied in the inclusion of allied health professionals from various backgrounds, although all teams included a medical and a psychology professional. The research also emphasized high levels of specialist FASD training with two thirds of participant clinics reporting that specialist diagnostic training had been undertake by some staff members (Peadon et al. 2009).

The study concluded that there are a range of possible models for FASD diagnostic service provisions and criteria used for FASD diagnosis however strong support existed overall for a multidisciplinary approach to FASD where professionals are
trained in FASD diagnosis and assessment. They expressed concerns about the lack of agreement around FASD diagnostic criteria internationally, stating that this impacts on the ability of researchers and clinicians to compare clinical data on FASD and contributes to health professionals’ confusion around FASD diagnosis (Peadon et al. 2009, p. 7). They argued this is key issue that needs further attention and consideration by clinicians and researchers.

**Critiques, comparisons and commonalities**

While there have been disagreements and spoken critiques of the current guidelines there have been few written critiques published in international literature, and these critiques are generally restricted to key researchers noted above addressing each others’ sets of guidelines. All of the guidelines credit the initial work of the IOM in developing a response to FASD diagnosis. Each of the authors state that they have built on and developed the IOM’s work on FASD and in doing so provide critiques that had led to the development of their own guidelines. For example, Hoyme, Astley and Clarren, and Chudley were in agreement with each other that the IOM guidelines were too vague for clinical practice application. Hoyme believed that they did not adequately account for family and genetic history as influencing factors and that there was a poor clinical definition of ARBD and ARND. Astley disagrees with the diagnostic terms in the IOM guidelines, expressing particular concerns about ARND and ARBD, which are terms employed in both the Hoyme and Chudley in the Canadian harmonization, and indeed Astley argues that the diagnosis of ARND should be abandoned because currently medical technology and research is unable to exclude or confirm the etiological role of alcohol in cases where the facial phenotype is absent (Astley 2006, p. 1543).

One of the main criticisms of the 4-digit code raised by participants in my own research was that the diagnostic categories in the 4-digit code are too complex, impractical in a clinical setting, and challenging to explain to families. This is also the main criticism of the 4-Digit Diagnostic Code in international literature (Peadon et al. 2009, Hoyme et al. 2005), with Hoyme et al. stating “the myriad of diagnostic categories is confusing, and the system is impractical for routine use in clinical practice” (Hoyme et al. 2005, p. 41). The Canadian harmonization seeks to
mediate this issue by simplifying the diagnostic options to that of the IOM’s whilst employing the 4-digit code approach. However, by doing so the Canadian harmonization (and, indeed, Hoyme’s guidelines) has the potential to compromise the evidence base of the diagnosis by employing the diagnostic category of ARND.

Other disagreements exist about the extent to which non alcohol-related factors can be present in a 4-Digit Diagnostic Code diagnosis. Hoyme emphasizes the need for all FASD assessments to include a differential diagnosis arguing “there is the potential for over-diagnosis of alcohol-related disabilities; any child with a disability who has been exposed to alcohol prenatally can be assigned a diagnostic classification easily, even if the cause of the disability is genetic” (Hoyme et al. 2005, p. 41). However Astley argues that there is conclusive scientific evidence that a specific facial phenotype exists in cases of FAS and PFAS. Further as discussed previously, Astley (2011) argues that diagnosis other than FAS and PFAS must separate out evidence and exposure within diagnostic nomenclature to ensure children are not misdiagnosed. While all the authors agree on the four main types of dysfunctions present in FASD as outlined in the IOM’s guidelines (face, growth, CNS, and alcohol exposure) they disagree on what constitutes the degree of dysfunction or impairment at each diagnostic level. These and other disagreements on FASD diagnostic categories and criteria are discussed at greater length by Astley (2011).

While there are clearly different approaches when it comes to FASD diagnosis, there are also unified positions. The strongest and most persistent of these is the advocacy and support that exists for multidisciplinary diagnostic teams. An ‘interdisciplinary’ or ‘multidisciplinary’ approach to diagnosis is now considered best practice for FASD diagnosis internationally (Hoyme et al. 2005, Peadon et al. 2009), and most specialist teams operating internationally employ such a team approach (Peadon et al. 2009). The main benefit of a multidisciplinary team is that they bring in a range of professionals with the specific expertise needed to assess the different facets of FASD identified in the varied diagnostic tools. At a minimum, this necessitates the involvement of a medical specialist, to assess physical and facial features associated with FASD and rule out alternative diagnoses (such as
genetic disorders), and a psychologist or neuropsychologist to assess the extent of central nervous system damage through psychometric testing. Other professionals employed in multidisciplinary teams internationally include speech and language therapists, social workers, occupational therapists and clinical coordinators.

Multidisciplinary teams are employed in a range of settings internationally including hospitals, specialist FASD clinical services, community health services, child and adolescent mental health services and disability services. In some cases where a multidisciplinary team is not practical or available, Hoyme and colleagues argued that multidisciplinary team assessments can be completed by individual members with support from other services. Remote conference-calling medicine is another option available for providing multidisciplinary team diagnosis in rural and remote areas, as well as in areas where multidisciplinary teams are not available. While multidisciplinary teams are generally considered to be important by FASD practitioners internationally, there are differing views as to what constitutes a best practice multidisciplinary team model for FASD, and what the professional composition of the multidisciplinary team should be. This is an issue that was raised extensively in my own research, as is discussed later in Chapter ten.

**Key service example: The Asante Centre**

A key example of good multidisciplinary team diagnostic practice is the Asante Centre, a respected FASD specialist diagnostic centre in British Colombia, Canada. It is one of only a few FASD specialist diagnostic services worldwide, and employs leading Canadian FASD practitioners. The Centre employs a ‘best practice’ multidisciplinary team approach, utilizing the Canadian guidelines for diagnosis. The Centre provides an interesting model for approaching FASD because it not only undertakes specialist FASD diagnosis, but also provides training to local and international medical practitioners on FASD diagnosis, as well as range of FASD services and research on FASD.

Established in 2000, the Asante Centre (formally the Asante Centre for Fetal Alcohol Syndrome) is a non-profit organization that provides specialist services for
FASDs as well as other complex developmental disorders. The Centre was named after Dr Kwadwo Asante, a paediatrician and one of the founders in FASD diagnosis in Canada. The centre developed as a result of a the work of a grassroots community group called the FASD society for British Columbia who set out to educate the community about FASD, advocate for policy, funding and services for FASD, and provide support and advocacy for families. Many of its members had a family member with FASD.

The Asante Centre’s primary role is to provide diagnostic services, but it also provides a range of other services including family and community support, research projects, resource development, secondary consultancy to professionals, and education and training on all aspects of FASD including specialist diagnostic training for clinicians. It is primarily funded through the Canadian Ministry of Children and Family Development, but also receives funding related to its research projects, its training programs, as well as from sponsors and benefactors. The Asante Centre undertakes both private and government funded assessments. Its diagnostic team comprises of paediatricians, speech and language therapists, psychologists, clinical coordinators (social workers or nurses) and contracted occupational therapists. The centre is coordinated by management and administrative teams who also engage volunteers.

The Centre uses the Canadian guidelines for FASD diagnosis (Chudley et al. 2005) in their practice and their training. The FASD diagnostic training model offered by the Asante Centre includes information and education, observation of the FASD assessment process including multidisciplinary team meetings and clinical assessments undertaken by the Asante Centre staff, and practical opportunities for trainees to participate in clinical practice with the Asante Centre staff. It includes multidisciplinary team group components as well as individual clinical components relevant to the clinicians’ area of expertise. The training is typically undertaken over three days in residence at the Asante Centre, which has been set up as a clinic with teaching and training facilities such as cameras and recording equipment in each room to enable observation of the FASD assessment processes of each clinician.
The Asante Centre's training is based on an experiential learning model that includes information provision, observation and practice experience. A core component of the training is the observation and participation in an FASD assessment of two or three clients (with consent of the client and family) selected from amongst those referred to the Asante Centre for an FASD assessment. According to Asante Centre’s executive director, Audrey Salahab, the Asante Centre’s training aims to give clinicians a broad understanding of not only the clinical elements required to undertake FASD diagnosis but also a ‘concept of what it takes to develop a diagnostic clinic’. This includes examining the reasons why FASD diagnosis is important, the implications for clinical practice, looking at the ‘roll out’ of a clinic, and the particular jobs of each of the clinicians.

The training program follows these assessments in full – from the client’s first visit to the centre, to the final meeting with the client and family to discuss the outcome of the assessment and any diagnosis. The training is tailored to the needs of the trainees, although the experiential model is the same for each training session. In the case of the New Zealand trainees, the Centre’s model proved to be especially effective.

**Part 2: International approaches to intervention for FASD**

In the context of FASD, intervention is a difficult practice to define because the effects of the disorder itself can be difficult to perceive or predict. Furthermore, given the interdisciplinary context for much FASD treatment and the current disagreement from place to place concerning how FASD is diagnosed and perceived, intervention strategies can vary significantly. FASD interventions employed in practice draw on disparate methods and ideologies that reflect the complexity of the condition and the varied perspectives and skills of professionals who engage with it. Medical and allied health interventions for FASD can include pharmacological and clinical interventions which target specific neuropsychological or physical aspects of the condition, while other allied health and social service interventions commonly include environmental accommodations, the provision of FASD education, information, advocacy and
support to individuals affected with FASD and their families. Owing to the diversity of FASD presentation, many generic services within health and community services benefit those with FASD, as well as services in other fields (such as education, juvenile justice, or drug and alcohol counselling) which can make significant contributions to FASD intervention, but are not discussed within this thesis.

Perhaps the best way of understanding FASD intervention is to consider it to include any actions that seek to understand the individual and their functioning and as a result provide accommodations for and/or improve opportunities and outcomes for individuals affected, which prevent secondary disabilities, which support individuals and families. Interventions employed in practice with FASD may be grounded in research, based on practice knowledge and experience, drawn from the lived experiences with individuals and families affected and/or grounded in theoretical frameworks.

Unlike the relatively clear models available for FASD diagnosis, researchers generally acknowledge that FASD intervention to date has received insufficient attention (cf. Premji et al. 2006, p. 394). Much of the available research relates to animal-based scientific experiments, and a small amount of evidence-based clinical studies of health and allied health interventions. There is little literature that covers qualitative research in the field, evaluated intervention programs or promising practice approaches drawn from practice experience and knowledge. Three recent publications (all in the last five years) provide reviews of international research-based intervention for children and young people with FASD: Premji et al. (2006), Peadon et al. (2009), and Bohjanen et al. (2009). These reviews aimed to identify, and in some cases evaluate, evidence-based interventions for FASD encountered in research publications. All of these reviews have raised concerns about the limited quantity and quality of research available on FASD intervention.

Premji et al. (2006) serves as an example of the disjuncture between the extent of research currently being undertaken, and the applicability of this research to
actual intervention strategies. This team conducted a systematic review of international literature in order to identify evidence-based intervention strategies for children and youth (0–18 years) with FASD, and to identify areas for further study. Their criteria for inclusion included experimental and quasi-experimental human studies. Their literature search, which included peer-reviewed and ‘grey’ literature, identified 16,913 references. Of these, only 665 were considered potentially relevant, with only ten of these met their criteria for relevance, and just three of these ten meeting the criteria for the review. Of the remaining studies, four were excluded because they were case studies and three were not able to be accessed in the timeframe of the research. Overall, while acknowledging the limitations of only drawing on three sources (2006, p. 394), they concluded “there is limited scientific evidence upon which to draw recommendations regarding efficacious interventions for children and youth with a fetal alcohol spectrum disorder” (2006, p. 398) and argued for the urgent need for further research in this area. However, as argued in my previous chapter, another way of looking at this issue would be to critically examine the primacy of evidence-based practice in research of this nature.

**International intervention strategies**

Existing literature reveals that many different approaches have been brought to bear on intervention for FASD, some more effectively than others, as it is not always clear exactly what an individual’s specific areas of need might be. The three key studies reviewed by Premji et al. reflect this. The first investigated the application of Cognitive Control Therapy (Adnams, in Riley et al. 2003), which concluded that, though there was no significant differences in neuropsychological or intelligence tests after implementation of the therapy program, teachers, therapists and school reports anecdotally reported qualitative improvements with trends towards functionality of the children (Premji et al. 2006, p. 394). The other two were studies of pharmacological interventions (Oesterheld et al. 1998 and Snyder et al. 1997) which both indicated that stimulant medications may provide some benefit in cases of FASD.
The 2009 literature review by Peadon (et.al.) extended the range of intervention strategies to include physiotherapy, behavioural, speech, and occupational therapies, early intervention programs and psychosocial and educations interventions for children with FASD up to the age of eighteen. Their criteria for inclusion in the review initially included the use of randomized control trials (RCT) however because other published reviews had indicated that there were limited numbers of such research, quasi RCT, non randomized control trials and cohort studies with pre- and post-intervention measurements were also included (although animal studies were excluded).

Despite a large search that identified 6,263 studies, only twelve met their criteria to be included in the research. Of these twelve, two related to pharmacological interventions (Oesterheld et al. 1998, and Snyder et al. 1997) – the same two as in the earlier (Premji et al. 2006) review of literature. A further seven studies related to educational and learning strategies. Their review provided “some evidence to suggest that virtual reality training, cognitive control therapy, language and literacy therapy, mathematics intervention and rehearsal training for memory may be beneficial strategies” (Peadon 2009, p. 3). Further intervention strategies canvassed for the review included three studies of behaviour strategies (Vernescu, 2007) and social communication (eg. Timler et al. 2005) which “suggested that social skills training may improve social skills and behaviour at home and attention process training may improve attention” (Peadon et al. 2009, p. 3) for clients with FASD.

Between them, both Peadon et al. and Premji et al. indicate two characteristics common to international practice for FASD intervention: first, that a wide range of intervention strategies are being attempted, and second, that the research available on the effectiveness of these strategies is not sufficiently systematic or rigorous for an evidence-base of effectiveness to be ascertained at this stage (Peadon et al. 2009, p. 9). A third, more recent review by Bohjanen et al. (2009) reinforces the view that existing FASD intervention studies are unreliable or of limited applicability (2009, p. 37). However, these claims also illustrate the limitations inherent in a solely evidence-based approach to the topic of
...reducing vulnerabilities, modifying environmental stressors and increasing protective factors (Olson et al. 2001) such as a nurturing caregiving environment with a supportive parental presence and a stable structured consistent home, which may lead to more positive developmental outcomes. In addition to research addressing the effectiveness of interventions, studies need to also examine the impact of co-morbidities such as ADHD and depression in the affected individual, as well as more practical aspects related to quality of life for the individual and his/her family. (Premji et al. 2006, p. 395)

Similarly, the 2009 study by Bohjanen et al. acknowledged that there is a great deal of empirical knowledge held by families and the health professionals who work with them, as well as strategies for coping with FASD affected children. These strategies include reducing external stimulation, using visual schedules, repeating instruction, using multiple methods, implementing positive behaviour supports, and striving to provide a stable home environment (2009, p. 33).

Bohjanen et al. are sceptical of the value of these knowledge bases, going as far as to suggest that “bypassing evidence-based practice may decrease access to the intervention strategies of potentially greatest benefit” (2009, p. 33). However, at present, the circumstances surrounding clinical research in intervention are not conducive to developing the sort of evidence base she calls for, and in the
meantime, her perspective has the potential to denigrate the real work that is being done in intervention practice and the results that can be achieved through best practice intervention strategies as they currently exist.

The current best practice intervention strategies that do exist are largely based on the efforts of significant individual practitioners in extrapolating findings from FASD and other (non-FASD) clinical research into brain function and central nervous system function, and applying this in a logical way to FASD practice. However, other than Malbin (2011) few of these are available as published accounts, and those that are, are intended more as practice guides than research publications (cf. Graefe 2006, Edmonton and Area Fetal Alcohol Network 2007).

Diane Malbin’s particular contribution to this field deserves some attention at this point. Her professional background is in social work, and her expertise draws from her professional training, practice experience in the field of FASD, international research and personal experience as the parent of a person with FASD. Her overall aim is to engender a ‘continuum of care’ through family, community and multidisciplinary intervention work. Malbin’s framework designing effective FASD intervention strategies, is called the Neurobehavioral Logic Model. It is a conceptual framework for linking brain function with behaviour (which Malbin terms the ‘neurobehavioral construct’), and follows the logic that:

The brain is a physical organ, like the heart and kidneys. Alcohol, other teratogens, and trauma kill cells in the brains of developing fetuses. Alcohol also alters the structure of cells, reducing myelination and the number of interconnections among cells. Changes at the cellular level alter how cells function and communicate. These and other changes affect memory storage and retrieval, processing speed, the ability to abstract, analyse, make decisions, and contribute to other behavioural symptoms. Since these are physical changes, Fetal Alcohol/Neurobehavioral conditions (FA/NB) is by definition a brain-based invisible physical disability with behavioral symptoms. (2011, p. 11)

5 For further information, see: http://www.fascets.org.
Malbin argues that there is a large gap between the knowledge of FASD developed in all areas of FASD research and the application and adaption of that knowledge in the area of FASD intervention. Her theoretical model is intended as a means of operationalizing research findings on neurobehavioral conditions in order to circumvent this gap. While Malbin focuses on FASD, the framework is applicable to all neurobehavioral conditions, thus Malbin developed the term Fetal Alcohol/Neurobehavioral (FA/NB) to describe interventions specifically for FASD. The conceptual framework advocates for interventions and accommodations that meet the needs of each individual taking into consideration their unique presentation and situation including the social context that surrounds them and their family’s needs. When this is done effectively, “…providing accommodations for people with FA/NB is as appropriate and effective as providing accommodations for people with other physical disabilities” (2011, p. 11). The difference between this model and others models of intervention commonly applied to FASD is that its focus is on adapting the environment to make it more relevant to the individual rather than changing the individual.

In Malbin’s model, behaviours are seen as cues for recognizing the aetiology of the disorder, and thus considering accommodations that are appropriate to brain function. While this may seem simple, it is not simplistic, because it requires professionals and parents to develop a different way of thinking about FASD, considering it less as a condition to be managed and more as a disability to be accommodated. This model challenges standard approaches to addressing such conditions which generally involve “learning theory-based behavioral interventions” and practices. Malbin argues that such interventions are generally ineffective because they attempt to change the superficial behavioural symptoms without consideration of brain function (2011, p. 29), a strategy which is, in Malbin’s words, “generally as effective as forcing the paraplegic to perform high jump” (2011, p. 49, 51). She argues that though these approaches are not right or wrong or fundamentally bad they are usually based on assumptions about brain function that is not relevant to FA/NB conditions, thus often not a good ‘fit’ for people with FA/NB.
Malbin recognizes that, frequently, “beliefs dictate interventions, [and thus], beliefs about the meaning of behaviors lead to attempts to change behaviors” (2011, p. 93). She proposes that instead of trying harder to change behaviours, professionals and families need to ‘try differently’ in ways that consider brain function and brain difference (2011, p. 11). Given the variability of FA/NB this means moving away from the idea that there are specific interventions that will work for all affected by FASD, instead following a theoretic framework with basic principles that guide the development and implementation of effective strategies (2011, p. 50). In this way the Neurobehavioral Logic Model is the “conceptual glue for reframing the meaning of behaviours and is the basis for developing person-specific, relevant and appropriate strategies and accommodations” that consider brain function (2011, p. 11).

Thinking about FASD as a brain-based disability helps to “shift perceptions from the person being the problem to having a problem” (Malbin 2011, p. 62). This redefinition of the problem changes people’s perception of the person and redefines the solutions, including approaches to interventions. Malbin terms these ‘paradigm shifts’ and provides a number of examples of how they work. One of the most well known examples is the following chart (Figure 5), which is commonly used in FASD intervention.

**Figure 5: Malbin’s Paradigm shift, from ‘won’t’ to ‘can’t’ (Malbin 2011, p. 156)**

<table>
<thead>
<tr>
<th>From seeing the person</th>
<th>To understanding the person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Won’t</td>
<td>Can’t</td>
</tr>
<tr>
<td>Bad</td>
<td>Frustrated, defended, challenged</td>
</tr>
<tr>
<td>Lazy</td>
<td>Tries hard</td>
</tr>
<tr>
<td>Lies</td>
<td>Confabulates; fills in</td>
</tr>
<tr>
<td>Doesn’t try</td>
<td>Tired of failing; exhausted or can’t start</td>
</tr>
<tr>
<td>Mean</td>
<td>Defensive, hurt, abused</td>
</tr>
<tr>
<td>Doesn’t care; shut down</td>
<td>Can’t identify or show feelings</td>
</tr>
<tr>
<td>Refuses to sit still</td>
<td>Over stimulated</td>
</tr>
<tr>
<td>Fussy, demanding</td>
<td>Oversensitive</td>
</tr>
<tr>
<td>Resisting</td>
<td>Doesn’t “get it”</td>
</tr>
<tr>
<td>Trying to make me mad</td>
<td>Can’t remember</td>
</tr>
<tr>
<td>Trying to get attention</td>
<td>Needs contact, support</td>
</tr>
<tr>
<td>Acting younger</td>
<td>Is developmentally younger</td>
</tr>
<tr>
<td>Thief</td>
<td>Doesn’t understand ownership</td>
</tr>
<tr>
<td>Inappropriate</td>
<td>May not understand proprieties</td>
</tr>
<tr>
<td>Not trying to get the obvious</td>
<td>Needs to be re-taught many times</td>
</tr>
</tbody>
</table>
Key service example: The Key Worker and Parent Support Program

The influence of Malbin’s Neurobehavioral Logic Model in FASD intervention pervades a range of contexts. One of the most successful of these is the Canadian Key Worker and Family Support Program, which was developed in British Columbia and implemented in 2006 (cf. Hume et al. 2009, British Columbia Ministry of Children and Family Development 2009). This intervention program, which continues to be employed in practice today, is the most comprehensively evaluated and documented program in the field of FASD intervention. The model for the program was developed by a range of specialists, and drew on international research and practice experience in the fields of FASD and disability. It was the subject of a comprehensive external evaluation from 2006 to 2009. Information presented here has been drawn from written reports and evaluations of the project, other academic literature, information presented in conferences and data drawn from my ethnographic engagement with professional Key Workers in Canada, and conversations with Diane Malbin regarding her role as a consultant for the program.

In 2003, the province of British Columbia released the first comprehensive strategic plan to address FASD in Canada. This document, entitled *Fetal Alcohol Spectrum Disorder: A Strategic Plan For British Columbia*, recognized the need for cross-ministry support for children, youth and families with FASD and identified seven key areas for addressing FASD, including diagnosis and assessment, public awareness and education, early intervention and prevention, lifelong support for those affected, and research and evaluation (Government of British Columbia 2003, p. 10). As a result, the British Columbia Ministry of Health established new screening and diagnostic teams to improve diagnostic capacity for FASD, the Ministry of Education created a FASD outreach program which aimed to support teachers of students with FASD and share information, and the Ministry of Children and Family Development established the Key Worker and Parent Support Program to support families, children and youth with FASD and develop capacity for FASD intervention in the social and community service system at large (Rutman, Hubberstey & Hume 2011, p. 297).
The Key Worker program was rolled out through the province in 2005–2006. Pre-existing services within the community sector tendered for Key Worker positions, which were funded and placed within various service contexts. In 2008, practice standards were developed to guide and support workers within the program.

The program model

The Key Worker and Parent Support Program (henceforth the Key Worker Program) aims to provide support, education and intervention services to children, youth and families affected by FASD, suspected FASD and similar neurodevelopmental conditions as well as education, consultancy and support to professionals within pre-existing services across systems who engage with FASD. The overall goal of the program is “to maintain and enhance the stability of families with children and youth with FASD and similar neurodevelopmental conditions” (British Columbia Ministry of Children and Family Development 2009, p. 3).

The success of the Key Worker program hinges on the strategy of constructing a role for a professional ‘Key Worker’ who engages with the family and, in recognition of the diversity of FASD presentations and the need for those with FASD to access specialist services across sectors, links families and individuals to existing services across health, allied health, community and social services, education, justice and other relevant areas. Thus, “Key Workers supplement and enhance, but do not replace, existing community resources” (British Columbia Ministry of Children and Family Development 2009, p. 3). The dual role of Key Workers, as both family support professionals and consultants to professionals, helps to ensure a coordinated effective approach to FASD management, which in turn decreases the chance of the duplication of services. This helps all involved to “come to a common understanding of the child’s/youth’s needs and to develop supportive environmental accommodations accordingly” (Hume et al. 2009, p. i). Key Workers may be involved in: “(i) integrated service/care planning; (ii) bringing an FASD-lens to discussions; and (iii) (re)-interpreting a child’s behaviors,
strengths and needs in light of this understanding” (Rutman, Hubberstey & Hume 2011, p. 298).

The program builds on a regional service delivery model that allows for regional variation and modifications to meet local needs and family circumstances. It requires the availability of an expert in FASD who can provide consultation to the contracted agencies and Ministry of Children and Family development to ensure the facilitation of learning strategies related to the model. The program also requires ongoing FASD training and professional development and supervision for Key Workers by a suitably qualified professional with FASD expertise and knowledge of the program (Hume et al. 2009, p. i). The program model includes an optional Parent Support Program, which takes the form of a support group. The Key Worker Program and the Parent Support Program could be delivered together or independently by different agencies.

The development of the program was substantially grounded in Diane Malbin’s, theoretical framework for FASD and neurobehavioral conditions discussed above, which is rooted in the understanding of FASD as a brain-based physical disability with behavioural symptoms. Further theoretical guidance was drawn from Streissguth (1996, 2004). The program’s model emphasizes the importance for all involved, including the client, family, professionals and other relevant people to have an understanding of the nature of FASD, which in turn underpins all practice, management and intervention (Rutman, Hubberstey & Hume 2011, p. 298).

Alongside these sources, the program also drew on research in the field of disabilities. In particular, the results of an evaluation of the UK Key Worker program for families of children with disabilities, provided the basis for parts of the model. In this model, Key Workers facilitated access and coordination of a range of services involving with the child and family using a family-centred approach. Research findings on this project identified a range of positive outcomes for families including increased “cooperation between all parties which resulted in increased access to resources for parents and families” (Rutman, Hubberstey & Hume 2011, p. 300). A key learning from the evaluation of this project, identified
by the Canadians, was the importance of engaging with “multiple client groups (ie, the parents/caregivers and families, community partners and if appropriate, the child/youth him/herself)” in order to ensure a coordinated and effective approach with ‘maximal benefit to those served by the program’ (Hume et al. 2009, p. 6).

The 2006–2009 evaluation of the Key Worker Program highlighted a range of positive outcomes for parents, carers and community service providers. Parents reported increased understandings about FASD and their child(ren)’s needs, strengths and capabilities. They also reported increased confidence in their parenting, improved access to community services and resources, increased emotional and practical support and increased emotional well-being with a decrease in their stress. They developed a shared understanding about FASD and appropriate strategies/interventions with service providers and increased their understanding of the assessment process and its recommendations (Hume et al. 2009, p. iii). The Key Worker Program evaluation also reported that:

For many parents and caregivers, their new knowledge about FASD as a neurodevelopmental disability had led to important shifts in their interpretations of their child’s behaviors; their expectations for their child that were now more in keeping with the child’s developmental age rather than his/her chronological age; and parenting behaviors and practices either in response to their child’s problematic behaviors or as a means to avoid triggers giving rise to problematic behaviors. (Hume et al. 2009, p. iii)

In relation to professionals within the community service sector, the program findings suggested an increase in their understanding of FASD as a neurodevelopmental disability and a change in their practice and skills in keeping with this learning and understanding. Professionals felt “supported and encouraged to try out relevant and appropriate strategies and interventions” for FASD (Hume et al. 2009, p. 69). According to the executive report, this knowledge and skills base broadened and deepened throughout the duration of the program and provided evidence for how an increase in knowledge about FASD can translate
into shifts in practice over time and increase collaborative practice in support of children's and families’ needs.

The Key Worker program’s main strength, then, lies in its ability to be "sensitive to and build capacity within families and communities [because] the effects of this approach reach many more individuals than typical intervention programs targeted to individuals” (Hume et al. 2009, p. v). In other words:

The model holds that when all who live and work with the child/youth have a common understanding of the disability, then the behavioural symptoms associated with FASD will be reinterpreted, expectations for the child/youth will shift and appropriate environmental accommodations and supports can be identified and implemented; and positive outcomes for families, including reduced stress and increased stability can ensue. (Hume et al. 2009, p. i)

The program review nominated six promising practices demonstrated in the Key Worker Program that were of particular benefit to families and professionals involved with FASD: maintaining a family-centred or family-directed approach; a relational approach grounded in a non-judgmental and empathic engagement; a holistic approach that takes the whole family and social context into consideration; a flexible approach with flexible intervention timeframes and collaboration with other community partners; multi-faceted support and advocacy; and thinking beyond just service provision to include other factors such as the consideration of a child's need to be part of a larger community (Hume et al. 2009, p. v).

Overall the evaluation of the Key Worker Program found it to be an effective intervention program with benefits to families, professionals and the community. This evaluation was also a true reflection of the feelings of the Key Workers with whom I engaged during my fieldwork in Canada. My informal discussions, attendance at Key Worker meetings and dinners, a formal interview with an experienced Key Worker who had been working within the program since its inception and discussion with Diane Malbin revealed that Key Workers agreed that
the overall program had been a huge success. However these discussions, many of which came after the formal evaluation of the program, also revealed some limitations or teething problems.

Continued training of Key Workers was an issue. As professionals who were trained in the initial phase left the program, the new Key Workers had not necessarily received the same extent of training, and in some cases, no training at all. Given the centrality of Malbin’s Neurobehavioral Logic Model and theoretical framework for understanding FASD, Key Workers reported that new workers without this understanding and training had reverted to more traditional behaviour management and learning theory-based approaches which aimed to address the symptoms and not the underlying brain damage. This resulted in inconsistencies in the program and according to some Key Workers poor outcomes for clients and thus undermined the program’s key tenets.

The Key Worker positions were tendered out to existing social and community-based organizations each with different roles and resources. While many Key Workers considered this as a benefit because of the normalization of FASD in the existing social and community service system, other Key Workers felt that this had lead to inconsistency in the level of resourcing, supervision, caseloads and experience of Key Workers. A number of Key Workers with Social Work degrees were concerned that some Key Workers had limited training in Social and Community Services and thus a limited ability to apply the Key Worker model which relies on a certain amount of professional experience, knowledge and professional training in a discipline like social work or community nursing.

Key workers also identified a number of barriers to their work with other professionals, which impacted on the outcomes for the families they worked with. Many had some difficulty accessing services for individuals who did not meet the criteria for certain generalist services. In some cases generalist services refused a service to the family because they did not consider FASD within their remit. Many of the Key Workers who had been working in the program since its inception however did add that they had seen a positive change in the way professionals and
services consider FASD, with more professionals and services willing to engage with FASD once they had developed closer networks with the Key Worker and understood FASD better. Key Workers have found it difficult to develop pathways for their clients who had reached the age of eighteen and were transitioning into adult services. FASD is considered to be a lifelong condition however the lack of continuity of care across the life span for those with FASD was identified as a significant issue by the Key Workers. Overall both the Key Worker evaluation and the Key Workers I have engaged with during my fieldwork consider the program to be an innovative response to addressing the needs of individuals with FASD and their families in the community.

Conclusion
This overview of international practice models for diagnosis and intervention reveals that service provision is still in a process of development in a number of areas, and even where comprehensive models exist, there is professional disagreement about what they consist of and how they should be deployed. This said, the key practice examples provided for each section reveal instances of deep engagement and influence within diagnosis and intervention settings. On the one hand, there is general agreement that, regardless of the codifying system used for diagnosis, substantial benefit can be derived from the implementation of multidisciplinary teams in diagnostic services. Likewise, the example of the Key Worker Program demonstrates that cross-sector communication and collaboration can result in benefits for clients and services (in terms of reducing service duplication), thus also leaning towards an emphasis on multidisciplinarity and collaboration.

In response to these international models, countries in the process of developing services for FASD are doing so in varied ways. In the Australian context, for example, specialists are responding to the challenges of diagnosis by suggesting that an Australia-specific diagnostic tool needs to be developed. Whereas in New Zealand, where strong interpersonal professional links to Canadian service providers have been developed, practitioners are adhering much more closely to Canadian guidelines without articulating (at least at this stage) any need to make
them more New Zealand-specific. Despite these differences, both Australian and New Zealand specialists are responsive to the benefits of multidisciplinarity, and this is discussed in relation to New Zealand’s FAD service provision in the subsequent chapters.

Another significant factor revealed by this foray into international practices is that, despite some professionals’ advocacy for evidence-based clinical research, and despite the extensive modelling that is available for diagnosis, much of the extant service provision for FASD is affected by individual perceptions of FASD and subjective (albeit experience-informed) opinions concerning issues surrounding severity, disability, and function. As revealed by the Key Worker Program review, one of the main benefits of the program has to do with its influence in providing information to all parties about FASD, resulting in constructive changes in professionals’ and family members’ perceptions about FASD. The issue of perception is no less relevant to the New Zealand context, and now provides an entry point for the exposition of data from the national study underpinning this dissertation.
Chapter 6: Developing diagnostic expertise for FASD in New Zealand

This chapter describes the process by which Alcohol Healthwatch, a small Trust based in Auckland, and collaborators from the health sector, developed diagnostic capacity for FASD in New Zealand between 2008 and 2012. Their undertaking demonstrates strategic innovation and serves as a model for developing diagnostic capacity in areas where health system engagement with FASD is limited. Through this process, professional collaborators researched, networked internationally, and designed and developed two projects. First, a research and training initiative that investigated international models for developing diagnostic capacity that could be applied to the New Zealand context; and second, a pilot program that trained a group of health professionals to undertake complex diagnostic service provision, and to be able to do so despite systematic non-recognition of FASD in New Zealand.

This chapter outlines these projects and their outcomes with a focus on the pilot project for FASD diagnosis as an example of the sort of paradigm shift described by Kuhn (2012) and discussed in Chapter four of this thesis. This description draws from Alcohol Healthwatch reports, international literature, interviews with a key health promoter from Alcohol Healthwatch, and my own ethnographic engagement in the process, as well as interviews with clinicians who participated in the pilot project.

The importance of examining and explaining the Alcohol Healthwatch project became clear to me at a relatively late stage in my research, when I attended an FASD research symposium for International FASD day 2012 in Brisbane, Australia. This symposium revealed Australian approaches to FASD, including the fact that, like New Zealand, there is insufficient resourcing or information for FASD at clinical and practical levels. At this symposium, the frustration from parents, families and professionals regarding the lack of access to diagnostic and intervention services as well as prevention programs was clear. It was also clear
that, while New Zealand and Australia are both in the beginning stages of developing responses to FASD, professionals in these countries are approaching the issues relating to FASD in very different ways: Australia mainly by researching and lobbying the federal government for resources; New Zealand by networking internationally with experts, developing and adapting international best practice models and implementing them in a 'grassroots' manner at a clinical level.

The success of the New Zealand approach to developing active diagnostic services, relative to what has been achieved in Australia with much greater resourcing, warrants detailed investigation, and this discussion goes some way to achieving that. New Zealand’s response to FASD is unique, but draws from well-researched international models, and is careful to not ‘reinvent the wheel’. In particular, the strategy of approaching FASD diagnosis by developing capacity within pre-existing paediatric and mental health diagnostic services demonstrates how important grassroots capacity building can be.

**Developing diagnostic capacity for FASD**

In New Zealand, there is no national systematic approach to FASD diagnosis in health services and health policy. Prior to the development of the two projects discussed in this chapter, FASD diagnosis in New Zealand tended to be undertaken in an ad hoc manner, often by solitary clinicians with limited clinical FASD knowledge and no specialist FASD training. Auckland-based charitable trust Alcohol Healthwatch has been a key player in advocating for, and building capacity to address, this important health issue. The trust is contracted by the New Zealand Government Ministry of Health to provide a range of national and regional health promotion services to reduce alcohol-related harm. The organization approaches health promotion in a holistic manner, including campaigns aimed at raising awareness, building knowledge and skills, promoting healthy public policy and best practice, and fostering coalitions and networks around key public health topics and needs. Christine Rogan, a health promoter from Alcohol Healthwatch charged with overseeing their approach to FASD, has been involved as a key player in this field for sixteen years. Rogan's role in FASD prevention has largely involved working towards developing FASD diagnosis and intervention:
You don’t have to go very far into that prevention domain to recognize that you can’t just create awareness, you must provide intervention and support if this is going to go anywhere and if this is going to be an ethical approach to health promotion. Otherwise you are raising awareness in a very unsafe way for people. (Personal communication, 10/11/2010)

Whilst Alcohol Healthwatch has been engaged in advocating for adequate recognition and resourcing for FASD, interest from government and other key players in New Zealand has been inconsistent. In 2007, FASD was considered for inclusion at a policy level in the National Alcohol Strategy, however nothing eventuated from this. More recently, there has been significant growth of interest in FASD from judges and others in the criminal justice field. Whilst this interest continues to evolve, it has yet to result in any systematic response to addressing or managing FASD in the justice system. The invisibility of FASD has been identified as a key barrier to addressing it systematically in New Zealand. Christine Rogan suggests that FASD is caught in a ‘catch 22’ situation, where the lack of documented prevalence of FASD resulted in no action, resulting in no diagnostic capacity to identify and make visible FASD resulting in no record of prevalence. This cyclic barrier is also demonstrated in service provision, where no diagnostic capacity has previously resulted in no diagnoses, therefore no recorded prevalence, and thus no social support or education service provision. Inadequate service for FASD has, in turn, resulted in practitioners questioning the ethics of undertaking FASD diagnosis, given the lack of management and support options for individuals if they were to be diagnosed.

After years of lobbying key stakeholders and government and awareness raising in the community, as well as with advocacy professionals, with varying degrees of success, Alcohol Healthwatch shifted strategy to a “quite deliberate decision to target the workforce, as opposed to putting all our energy into the big public campaigns... ...because what happens at that interface, between client and counsellor or midwife and women is very much where the rubber hits the road” (personal communication, 10/11/2010). Indeed, after extensive discussions and
research with professionals locally and internationally, Rogan formed the opinion that “diagnosis was the key to unlocking what had become a paralysing stalemate” (personal communication, 10/11/2010).

Around 2007, Alcohol Healthwatch, along with a coalition of health professionals with an interest in FASD, set out to target diagnosis as an area for development. Whilst continuing to provide government departments and other interested parties with information about FASD, as well as writing submissions to relevant government inquiries, Alcohol Healthwatch began discussing strategies for building capacity for FASD diagnosis within the funding, infrastructure and personnel constraints of the existing health system. Their aim was twofold: to increase FASD diagnostic capacity with particular focus on multidisciplinary team diagnosis, and to generate evidence for the need for a systematic national approach to FASD diagnosis, intervention and prevention programs. The group’s first step was to develop an investigative research project to determine the practical and clinical elements that were needed to develop evidence-based clinical capacity with health professionals at a grassroots level.

**Phase 1: Towards multidisciplinary diagnostic services for FASD**

In 2008, Alcohol Healthwatch and their health sector collaborators developed the project *Towards Multidisciplinary Diagnostic Services for Fetal Alcohol Spectrum Disorder*, which was funded by a one-off research grant from the National Drug Policy Discretionary Grant Fund. This project aimed to ascertain the clinical elements that would be required in order to establish a multidisciplinary approach to FASD diagnosis in New Zealand, and to provide clinicians and policy makers with better information regarding FASD diagnosis (Alcohol Healthwatch 2011). The project drew on previous work by Alcohol Healthwatch, including a scoping visit in 2007 to FASD clinics in the USA and Canada by Rogan and other professionals engaged with FASD to inform the development of this project. Drawing on this work, on literature searches, and on international professional networks developed by Rogan over a number of years, the group identified pertinent research and transferable international models for FASD diagnosis, and
fostered connections with leading clinicians, researchers and programs internationally (the results of this process are discussed below).

A select group of New Zealand clinicians who had indicated an interest in FASD via involvement with Alcohol Healthwatch initiatives, and who had the appropriate skills to be able to contribute effectively to multidisciplinary team diagnostic training, were selected for the project. As part of the project, these practitioners flew to Canada and the USA and undertook training in best practice models of FASD diagnosis, including the University of Washington 4-Digit Diagnostic Code and the Canadian guidelines for diagnosis. They also took advantage of the opportunity to discuss their ideas regarding developing diagnostic capacity in New Zealand with leading practitioners and researchers at specialized diagnostic centres, and gathered written information and insights that informed their plans for expanding their work in New Zealand. Once returned from their North American fieldwork, the clinicians undertook eleven FASD assessments as case studies to further develop their skills and expertise in this area, with support and supervision from international experts provided through the project.

As an outcome of this project, six practitioners were trained in FASD multidisciplinary team diagnosis and three of these practitioners went on to employ the FASD diagnostic practice skills that they had developed in their broader professional capacities in New Zealand – two in private practice and one in a District Health Board service. At the conclusion of the project, three of these diagnosticians were engaged by publicly funded institutions, such as the Youth Court, and Child, Youth and Family Services, to undertake assessments of children and young people for FASD throughout New Zealand, demonstrating clear demand for services in this area. These highly trained professionals in turn became New Zealand-based trainers and consultants for FASD, and were involved in the development and training of the next group of professionals to be engaged in training by Alcohol Healthwatch.

Six recommendations resulted from this initial project. First, that establishing FASD multidisciplinary diagnosis in New Zealand was shown to be urgent,
justifiable and feasible. Second, the project established that a training program was required to enable future clinicians who are willing to work as a multidisciplinary team to do so effectively within their own organization or region. The project also posited that appropriately trained neuropsychological capacity to support effective multidisciplinary FASD diagnosis should be generated within the public health system. The project indicated that investigation should be made into the feasibility of establishing a specialist FASD diagnostic, training and research organization to guide FASD diagnosis and treatment in New Zealand and to ensure this developed in a well-informed, consistent and supported manner. The project established that clear and consistent New Zealand-based FASD diagnostic guidelines (based on international guidelines) were needed, and finally, that an education program should be established to ensure the workforce in community-based services become more familiar with FASD. This would allow them to “screen, refer and respond more appropriately and cost-effectively to the needs of the affected individual and their family following diagnosis” (Alcohol Healthwatch 2011, p. 2–3).

In the process of reaching these recommendations, the research team drew heavily on insights gained from establishing professional networks in North America, where they also identified appropriate models for further training initiatives. The project participants’ engagement with North American colleagues alerted them to the community of practice surrounding the Vancouver conference, which was identified as a potential future source of information and point of engagement with FASD specialists. Furthermore, participants became familiar with the activities of the Asante Centre, and began to develop a plan for engaging in training offered by the centre.

**Phase 2: The pilot project for FASD diagnosis**

The *Fetal Alcohol Spectrum Disorder Multidisciplinary Diagnostic Services Training Project* was a pilot project undertaken in 2010–2011 aimed at building clinical capacity for FASD diagnosis in New Zealand. Following the establishment of a clinical task force to guide the project, the training program involved the development of a training strategy aimed at fostering the creation of
multidisciplinary teams, aiming to have at least two teams established and ready to operate FASD diagnostic services in New Zealand.

The project received $50,000 in funding from the Alcohol Advisory Council of New Zealand (ALAC), which supported costs associated with travel and training. However, the success of the project also relied on the donated time of the clinicians involved, support from their employers, including time off to participate in the international training, and direct financial and logistical contributions from Alcohol Healthwatch. Though the project was aimed at developing FASD diagnostic practice in New Zealand, there was no specific ongoing funding for this project and thus continued FASD diagnostic practice would be dependent on the clinicians’ personal commitment to continuing the practice, continuing support from their managers, and the willingness of the trainers, two of whom worked in private practice, to provide ongoing mentoring support while individuals’ skills continued to be developed.

A clinical task force was established to oversee the success of the project, which included Alcohol Healthwatch, interested professionals from health, social service and juvenile justice fields who had become engaged with FASD through Alcohol Healthwatch in some way, and the three professionals trained in the previous project. This group met regularly to develop and guide the project, drawing on recent international research in the field, their own experience from the previous project, experience gained in clinical practice by the three professionals engaging in FASD diagnosis in New Zealand, and correspondence with international networks of leading researchers and practitioners in the field.

**Project participation**

Where the 2008 project had revolved around the training of selected individuals, this second phase was entirely based around team training. Potential team members were identified through the professional networks of those involved in the development of the initial pilot project. The teams were then constructed based on individuals’ interest in FASD, particular professional skill sets (it was a requirement of the project that only multidisciplinary team or interdisciplinary
teams may partake in this project), access to potential cases of FASD that could be used in developing diagnosis skills, and the willingness and capacity of individuals and their employers to commit to the year-long project, including time away from the normal workplace to undertake intensive training in Auckland and Canada as well regular meetings in Auckland to discuss cases and engage in supervision.

The first group selected for training comprised three people from a child development service based within a hospital. This service already had a multidisciplinary team called the Developmental Assessment Programme (DAP), which included one paediatrician and two clinical psychologists. At the time of their engagement with the project, the DAP team members were primarily assessing referrals for ADHD and autism spectrum disorders, however the team had considered FASD diagnosis in some of their cases and had begun investigating FASD further through literature, but did not have any formal FASD triage or screening process for referrals. Ultimately, these clinicians were able to share information from their training with other professionals within the service, including a speech and language therapist, an occupational therapist, a social worker and a paediatric registrar, who were then all able to contribute to the multidisciplinary team undertaking assessments within the service.

The second group was a two-person team based at a Child and Adolescent Mental Health Service, comprising a psychiatrist and a clinical psychologist. The psychiatrist became engaged in the project through contact with one of the trainers. As well as mental health, she had an interest in children and disabilities and both the psychiatrist and the psychologist had a strong interest in Neurodevelopmental issues. Their service had established a Neurodevelopmental Pathway for ADHD and autism, however they were not screening for or assessing for FASD.

The third group was from a community-oriented child and adolescent outpatient service based at a hospital. It included a paediatrician who had been trained in the previous project. This paediatrician was keen to see an FASD service develop for children in his region, but at the time of indicating his interest did not have the
multidisciplinary team required for participation in the project. However, following negotiation with DHB management, he engaged the interest of a clinical psychologist and a speech and language therapist from other services within the DHB and developed a multi-sited team for the purposes of this project. The team also engaged a high needs service coordinator who did not participate in the training but assisted in the collection of information and liaison with families. This team also negotiated with their DHB to secure the resources needed to undertake twelve full FASD assessments over a twelve-month period.

**Training structure and content**

The project steering committee was largely responsible for developing the structure and determining the content of the training program. This would ultimately include theoretical components, practical skill development and the opportunity to undertake guided practice with support and supervision from experienced diagnosticians. The training was structured to include components in both New Zealand and Canada, with FASD experts from New Zealand, Canada and the USA. It was undertaken in four stages, and was designed to build on the knowledge and skill acquisition developed at each stage. Throughout the project the participants had access to supervision and mentoring from New Zealand-based trainers who had previously developed knowledge of FASD diagnosis.

The first stage was conducted in New Zealand. It involved orienting the participants to FASD through current research and literature surveys, in order to develop a research-informed understanding of FASD and the diagnostic process. The participants then engaged in workshops with the New Zealand trainers that covered the basic principles of FASD diagnosis, including multidisciplinary team diagnosis under the University of Washington 4-Digit Diagnostic Code system and the Canadian guidelines for diagnosis. Subsequent to this, the teams were each asked to work a referral for FASD assessment, and were mentored through the assessment process by the New Zealand trainers. The participants also undertook a one-day diagnostic workshop with Dr Albert Chudley, a professor of paediatrics and genetics and co-author of the Canadian Guidelines for Diagnosis. Dr Chudley is an expert in FASD diagnosis and establishing and mentoring Canadian clinical
teams and was in New Zealand as the Keynote speaker for a paediatric conference in New Plymouth (sponsored by Alcohol Healthwatch). This workshop took a ‘hands on approach’ that allowed participants to ‘fine tune’ their skills and ask questions about the specifics of diagnosis. During this workshop, two case studies from one of the teams were presented and discussed in light of the skills developed.

In the second stage, the clinicians flew to Canada to attend the 2011 International conference on FASD in Vancouver. This conference, which was first held in 2005, is the peak international forum for research and professional practice concerning FASD, and is unparalleled in terms of access to ‘cutting edge’ information on and approaches to FASD. In conjunction with the conference, they attended seminars and workshops on a range of topics including recent scientific research developments, FASD diagnosis, intervention and prevention models, social and legal issues relating to FASD, and families and birth mothers’ experiences of FASD. This provided an opportunity for the clinicians to gain a more holistic understanding of the issues surrounding FASD, to network with other diagnosticians worldwide, and to gain a greater understanding of FASD in relation to its cultural and social contexts.

In the third stage, the clinicians participated in three days of intensive diagnostic training at the Asante Centre. During their time at the Asante Centre, the participants observed and participated in a multidisciplinary assessment process that involved following two patients throughout an entire assessment and diagnosis. Participants were given training on how to conduct assessments and provide diagnosis, including information from specialists specific to each of their disciplines. Participants had the opportunity to discuss ideas, ask questions and reflect on their own and the Asante Centre team’s practice.

On their return to New Zealand, the clinicians were involved in a process of consolidation of skills. This largely revolved around identifying potential cases within their own caseloads in which they might be able to apply the skills they had learnt in Canada. Participants collectively attended meetings with the New
Zealand-based trainers to discuss their individual cases and the practical application of their skills. In some cases, individual clinicians also participated in supervision with trainers from their own particular professions. Finally, participants met together to discuss their experiences, the benefits of the training, how their professional practice had changed and provided feedback and ideas on the project model.

**The Asante Centre training**

By far the most important part of the training process was the opportunity for clinicians to participate in training provided by the Asante Centre. In the context of the 2011 project, this training included all three New Zealand teams, together with a two-person team from the Reunion Islands, as well Christine Rogan from Alcohol Healthwatch and myself as a participant-observer accompanying the New Zealanders. This training was undertaken over a three-day period, directly following the 2011 International Conference on Fetal Alcohol Spectrum Disorders in Vancouver.

The 2011 Asante Centre training centred on the role of diagnosis in prevention and intervention and how and why it can be seen as a cost and resource effective way to meet the needs of patients with prenatal alcohol exposure and possible FASD. The clinical component outlined how to go about a FASD clinical assessment – the nuts and bolts for each clinician, including opportunities for skill development through practice experience. It also explored ethical practice approaches (how to interview parents/carers and families, how to support families at the beginning, during and after the assessment as well as how to deal with the end result for all involved including useful reports and information dissemination). According to Mrs Salahab, there are many clinical environments that can incorporate FASD diagnosis into their clinical practice, from hospitals to community-based health services, private centres and even remote video medicine. The Asante Centre provides an overall grounding of the skills needed and the issues related to FASD, allowing people to “go off and adapt that to their own clinical situation” (personal communication, 1/3/2011).
The first day of training provided an overview of the Asante Centre, including information on how it operates, a tour of the facility and introduction to the staff. The Asante Centre staff includes both permanent and contracted staff. In 2011, the multidisciplinary team for the training included many of its permanent staff, including Dr Asante, who provided much of the informational component of the training, as well as the medical component of the first assessment, a second contracted paediatrician who undertook the medical component of the second assessment, a psychologist who provided information on FASD and the brain, and training related to psychometric testing, two speech and language therapists who both contributed to training related to the speech and language part of the assessment, as well as undertaking the speech and language component of the assessment, and the Centre coordinator, Audrey Salahab who filled the teams in on the role of the clinical coordinators, as the social worker who normally undertakes this role was not available at this time.

Interestingly, this induction included an emphasis on the genesis for the creation of the centre itself, which was described as a kind of collaboration between families, advocates and clinicians, to improve access to FASD diagnosis, intervention, support and recognition in policy and funding. The centre’s vision is to foster “compassionate, knowledgeable communities that work together to prevent FASD and support persons and families affected by FASD to help them reach their full potential”. Clinical work at the Asante Centre informs the centre’s FASD research, training, consultancy and resource development. Members of the centre discussed the importance of understanding the connectedness between these areas in building capacity for FASD and how diagnosis impacts on other areas such as prevention, intervention, support, resourcing, funding and public and government funding. The induction then progressed to discussions on why FASD diagnosis is important and necessary, Dr Asante spent time explaining why it is important to diagnose, explaining the differentiation of diagnosis from ‘labelling’ and highlighting the potential benefits of diagnosis for patients and their families. This included a discussion around supporting families, with specific attention paid to welcoming and supporting birth mothers through the diagnostic process. It also

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foreshadowed some potential issues, addressing questions and providing support before, during and after the assessment in ways that are sensitive to the needs, thoughts and feelings of the mother and/or the family. There was an emphasis of the importance of the role of a support coordinator, often a social worker, to support the family throughout the process, answer their questions and provide information as relevant as well as collect information from families to present to the team for the assessment process and facilitate appropriate support and intervention post assessment.

Particular attention was paid to the skills and sensitivity needed to gain an appropriate maternal alcohol history from families and also the importance of accessing information from credible sources. This included ways to talk and ask about alcohol consumption before and during pregnancy with birth mothers in ways that were non-blaming. The discussion regarding what constituted a credible source for obtaining an alcohol exposure history was of particular interest to the trainees. This was considered an important issue because in many cases the clinicians said they did not have access to the birth mother, such as in cases where the child has been adopted or is in foster care with no access to the birth mother or where the mother has died. The Asante Centre places high importance on the maternal alcohol history coming from the birth mother if possible (and if not possible from documented medical or social work files). The trainees were surprised at the ability of the Asante Centre’s team to access files which in many cases they would not have access to in New Zealand. They also commented that alcohol consumption was not often documented in their patients’ medical files. Dr Asante said that this was sometimes the case in Canada as well, though there had been increasing improvements over the years in the documentation of alcohol exposure. Both teams talked about how the profile of FASD has impacted on the documentation of alcohol exposure. The Asante staff and the trainees discussed the complexity of this issue, including when they would and would not accept confirmation of alcohol consumption from other family members and others such as foster carers or adoptive parents, and the importance of not accepting hearsay as confirmation.
Attention was also paid to discussing the diagnosis with individuals and families in appropriate ways which take account of their understanding of FASD as a starting point and the patient’s awareness of their disability, their age and developmental level. It was explained that this process had to be relevant to the family and that, whilst this was an individualized process, it should provide a clear understanding of the test results, physical examination and diagnosis as well as an explanation of fetal development, brain development and the effect of alcohol in utero on growth, facial features and learning behaviour and memory. All of these measures were intended to circumvent, or at least minimize, mother blaming.

The Asante team then gave an overview of the Canadian FASD diagnostic guidelines and Dr Asante explained that a multidisciplinary team approach to FASD diagnosis is important given the complexity of the presentation, confounding issues, and the necessary rigour of a diagnostic process involving the specialist assessment of physical features, growth and central nervous system damage.

Further to this, Asante presented the view that to be involved in such a team, clinicians need certain traits, such as the ability and willingness to work well with other disciplines based on mutual respect of the expertise of others in their team. In my observation, it became very clear throughout the assessment process that this issue was central to how the Asante Centre worked and was evidenced in team discussions meetings and patient reviews that required a compilation of each clinician’s work in order to determine a diagnosis and make recommendations. In these meetings there was no hierarchical structure or leader evident in their discussions. Each clinician contributed their specialist knowledge to the picture of the patient in reporting the outcomes of their assessments and contributing to the discussion and formulations of the diagnosis. The trainees commented at how respectful and inclusive the Asante Centre clinicians were of them. A paediatrician commented that these clinicians “…knew so much more about it than we did, but they made us feel valid and, you know, just great, absolutely great” (Participant 28, 30/5/2011).
The importance of multidisciplinary team is discussed widely in international literature, however this view that certain clinicians were more suited to this work than others was the first time I had come across this discussion. The day concluded with a chart review of a patient who would be attending the centre for an assessment the following day, and whose assessment would be observed by the training participants.

The second day focused on the practical process of undertaking the clinical assessment of FASD. This included observation of the assessment of a patient, including a psychology assessment, adaptive functioning interview, medical interview and medical assessment and chart review by the multidisciplinary team. In some cases, such as the medical assessment, suitably trained New Zealand participants sat in and participated in the assessment process, giving them first hand experience of the process and skills needed to undertake the assessments. All other observations were undertaken via a video link program, where the client was videoed in real time, and this was viewed by all participants jointly in a separate room. In some cases, this allowed New Zealand team members to objectively observe their own colleagues at work, often for the first time.

In many cases the participants were familiar with the assessments being undertaken and commented on how similar or different their own approaches were in practice. Participants gave their own opinions as to the client’s response to the assessments, and this was discussed with other team members in ways that focused on how they would handle the situation and environment and how they do the assessments or could do the assessments. This experience also had unintended benefits with many of the participants commenting that they found watching clinicians from different disciplines to their own very insightful and helpful. In some cases they had never had this opportunity before, and said that it gave them greater insight, better understanding and a greater appreciation for their colleagues’ work. This also initiated conversations between participants and team members about how their clinical work is similar and different to others and how they complement each other’s work and in some cases overlap.
The final section of the day drew together all the Asante Centre multidisciplinary team to talk to all participants about FASD and its impact on the brain, drawing from recent international research, the Canadian guidelines for diagnosis, and their own specialist tests and assessments. This provided a deeper level of information on the impact of FASD on the brain and included discussions related to why certain assessments were employed during the diagnostic process as well pertinent examples from the assessments throughout the day.

This final day included further clinical observations and opportunities for discussion and questions relating to the cases observed and the general process of FASD diagnosis and other areas of interest. This included the observation of a speech and language assessment, with moderation from a second speech and language therapist who was able to sit in on the observation and discuss the process whilst it was occurring. It also included a foster parent interview by a paediatrician, medical assessment discussion, a multidisciplinary team meeting to discuss the cases with where participants were able to observe and participate, and a family conference where the multidisciplinary team discussed the outcomes of the assessment including the diagnosis and recommendations and future plans. The training concluded with a debriefing.

**Project outcomes**

As a result of the pilot project, three New Zealand-based teams were trained in multidisciplinary team FASD diagnosis, and at the conclusion of the project all teams had integrated the skills they had gained into their clinical work, resulting in the provision of FASD diagnostic services within their workplaces. In addition to the clinical skills and expertise gained, project participants highlighted a range of outcomes of the training that they felt indicated positive impacts for health services, patients, families and co-workers. As a result of the project, there was an immediate increase in the number of FASD assessments and diagnosis within the services that participated. Interestingly, for two of the teams, this did not necessarily mean an increase in the number of children seen by the service, because many of the children would have been referred to them for some type of assessment anyway. The ability to offer assessment for FASD has made the project
participants feel more confident about providing services that are relevant to their needs of their clients.

Further to this, participants indicated an increase in general FASD awareness in the health and community services within their region as a result of their new diagnostic services, leading to increased interest from health and community service professionals to learn more about FASD. Participants from all three teams have since provided training, or shared information regarding FASD, within their organizations and with other services within their regions. Indeed, during the one-year term of the project alone, participants provided FASD training for a range of health and allied health service providers in the North Island, including DHB staff, paediatric groups, Whanau Services, and training for resource teachers for learning and behaviour. Beyond the term of the project, further training has been scheduled for other support services, such as disability support services and needs assessment services.

Training and information sharing was identified as important, not just to raise greater awareness of FASD in the health, education and service system, but because it also has direct impact on each team’s capacity to gain appropriate screening and historical information from referrers, making for more efficient assessment and diagnostic processes. Participants have also developed tools to assist their colleagues in the referral process.

In a number of cases, participants considered that their increased skills in FASD diagnosis have resulted in more accurate and detailed assessment and diagnosis for patients. A clearer understanding of patients’ deficits and strengths allowed for more appropriate interventions and support resulting in improved outcomes for patients, even though intervention services were lacking in some areas. Finally, participants improved their ability to explain FASD to families and other professionals and identify intervention strategies appropriate to FASD that could be employed in assisting families in FASD management.
**Project challenges**

There were a number of practical challenges to participation in the training project identified by participants, both prior and subsequent to the project. Perhaps chief among these was the commitment of time that was needed to undertake the training, compounded by the perception of how the training might impact on time management over the course of a one-year commitment to the project. This involved not only individual commitment, but also workplace support. While some of the project participants were supported financially and with paid training leave, others had to take annual leave or use non-work hours to participate in parts of the training, especially the Canadian conference and training component. Some participants had to complete assessment reports in their own time on weekends because the process was new to them and the reports took longer to write than they usually would, and there was no allowance for this. Other participants said that there was little allowance for the increased workload that came as a result of their participation in the project (this was especially the case for participants from the team that had been assembled specifically for the project).

Another challenge to participation in the project was the lack of existing practical resources for diagnosis, including diagnostic rulers for FASD measurements, speech and language tests and psychological tests. In some cases participants, borrowed these resources from other services but had to return them after use, thus impacting on when they could undertake their work and for how long. Furthermore, a lack of information resources on FASD for both professionals and patients was also an issue. Over the course of the project, where information was required, participants mostly used Canadian resources sourced from the conference or Asante Centre Training, or American and Canadian online resources.

A further challenge identified by some participants was that other health, education and community service professionals’ lack of skills or knowledge concerning FASD impacted on their ability to obtain appropriate referrals to their service, which impacted on their ability to identify appropriate cases for practice. This issue also impacted on the clinicians’ ability to access appropriate intervention services for their patients. In an effort to increase professional
awareness in the sector, most team members became involved in offering training to allied health, social and community service and education services about FASD. While this was seen as a valuable contribution, it also impacted on the clinicians’ work time.

**Incorporating FASD training into practice: Team experiences**

Each team in the project had a different professional make up, came from different work environments, and had varied levels of support and resourcing. Accordingly, team members differed in their experience of incorporating FASD into their existing practices. The Developmental Assessment Programme team, who felt the most supported within their work environment to participate in this training, and who were already operating as a multidisciplinary team, found integrating FASD assessments into their work relatively easy:

> It was pretty easy because we have a [multidisciplinary] team...we work in very similar ways to how the Asante Centre works. We have all the disciplines. So it’s just putting it in a diagnostic practice and that was pretty easy. (Participant 28, 30/5/2011)

FASD assessments fitted well into their current practice regarding neurodevelopmental assessments of children, and the provision of community education was already within their remit. Unsurprisingly, this team has undertaken the most assessments and provided the most amount of FASD training to other professionals to date. They have developed their own tools for colleagues to use in the referral process, as well as resources for families, and are using and adapting Canadian resources for patients, families and professionals in the community.

Participants from the other two teams varied in their appraisal of integrating FASD into their practice. One team faced the challenge of developing a multidisciplinary team across different services, and participants from both teams experienced resistance to FASD being recognized within their professional roles and responsibilities. They also lacked resources essential to assessment and diagnosis,
including access to appropriate diagnostic tests. There was also little or no allowance made for their increased workload, and this was especially the case for professionals within the team that was formed across services. It was interesting to observe, however, that while some participants felt that incorporating FASD assessment into their practice had increased their workload, others did not, and some associated the increase in workload to the time it takes to acquire and implement a new skill set rather than an increase in the number of children being seen for assessment. Participants felt that while developing a new skill set was time consuming, it allowed them to provide assessments that were more relevant to their patients presenting problems and did not anticipate any large changes in their workloads in the longer term.

Management support was an issue identified by team members as crucial to their success in integrating FASD assessment and diagnosis into their practice. While all three teams received management support for their participation, the level of support varied from team to team. One team felt very supported throughout the process and indicated that the support for FASD assessment is likely to be ongoing in their service. One team felt that support 'had to be earned', and that individual support was limited, but once they had proven the worth of the service, support for the program increased. The other team felt supported through the training process, but was unsure about ongoing management support for FASD assessment within their service.

In the case of the group from the Child and Adolescent Mental Health Service, there were questions posed by management as to whether FASD diagnostic services fits within mental health. Because of this question, it was decided that this team could not accept referrals specifically for an FASD assessment, but could accept referrals that query/suspect ADHD and document prenatal alcohol exposure. The team was able to undertake FASD assessments in cases where there was a suspicion of FASD post referral, but this was not considered core work and had to be done as part of a differential diagnosis that considered other mental health diagnoses under the DSM guidelines. This situation has affected the team’s ability to identify and assess clients for FASD, which has affected their ability to present cases during the
training project and brings into question whether an FASD diagnostic team within this service is sustainable or appropriate.

While at the conclusion of the project all teams intended to continue their work in FASD assessment and diagnosis, the issues above make some participants uncertain about the sustainability of their work with FASD. A key concern for the participants was that, given the lack of resources and policy support for FASD, if any of the trained clinicians were to leave their service it would likely have a negative impact on FASD diagnostic capacity within the service.

**Participant feedback on the project**

Despite the challenges identified above, participants’ experiences of the project were overwhelmingly positive, and all participants viewed the training as successful. A factor identified as essential to the success of the training was the strength of the project’s organization, which was in turn a reflection of the steering group’s familiarity with the domain. Participants considered the project’s coordination and organization were particularly important because this involved coordinating professionals with varying roles, timetables, work pressures and responsibilities. According to participants, the professionalism with which the training was organized had a direct impact on their capacity to participate in each stage of the training, as one participant commented, “To get all of us up to Auckland all the time with all our schedules and plan those days and then get us all over to Canada...she (the organizer) was like the glue that held everything together” (Participant 26, 26/5/2011). Participants felt that the organizers had a clear understanding of their work responsibilities with one participant stating, “It was particularly well organized which made it really easy for me to do. It felt manageable within the constraints of having to still do my normal job” (Participant 28, 30/5/2011).

Participants were equally pleased with the specific content of the training. Many complimented the comprehensiveness of the training and the combination of training experiences. According to the participants, the New Zealand-based training undertaken prior to the Canada trip was an important building block in
the program because it helped ground their understanding of FASD. A number of participants said that if they had not had the training sessions in New Zealand they would not have received as much benefit from their trip to Canada.

Attendance at the 2011 International conference on FASD in Vancouver Canada helped participants to gain a greater understanding of FASD in a broader sense including its cultural and social contexts. One participant said the breadth and depth of information presented at the international conference provided opportunities simply not available in New Zealand: “Vancouver was much more important than I would have thought, there isn’t anything available even close to what the international conference provided here in New Zealand” (Participant 26, 26/5/2011).

Whilst most participants felt the conference was helpful, some thought that there were parts of the conference that were not so useful. As the conference preceded the intensive diagnostic training, some of the participants felt frustrated at the lack of clinical information about FASD provided at that stage. They thought that there was an overwhelming focus on scientific research at the expense of practical work with FASD, as one participant put it:

I did come out of the conference feeling a little bit frustrated thinking, well I’m a clinician that’s going to work in this area and I don’t think I have enough, um, new ideas or tools or skills to actually take away and develop and work on. (Participant 27, 27/5/2011)

However, most participants (including the one above) said that the Asante Centre intensive diagnostic training, which followed the conference, addressed that need.

Whilst all participants agreed that the conference provided useful information and opportunities for networking, they had mixed views on whether the conference was essential to the training process. Some felt it was an important part of their learning and engagement with FASD, while others said they would not consider it an essential part of the training program if the program were to be run again in the
future. In contrast, participant feedback indicated that the Asante Centre component of their training was unanimously considered very important. Their comments reveal a clear appreciation for the uniqueness of this aspect of their training. Participants found the opportunity to both observe and participate in the diagnostic practice very helpful. Some elements of the training were identified as particularly useful, for example the opportunity to observe the Asante Centre multidisciplinary team’s diagnostic formulations and meeting with the families:

I liked the way, we watched how they sat down and did their formulations, its slightly different to how we do it and it was interesting the way they fed back without a written report, whereas we always have our report done first and then feedback. There were some interesting differences that we talked about, sort of pros and cons but they formulated and they thought about the cases so similar...the way that we work in our team that was really good. (Participant 26, 26/5/2011)

Participants found the attention given to each discipline helpful, including the opportunity to ask questions and to discuss diagnostic process and case examples with their equivalent Canadian clinician. A number of participants commented that observing the whole diagnostic process gave them new insight into the work of some of their New Zealand colleagues. A paediatrician commented, “I really liked the speech language therapy information we got from there. That was really helpful for us to take back and strengthen our case for including a speech therapist in what we were doing” (Participant 28, 30/5/2011). The participants considered that the Asante Centre training was well organized. They were made to feel welcome and encouraged during the training, and the process gave them a good grounding to take back to their own working environments.

Ongoing access to New Zealand diagnosticians, and opportunities to get together and have group discussions, were also identified as very important parts of the training process. One participant said, “[It is important to] get the information, get the really, really good training and have that ongoing support for a while so we can go off...and do it ourselves really” (Participant 25, 26/5/2011). Access to the New
Zealand trainers who were clinicians with experience in the field helped the participants to put their learning into practice with the support of professionals with experience in the area and knowledge of the New Zealand context. However there were concerns about what would happen once the pilot project finished, as many of the participants felt that ongoing mentoring would be necessary while they continued to fine tune their skills in the area. Subsequent discussions with one of the New Zealand trainers revealed that some level of mentoring is still occurring, however, this is not funded and is done out of the goodwill of the trainer, who works in private practice.

**Conclusion: Post-training developments**

While the training project ended in 2011, there have been further developments arising from the project and the ongoing capacity building for FASD in New Zealand as result of work by Alcohol Healthwatch, the project’s trainers and professionals who have become aware of FASD through those involved in the project. There has been recent training in mid 2012 of a further three diagnostic teams in the North Island of New Zealand in a similar manner to the pilot project (without the International conference component, which was not available at the time) and the development of an online support group which was originally set up by Alcohol Healthwatch as a general FASD network site (FASD network New Zealand) but has recently been taken over by families as a network and support group for families. The development of this family-based network is largely a result of an increase in the number of individuals diagnosed with FASD by the teams involved in the pilot project. Whilst a systematic governmental response to FASD is yet to eventuate, it is clear that the projects described above and other capacity building efforts by interested organizations and professionals have contributed to building momentum for addressing FASD in New Zealand.
Chapter 7: Perceptions of alcohol consumption and FASD

As already established in this thesis (in Chapter four), professionals’ personal views and experiences play a role in their practice. This chapter intends to explore this phenomenon in more depth by presenting the personal views and experiences of the health, allied health and social service professionals who participated in my research. While I did not initially envision this topic as the subject of an entire chapter, the extent of the commentary I received during the interview process made it impossible to ignore. Many of the research participants articulated an experience of reflecting on their own past drinking, and often on their own or their family or friends’ pregnancies, after participating in training for FASD, and this produced a rich body of discourse, from which the excerpts in this chapter are drawn.

This chapter is structured in two sections, reflecting the two alcohol-related issues most commonly discussed in the interviews. The first of these is a discussion of participants’ own experiences of pregnancy and views regarding alcohol consumption. The second is a broader discussion of the issues that the participants perceived in New Zealand drinking culture in general.

Personal views and experiences of drinking and pregnancy
Health professionals are not excluded from direct, personal experiences of, and attitudes towards, drinking and pregnancy. Many of the participants in the training were parents themselves, and they discussed stories about their own experiences of alcohol consumption or those of their spouses, friends and peers. They also drew on their personal experiences to talk about their broader views on alcohol, New Zealand’s drinking culture, societal attitudes to drinking, drinking during pregnancy, and FASD. The complexity of this issue is reflected in the observation that many participants were not aware of the risks associated with consuming alcohol when they (or their partner) were pregnant with their own children, regardless of whether this was twenty years ago, or somewhat more recently. This indicates that a lack of awareness of the risks of alcohol consumption during pregnancy is an ongoing issue. As one participant shared:
I think that people still believe, and I still believed five years ago, not two years ago when I had [my second child], but five years ago when I had my first daughter, I thought I could have a drink or two in pregnancy and they would be fine and it probably is true, and it isn’t [true] for people who drink a cask…now, having been to the conference, I wouldn’t drink in pregnancy. And I would tell my friends not to. They can make their own choices, but having seen [in research] from my very scientific brain, how it affects molecules in the brain, that’s what made the difference for me… (Participant 30, 21/6/2011)

A number of participants said that, while they had an awareness that alcohol consumption during pregnancy was ‘not ideal’ or could ‘affect the fetus’, they did not understand exactly how the fetus could be affected and what the potential risks of alcohol consumption were. A number of the participants from the interventionist group did not previously know that FASD was a possible outcome of alcohol consumption during pregnancy, such as one social worker, who said:

When I had my children I didn’t know about fetal alcohol…the midwives never said anything, the hospital never said anything about it, there was nothing at all... I knew that drinking alcohol during pregnancy was wrong [but] I didn’t have any further knowledge... or that one drink or two drinks could have a huge impact on that baby, I didn’t know at all. I think I just went on my basic knowledge of right and wrong, that you shouldn’t really drink alcohol because it is not that good. (Participant 23, 23/5/2011)

Despite the now standard warnings provided by the Ministry of Health concerning alcohol consumption in pregnancy, most of the participants in this research were unable to recall, when asked, whether they had been given any formal information about the risks of alcohol consumption during their own pregnancies or those of their partners. For one participant who was able to recall being given a resource, the information in the pamphlet provided to her was contradicted by the advice of her obstetrician that having a glass of wine would be fine, as she said:
I mean you get the pamphlets around, I mean I'm just thinking my experience of being pregnant, my obstetrician, he said to me: “do you have any funny cravings?” And I said: “Oh it's really weird, I'm really craving beer”, and he laughed, and he said: “Well, if you wanna have a glass of wine every now and then, that would be fine”. And I thought that's only five years ago, and [so] it's really interesting how the message out there is still not actually [clear]. I mean, we know it's dose dependent, you know, but he had made a, what's the word, an assumption on me that I was a white middle class woman who wouldn't [binge drink] whilst I was pregnant. How does he know that I wasn't a raving alcoholic, you know and that one glass of wine would actually lead to five? So, I don't think there's enough care around the information that's given. I mean, there's posters up where you go into the midwives, but you know, they ask you alcohol and drugs in your first [session, and] if you just say no then it's glossed over, I mean I really don't think much attention’s paid to it at all. (Participant 26, 26/5/2011)

Mixed messages that women receive about the safety and risks associated with prenatal alcohol consumption permeate both the health sector and society in general according to participants, resulting in unclear information for women. These confusing messages, coupled with a lack of community awareness of the potential risks of alcohol consumption during pregnancy, make alcohol consumption during pregnancy a difficult topic to broach with clients. Whilst participants developed ways of asking about alcohol use within their professional practice as a result of the training (as discussed in Chapters five and six) they still considered this a challenging thing to do. Some also talked about how uncomfortable it is to just talk about alcohol and pregnancy in familiar social settings, including with their friends and family, for example one said:

A friend of a friend of mine was pregnant quite recently and I was talking to my friend and I knew she was a bit of a drinker and I said: “Oh, is she still drinking?” And she said: “yep, she is still drinking” – two units twice a week because she thinks that is OK, and you can’t tell her otherwise, and I kind of
didn’t see her because I didn’t want to. I felt quite torn because I knew I would lose a friendship… (Participant 30, 21/6/2011)

This participant attributed her discomfort, at least in part, to unclear messages about alcohol and pregnancy, and insufficiently clear information about the risks of alcohol consumption during pregnancy compared to other risks in pregnancy such as smoking:

I think there needs to be a global message of drinking in pregnancy… you know women don’t smoke in pregnancy, well very rarely. And if you see a woman smoking and they are pregnant … it makes [me] feel quite physically sick and I want to go up and say to her: “You shouldn’t be smoking.” But I know that she knows, and so I often don’t, [and] I don’t think we have got there with alcohol in pregnancy. I do see a time when we will be there, but it kind of has to be a gently, gently approach. And it does have to be [gentle]: you are going to have to break down some of those other myths like, you know, teenage sex… …you’re teenagers, you are drinking, you are having sex, do you want a fetal alcohol child? (Participant 30, 21/6/2011)

Another participant reflected on her personal experience to talk about how ‘risk’ should be discussed in the community, using her own experience of pregnancy to highlight her concerns on the lack of community awareness:

Obviously I would like to see that all woman get advice, I mean even my own, you know, me having had kids, twenty-odd years ago and I think I didn’t know that … you should stop drinking when you started to think about having a child. And then you start to look at your own child [and think] “Oh, my God is there [a risk] there? I didn’t know that”. I did drink and I stopped when I got, when I found out I was pregnant, you know. So there’s always that, but I think it’s getting out that knowledge… you know, and that it’s a Russian roulette. Now, if you’re into playing Russian roulette that’s fine, play the game, but that’s what you’re playing and I guess that’s
the concept I'd never, never had, as someone wanting to have babies.
(Participant 27, 27/5/2011)

Another participant compared the social complexity of alcohol consumption
during pregnancy to smoking and cancer:

It’s like people used to say about smoking and cancer years ago: “but my
grandfather smoked 80 a day and he lived until he was 98 and he was fine”.
You know there has to be genetics in there as well and I think it's still really
hard, I think there is a whole sense of people can make their own decisions
but I don't think people are educated enough. (Participant 30, 21/6/2011)

On the topic of education, another participant used the analogy of 'Russian
roulette’ in order to emphasize the importance of educating the community of the
risks of alcohol consumption in a way that is clear and realistic, others used other
health issues to draw analogies of risk. A number of participants associated the
risk of alcohol consumption in pregnancy and FASD to that of smoking:

I guess for me the analogue is a little bit like smoking and lung cancer. You
know, if you smoke, everyone can probably quote someone who smoked for
years and years and years, but they didn't get lung cancer. But [there is]
clear clinical evidence to show the risk is significantly increased, because of
the people who get lung cancer, a huge percentage of them are smokers...
So I think... if we start making rules our society will reject the rules unless
the rules are actually explained fully. (Participant 27, 27/5/2011)

Confusion surrounding the risks of alcohol consumption in pregnancy also extends
to misinformation about FASD within the allied health sector and general
community, according to the participants. One commented that:

I had a mum at [my child's] school ask me about it and she is a mental
health nurse and she kept on saying: “Oh yeah, yeah I know a bit about it
and it’s about facial features... it’s about the [distance] between their eyes.”
And I went: “No, no, no, no, it doesn’t have anything to do with it,” and there is a lot of misinformation. There is a lot of things that people think, they think they know a little bit about it and so that was a bit scary for me because if I am going to diagnose somebody, I don’t want you thinking that the distance between their eyes is too big, kind of thing, yes it might be but that actually has no effect on the whole thing. So [it is about] getting some information out there but getting the right information. (Participant 31, 7/6/2011)

This confusion was also understood by the training participants to extend to misinformation between and amongst health professionals, as one participant stated: "We have had some of the paediatricians here, after the diagnosis of partial FAS say, well that is not as bad as full blown [FAS]. And it’s like well hang on a second, its partial but that is probably because of the [lack of] facial features, [even though] the cognitive stuff is the same.” (Participant 31, 7/6/2011)

One participant said that she had first come into contact with FASD in the 1990’s when she fostered two children affected by FASD. She knew nothing about it at the time, and explained that she was given very little information other than an explanation of the physical features:

The doctor just went over, explained more of physical symptoms, you know, like the wide bridge of the nose and the almond shaped eyes, and I distinctly remember him talking about an odd shaped bottom, I can’t remember – it was a long time ago – but a whole lot of different things like that. We weren’t informed about anything, any developmental issues or anything on how to deal with any behaviours, or anything like that. After knowing a bit more about it now, it would have been really useful back then, because you go from a completely different approach. You know rather than that corrective behaviour thing, [you might pursue generating] awareness and acceptance and working within their limitations. (Participant 12, 9/2/2011)
Some participants postulated that lack of knowledge of FASD was one reason why health professionals do not engage with FASD in their practice. Another reason given was that health professionals can feel challenged by FASD because of their own experiences with alcohol. Personal experience can impact professional practice, as one paediatrician illustrated through her own experience:

I think we [health professionals] all just try and keep deluding ourselves. My GP doesn’t like to ask me about my alcohol use. It’s really funny, he doesn’t want to go there, but I think that’s because he drinks like I do, and so he doesn’t want to have to think about it himself... So one of the things, in all the stuff [Alcohol Healthwatch] sent us, there was loads of stuff about assessing people’s drinking habits, and my husband and I sat down with it and went “huh” and immediately went out and bought smaller glasses. So it’s things like that can make you stop and look at it a bit further. Like, you know, we don’t consider ourselves problem drinkers, but we drink very much like an awful lot of our peers, which is more than what the booklet suggests. But it’s just that societal concept that drinking is acceptable isn’t it – it’s the drug of choice. (Participant 28, 30/5/2011)

A male participant demonstrated similar awareness of the issue:

It is such a pervasive social issue, it’s got political and economic ramifications which then impacts on kind of how... it shapes our thinking, I think that’s where you’ll find some of these kind of sceptical attitudes and certainly some of my colleagues you know have said: “Oh, I don’t really like to think about fetal alcohol because you know I think of when I was pregnant and I drank a tiny bit or I drank quite a bit, did that damage my kids? But they kind of turned out all right.” Or when my wife was pregnant or my friend... (Participant 33, 20/6/2011)

Overall, these commentaries reveal a strong degree of self critique, as well as social critique, that may have been absent, or at least not articulated, prior to the participants’ engagement with FASD training. In most cases, participants reflected
not just on themselves but also on their peers, indicating a willingness to view the problems associated with prenatal alcohol consumption as existing at the wider community level. I will now explore this further through a discussion of participants’ comments about New Zealand’s drinking culture.

**Attitudes towards New Zealand’s drinking culture**

Most of the participants in this research reflected to some extent on the broader problems associated with alcohol consumption in New Zealand, which they related to their own observations of (and participation in) New Zealand drinking culture. These views, which were also informed by media coverage and, in some cases, research, reflected a general opinion amongst the participants that New Zealand has a problematic drinking culture, especially with regard to binge drinking.

Participants articulated their own perceptions of the likelihood of risk and harm arising from binging for particular segments of society, especially youth, and whether economic factors also have a role to play in some segments of society being more exposed to FASD-related problems, and what assumptions result from this. One broadly acknowledged observation arising from this broad discussion was that society’s perception of risk and harm seemed to be linked to notions of acceptability and legality, as one paediatrician elaborated:

> If I went home and smoked a joint every night people would think badly of me, when in actual fact I’d probably do myself less harm… ...It seems to be more about, um, you know, whether it’s legal or illegal rather than risk. It’s another construct I’m trying to bash away at in the community. (Participant 28, 30/5/2011)

Another participant extended the idea that illegal drugs are more dangerous than alcohol arguing there is a perception in the community that some types of alcohol pose more risk than other types of alcohol:

> Some people would say [that] a glass a wine [or] a glass of beer is not as dangerous as a hard spirit, you know, people might categorize things, oh there’s no harm in a beer, you know people have a beer every night, there’s
nothing wrong with a glass of wine, because they drink wine like they do coffee. (Participant 19, 29/4/2011)

Participants observed a tendency in society for alcohol-related harm to be linked to the problem of addiction, and there was a perception by some participants that the other potential risks of social drinking were minimized, whilst addiction was foregrounded. As one paediatrician put it:

I think we're so fixated on drunk people that we're just letting all the drinkers who are not drunk kind of swing by, but it's pretty easy to drink at home and drink more than is good for you without ever feeling drunk or getting into any sort of trouble or mischief, but just quietly drinking more than you should. (Participant 28, 30/5/2011)

Another participant believed there to be a considerable lack of understanding of addiction in the community, and framed the problematization of addiction in terms of oppositional discourses of individual vs. social responsibility:

If people feel like you drank in pregnancy, and you have a difficult child, then that's your problem, not seeing that addiction is, it's like most mental health [illnesses]. People feel it's the individuals responsibility and don't see it as a disorder or disease or something that needs treatment and so until there is a shift in that kind of thinking. People don't feel like they need to take a societal responsibility for managing it. (Participant 30, 21/6/2011)

The complexity of the discourse around perceptions of risk, addiction, 'social' drinking, blame and stigma, was further expanded by a paediatrician who compared the perception of alcohol and illegal drugs with that of legal but socially stigmatized methadone programs:

To say, you know, that somebody on a methadone program is probably safer than somebody who's drinking in a white middle class way... ...Although methadone means you're probably using other things too, but,
you know, actually it’s easy to point your finger at certain sector of society when we should be pointing it more widely. (Participant 28, 30/5/2011)

This view, particularly the notion of ‘drinking in a middle class way’, points to further views raised by a number of participants about drinking norms and perceptions of risk-based on class and gender lines. Whilst some participants articulated that the risk of prenatal alcohol consumption crosses social strata, some of participants, though hesitantly, expressed a perception that there is an imbalance between working and middle class families’ education and knowledge around the risks of alcohol consumption and pregnancy. For example a social worker said:

I think the educated young women now don’t drink during pregnancy. I might be wrong, because I’m aware that there’s a whole sort of middle class of educated women who drink quite heavily too. So I’m not sure about the effects of that. I guess the people I see tend to be at the lower end of the social economic strata... ...For the wider community, I’m not sure that there is enough [information] out there. Certainly at the lower socioeconomic level, I would very much doubt it, and I would question – and have done for a long time – what is taught in school about these things? (Participant 22, 24/5/2011)

Whilst not all participants agreed on this issue, a large number suspected that women often reverted to uninformed opinion as the basis for their decisions about drinking:

Lots of our people drink through pregnancy, and nothing – there is no noticeable effect on the child that emerges. So you get: “Oh well, I drank with my last two pregnancies and nothing happened so why would it happen now?” Or: “My mother drank through all [her pregnancies]” – and that’s the attitude that you get. ( Participant 2, 18/11/2010)
Many participants attributed this fall back position to poor community education concerning the risks of alcohol consumption, and conflicting information and messages in the community from the media and health professionals about what is a safe amount of alcohol to consume during pregnancy. For example an allied health service manager said:

I think there’s still mixed messages to pregnant women. We’ve still got conflicting information coming out on national TV around the use of alcohol. And we’ve still got the perception it’s not OK to challenge pregnant women if they’re drinking, you know. So we’ve got a society that doesn’t want to address these issues, and that makes it really quite difficult. (Participant 13, 31/1/2011)

Access to information and support was paramount according to participants, especially in situations of habitual alcohol use. One social worker was adamant that FASD would likely be a major unacknowledged issue for families in which there was entrenched alcoholism:

I know that I’m horrified at the number of referrals I get for domestic violence where over-consumption of alcohol is an issue... women are drinking a lot more in a way that they weren’t back a generation or so. Therefore, one has to, I guess, assume that that affects women who are pregnant... ... So if you live in an environment of alcohol, heavy alcohol consumption, whether it’s with a partner, whether it’s with a family history – I think there are some women who are aware and would give up alcohol, but within those sorts of groupings, I would be cynical about how many. That’s where, I think, the education needs to be targeted. (Participant 22, 24/5/2011)

The issues surrounding alcohol, women and social control, as identified in the theory discussion earlier, was raised by some participants, with some highlighting discourses around women’s rights and equality that need to be considered when discussing maternal alcohol consumption and risk. One participant went as far to
suggest the potential for legal and moral consequences for FASD-related harm, questioning why nothing can be done legally prior to birth to stop women from consuming alcohol and keeping the baby-to-be safe. However, despite these views, she considered how such social and legal controls could impact on the rights of women:

It’s a difficult one, I think, because I’m a person who does believe in people’s human rights and the right to make decisions for themselves and to live life the way they want to live it. However, because I work right in the midst of this, I think it’s hard not to be asking the questions of yourself when it comes to children, and unborn children. Who do they actually belong to? Do they actually belong to the woman who’s having them? Do they belong to wider society? (Participant 22, 24/5/2011)

Despite a broad discussion by a number of participants around discourses of women and social control, only one, a male participant, discussed the role of men within the discourse of women and alcohol consumption. He was one of two participants, both male, who discussed concerns related to the politics of social control in depth:

Are we trying to control women? It’s the whole thing about social medicine as well, so much seems to be about social control and because… we focus so much on in terms of individuals as well… it focuses on women as the problem, and women’s drinking happens in a context: it happens in the context of a society that values alcohol and is permissive around that. How are the men talking and supporting the women around this? I still think, within our cultural framework, it sets women up to be the problem and that makes it really hard for them to actually talk about it, for professionals to ask those questions, for women to actually answer honestly. It positions women as harming their children and women don’t go out intentionally to harm their children. (Participant 11, 27/1/2011)
A number of participants discussed their concerns, research-informed or otherwise, around an increase in alcohol consumption by women that might have an adverse effect where FASD is concerned. A number held the view that women in New Zealand are drinking more than in the past, while others extended this to a newer acceptance of binge drinking by women as a norm. However where the issue of binge drinking is concerned, participants framed this as largely a youth issue, linking binge drinking to other aspects of behaviour such as unprotected sex, which was itself singled out because of the possibility for pregnancy to result, given the FASD-oriented context of the discussion. Some of these observations probably reflect the current life-stage of the largely middle-aged, established, professional participants, for example: “I’m old and I’m really concerned about the young people and their binge drinking... ...hopefully most of those young people who are really binge drinking by the time they’re thinking about having children won’t be doing it quite the same way.” (Participant 27, 27/5/2011)

On one hand one participant expressed concern about the high levels of binge drinking happening with young women and how, this coupled with unplanned and teenage pregnancy presented high risks for young women:

Young people are the biggest, you know, drinkers, and like to take sexual risks. It kind of links in together with pregnancies that are unplanned, [which] might be alcohol exposed. So, just because of our particular demographic, there would be group there that we would be keen to get to, but I don’t feel I want to take my eye off myself and my peers, who are equally capable of spawning children and putting their children at risk by what they consider to be reasonable drinking behaviour. (Participant 28, 30/5/2011)

But, on the other hand, another participant highlighted a particularly personal training experience where a mother with whom she identified talked about her experience of having a child with FASD: “I really appreciated her talk, I thought, oh, my God, this woman is me and yet it can happen to her. That’s what I think we
need to get across, I don’t think it is a socioeconomic effect purely” (Participant 27, 27/5/2011).

Despite their concerns regarding the perception of an increase in women’s drinking, participants observed a general view of the normalization of alcohol consumption, including binge drinking, amongst their peers and in society in general. On this matter many participants spoke at some length, including one paediatrician who said:

I’m really intrigued actually because I think that in my peer group we all drink too much, and we all [collude] in not thinking about it very hard. That we all accept it, it becomes normal to have a glass a wine most evenings, and it’s cheap and it’s not, you know, it’s not abnormal. And we’ve normalized it to a degree that we don’t stand back and go, actually, you know, thirty years ago people didn’t use to keep wine in their houses, and they didn’t have it every week, they had it on a Christmas and birthday’s and that’s it. And it was normalized enormously and because we’re drinking it changes it for our kids as well. It’s very normal, even if you’re not getting drunk, you know, I don’t get drunk every night, but I do enjoy a glass of wine, but I’m still drinking. (Participant 28, 30/5/2011)

When engaging in discussions on FASD and women’s drinking a number said they had to confront their own practices and experiences, as one admitted:

I would have to put my hand up and say I would consume alcohol several times a week, and I think that’s become quite normal. What I mean by that is a couple of drinks sometimes after a hard day at work, social events, that kind of thing, so I think the general consumption of alcohol by women in this country has increased. (Participant 22, 24/5/2011)

Participants perceived a resistance to acknowledging alcohol-related problems in society. In some cases participants attributed this to normalization of alcohol, which in turn minimized perceptions of risk:
You hear very little about FAS... because we’re a culture of drinkers and if we start talking about that, people are going to say: “Well, you know bugger you, I want to drink.” There’s no recognition in society that alcohol is probably one of the more damaging drugs that we actually have out there and it’s freely available. (Participant 2, 18/11/2010)

However, a number of participants raised the observation that alcohol consumption is a highly politicized issue in New Zealand. Some believe that alcohol-related harm is minimized in New Zealand because of politicians’ own personal views and experiences of alcohol and political and economic pressure on the government by the alcohol industry:

Think about how much the New Zealand government gets from excise duty in a year. I don’t carry this number in my head anymore because it is a horrifying number, and I think it’s in the billions, and if you think the sophistication of the alcohol industry in its marketing initiatives and just how much you can do with money in terms of shifting people’s perceptions... Juxtapose that with the [actions of the] tobacco industry prior to the acceptance that in fact smoking cigarettes does cause lung cancer, and does cause chronic obstructive pulmonary disease like emphysema, and is not that good for your health... (Participant 33, 20/6/2011)

Other participants said that New Zealand had progressed some way to highlighting alcohol-related harm in some areas such as drink driving, family violence and the impact on the criminal justice system, and so questioned why there was a reluctance to highlight health risks especially those related to pregnancy and alcohol use. One participant went as far as to claim outright that the politics around alcohol is one reason why FASD is not recognized in New Zealand. She argued that addressing alcohol-related risk in pregnancy mean the government would need to acknowledge and address FASD:
It’s really bigger than us, its hugely political, you know, because we are talking about alcohol as the poison that poisons our children in so [many] ways, but it does it even pre their birth, in-utero right through to teenagers and so if we face our own demons about that we have to face the FASD kids as well. (Participant 14, 22/10/2010)

**Conclusion**

In general, the overall impression provided by these discussions is that participants often viewed the problems associated with alcohol consumption as being well beyond their ability to control or even begin to approach. This was especially the case for participants from the interventionist group. These comments reveal that health and allied health professionals’ own experiences, views and opinions of alcohol and drinking culture play a part in how they conceptualize an issue like FASD. Many of them clearly have the capacity to imagine themselves in a position of harm or risk, despite their relatively high levels of education, income and professional status, dispelling the perception of FASD as an issue affecting only socially and economically marginalized segments of society. However, this empathy also revealed a level of insecurity with regard to how to broach the topic of prenatal alcohol consumption with peers.
Chapter 8: FASD and diagnosis

The training exercises that were central to the ethnographic process underpinning this research involved two cohorts of trainees: those working in the domain of clinical diagnosis, and those working in areas of social, behavioural and medical intervention. While both groups had similar reasons for engaging in FASD training, the nature of their work and the characteristics of their engagement with service users differed substantially. This chapter presents the views of the diagnosticians who participated in the training on multidisciplinary FASD diagnosis and their perspectives on how FASD might fit, or might not fit, within their professional practice. It explores, often in the participants’ own words, the challenges of providing diagnoses for FASD, and reveals the strategies that they use in approaching this particular issue in their work across a range of professions including paediatric medicine, neuropsychology, clinical psychology, psychiatry, and speech and language therapy.

In this chapter, the findings from the interviews and participant-observation ethnography undertaken with this cohort are presented. These findings reflect four discursive themes: the benefits that can eventuate from diagnosis, arguments against diagnosis, self-critique of current practice, and, overarching all these, the desire to strive for better outcomes for the individuals and families who they encounter in their work, whether through the provision of assessment and diagnosis of FASD, or even just through their enhanced awareness, as professionals, of the potential for prenatal alcohol consumption to be a factor in the complex presentations of those who fall into their care.

The benefits of diagnosis

Foremost within the views of participants in this research was the conviction that learning to provide FASD diagnosis was likely to result in a range of benefits for individuals affected, families, other health professionals, community service professionals, the New Zealand health system and the community at large. In all cases, this conviction was a factor in their decision to undertake the training in the first place. The benefits identified by the training participants fell into four broad
areas of discussion: the visibility of FASD, the effectiveness of intervention, the potential to reframe community perceptions of FASD, and most importantly, the potential for preventing secondary disabilities. These four categories will provide the structure for the ensuing discussion.

Visibility
The lack of visibility of FASD was a key concern of most of the diagnostician participants, who were adamant that public and professional awareness was a major barrier in handling FASD within the New Zealand health system. They noted that the invisibility of FASD impacts on how individuals with FASD are treated, how the health system deals with FASD and how the broader community understands the potential impacts of drinking during pregnancy. A shared sentiment was that, in the absence of diagnosis, “…it is very easy for people to say that it doesn’t exist” (Participant 31, 7/6/2011).

A clear diagnostic process had the potential to make FASD visible, and thus counter these potential issues, as well as providing a means to proactively seek further assistance through support service funding and even funding for research. By making FASD visible, diagnosis was seen by participants as a tool to begin to identify the scale of FASD, especially given that no prevalence studies of FASD in New Zealand yet exist. The health system was itself described as presenting cyclic barriers with regard to FASD, as explained by one participant:

If we don’t start diagnosing it, then we don’t create the evidence of a need and therefore we don’t ever get funding for an intervention because there’s no [evidence of] need… It becomes cyclic, so somewhere we’ve got to break that cycle. (Participant 1, 10/11/2010)

Participants saw diagnosis as a starting point to addressing this issue, however, a lack of resources for diagnostic teams and the general lack of intervention and support programs for diagnosed FASD presented a barrier to diagnosis. Some participants were hopeful that their role in the pilot project would not only allow
them to articulate a need for increased funding for FASD at a health management level, but that they might also have some direct utility at grassroots level.

The (preferred) multidisciplinary model of diagnosis had the added benefit of potentially highlighting an individual’s strengths and deficits more specifically, thus clarifying the challenges for the individual, including how apparent strengths can actually mask deficits. Indeed, one of the main post-training reflections of diagnosticians was that it is common for professionals and families to overestimate the abilities of an individual with FASD due to their apparent strengths, and that overestimating a person’s ability can lead to unrealistic expectations, which in turn can lead to frustration and negative perceptions of the individual with FASD. In the words of one neuropsychologist:

People would be shocked at how impaired these kids are… ...I have worked through most of my career with kids who have severe traumatic brain injuries; so they have had focal brain damage, global brain damage, but they have developed normally until the day of their injury, and these FASD kids have got as much brain damage as these kids who have had severe head injuries, but it’s been developmental, it is not evident when you just meet them and first look at them, until you test them you don’t know that. That’s the kind of power doing the neuropsych testing has. (Participant 32, 20/6/2011)

Finally, participants were positive about diagnosis as a means for making FASD visible in broader society. It was frequently suggested that increased visibility can create awareness of the potential harm of alcohol consumption during pregnancy, thus acting as a form of prevention. As one paediatrician stated:

Ultimately it’s [diagnosis is] prevention. It’s making people aware of it, so that it’s talked about, people think about it and it’s unacceptable for pregnant women to be with a glass in their hands...that people just start thinking about their drinking a little bit more really. (Participant 28, 30/5/2011)
**Diagnosis as a support for intervention**

With regard to intervention, diagnostician participants were unanimous in their appreciation of diagnosis as a means of providing explanations and assisting in the development of appropriate interventions for those affected, as well as providing support for their families. The significance of this is such that some participants argued that diagnosis should be seen as an intervention in itself. Reflecting a shared sentiment of many in the group, one participant stated that an individual’s ability to know and understand their disability should be seen as a basic right, as this knowledge can inform the individual’s engagement with society and shared an example of her practice to demonstrate why:

> Even though he’s [the patient] got quite a simple understanding, it was possible to explain that to him and I believe that is knowledge he is entitled to know and that not necessarily now, but in time, will improve his outlook, even though there may not be any services available to him. The fact that people acknowledge that he has got a disability and that’s why he has got these problems, and that family or services, CYF or the courts understand, that is important. (Participant 32, 20/6/2011)

Presentations of FASD can be varied because each individual is affected differently. However, a further benefit of diagnosis is that the needs of the child are clarified and the underlying cause of behaviours and disabilities are explained, as demonstrated by one participant:

> We have done two assessments, and one of the kids zones out, and the other lashes out. ...You know you need to identify both of those issues...and you need to understand why. One of the little girls...is not understanding at all... she just sits there and stares into space and she is at real risk because the teacher won’t notice...until further down the track and all of a sudden she can’t read. Whereas the other guy that lashes out, he has got all of these people involved because he is naughty...he has had twenty-four behaviour
things in six months...no wonder he doesn’t like school. (Participant 31, 7/6/2011)

Once professionals and families are aware of the nature of the challenges they can employ useful strategies for addressing them:

Unless you actually identify the nature of the problem and confirm that that is the problem, then you don’t know how to deal with it. You know these kids have got specific needs that are different to the needs of other kids, say with just ADHD without FASD or other conditions and it’s a much more global brain damage picture and it’s a much bigger disability... Unless that whole picture is taken into account in that child’s life, then whatever is put in is not going to be effective. (Participant 32, 20/6/2011)

**Reframing perceptions**

Diagnosis was also identified as having a potential role to play in fostering understanding and reframing perceptions amongst affected individuals and their families. Prior to diagnosis, individuals with FASD are often labelled as troublesome, defiant, bad, lazy, attention seeking, inappropriate and similar according to some participants. These labels can be a result of frustration by professionals and families who, with good intentions but a lack of understanding, have applied behaviour modification techniques to address perceived behavioural problems with no effect. Research participants raised behaviour modification techniques as a particular issue as these techniques commonly do not work with FASD-affected individuals because they do not account for the underlying brain dysfunction, which is usually the cause of the behavioural symptoms. In this context, FASD diagnosis helps individuals, families and professionals to understand the nature of the individual’s disabilities and reframe potentially negative perceptions. Thus, a diagnosis has the potential to help families and professionals to understand why some interventions don’t work and to reframe expectations, as one psychologist said:
It gives parents an explanation for why all the things that they are doing may not be working, and it helps parents set realistic goals for their children, so that they won’t constantly feel like their child’s letting them down in some way. (Participant 27, 27/5/2011)

A diagnosis can also help individuals with FASD to understand why they have certain challenges that may be different to their peers in some areas. These explanations can help individuals with FASD to reframe internalized negative perceptions of themselves. One participant raised this issue in relation to a particular client:

[Diagnosis is] very important, because she is now starting to have an understanding of the nature of her problems... She now knows that she was not a naughty girl who got expelled from school for no reason. She is now starting to understand why she didn’t learn to read when other people did, why she was different to her siblings and why she is at risk of offending because of impulsivity and recklessness and various other things. (Participant 32, 20/6/2011)

How people understand a condition dictates how they deal with it. The training participants argued that simple changes in the way professionals and families approach interventions can be an effective in addressing the needs of individuals with FASD, regardless of their access to services, in other words, approaching an understanding “of the young person’s difficulties and not to expect change in the person, but expect change in the environment” (Participant 25, 26/5/2011).

**Secondary disabilities**

This concern with reframing the perceptions of individuals also crosses into the domain of managing secondary disabilities. As established earlier, ‘secondary disability’ is a term used to describe disabilities that arise due to lack of understanding, support and effective interventions for an existing, underlying health issue. Diagnosticians were very interested in this with regard to FASD, and through their training became aware of international research that corroborated
their developing views concerning the benefits of preventing secondary disabilities:

[Diagnosis] help[s] the young person and the family understand what their strengths are and what their vulnerabilities are so they don’t wind up putting themselves in situations that are risky. I’ve seen a lot of good things come out of that...[and] having young people, their families and professionals, like police and judges actually understand why this is happening... rather than automatically focusing on the young person as ‘bad’ as the only explanation for their behaviour, when, actually, they have real problems in being able to plan and sequence and make good decisions. So I think [recognizing] secondary disabilities, and kind of playing to the person’s strengths, minimizing deficits, and also the insight and understanding that people effected by FAS can be treated better kind of gets them out of inappropriate places, like prison and places which can actually do increasing amounts of harm [is a benefit]. (Participant 33, 20/6/2011)

Arguments against diagnosis

While participants were firm in their perceptions that diagnosis could offer clear benefits to patients with FASD, these perceptions were accompanied by a corresponding awareness of the arguments against diagnosis that exist in discourse surrounding FASD, which relate to five areas of concern: the lack of intervention services, the inability to effect change because of permanent brain damage, the stigmatizing and blaming of mothers for the child’s condition, the lack of evidence for FASD prevalence in New Zealand, and the enduring (if inaccurate) perception that illicit drugs cause more prenatal damage than alcohol. While largely unperturbed by these concerns, participants nevertheless identified them as part of the picture where the decision to undertake or facilitate diagnosis is concerned.

Inadequate intervention services

As professionals trained in providing a range of diagnostic services for children, the participants in this research demonstrated a clear understanding of the
relationship between diagnosis and intervention, and identified the lack of intervention services for FASD as a barrier to providing effective diagnosis. Indeed, the lack of informed intervention service providers was used by some diagnosticians as a justification for not previously providing FASD diagnoses in their work, and was a matter of continuing concern, as one participant articulated, “I think for me, there is this whole thing about why are we diagnosing. Technically, they do not qualify for more services just because they have a diagnosis” (Participant 31, 7/6/2011). Another participant raised inadequate intervention services as a factor affecting the way she spoke about possible FASD to families accessing her services. While she found it difficult enough to ‘drag up the past’ in discussions with families, this difficulty was compounded by her lack of ability to direct families to appropriate ongoing support services post diagnosis. This concern, to greater or lesser extent, was shared by all of the participants in the research.

A number of participants highlighted that an FASD diagnosis does not necessarily qualify an individual to access existing services within the health, disability and education systems. This is exacerbated by the fact that little if any health funding is attached specifically to FASD. However, participants were also in agreement that this in itself was not a good enough reason to eschew FASD diagnosis completely, as to do so would constitute compromised service provision. Rather, as mentioned previously, health professionals argued that a multidisciplinary diagnosis with a list of recommendations may be seen as an intervention in itself because it allows for a nuanced understanding of the individual’s strengths and deficits. Beyond this, professionals also raised the point that simply providing the information in the first place was an important act of assistance for persons affected by FASD:

Even though there may not be places to refer to, I think it is important that families have that information and, you know, there is so much literature available, even though we may not be able to find services, you can give schools literature… …I think that thinking ‘there are no services, so why diagnose’, is ridiculous now. I don't know why I even used to worry about it because you know it’s our job to do this, and services will come as time goes
on, and you can’t just not say what you think because there is nothing down the line in my opinion. Just knowing is better than not knowing. And these kids are entitled to it, I think. (Participant 32, 20/6/2011)

FASD as a permanent condition
The brain damage associated with FASD is permanent. In the context of their health sector work, the participants in this research frequently encountered others who were disinclined to engage with FASD because of the perception that there was nothing that could be done to improve the health outcomes for affected individuals:

A child was diagnosed with FAS by a colleague at CAFS, and whilst I think it’s the correct diagnosis, what the social workers have come away with from that was that it’s a biological disorder we can’t do a thing to help it ...And it was like, no, if it’s a biological disorder we can’t fix it, but we can manage it and then, this is how you do the next bit. (Participant 28, 30/5/2011)

Participants explained that this argument stems from the premise that, in order to provide effective intervention, one must be able to treat or change the affected individual’s behaviour. Some participants viewed this as a particularly strong discourse within mental health service provision, as one put it:

I think they [health professionals] struggle with the fact, well, intervention, what do you do then because you know, you can’t change the brain injury. We [the diagnostic team] keep talking about, the more you have to create the external brain in the environment and change the environment. It’s a big shift from people doing individual talk therapy and CBT and all these other things that they’re trained in to actually work quite a different way. So I’m not saying they’re resistant, but it’s hard for them to get their head around... (Participant 26, 26/5/2011)
Another participant said that this issue has been an ongoing barrier amongst his colleagues, but that such blanket dismissal of FASD as a biological disorder does not consider the range of interventions available, nor the question of how secondary disabilities are managed or prevented. Participants agreed that FASD intervention required a shift in thinking from a focus on changing the individual to a focus on adapting and changing the familial and social environment to support the individual. Changing the focus in this way, they argue, creates a clearer pathway for relevant intervention.

**The stigmatizing effect of diagnosis**

FASD, by its name and nature, is a product of prenatal maternal alcohol consumption. It is not possible to talk about FASD without acknowledging this, and therefore, it is difficult to do so without directly or inadvertently stigmatizing or blaming birth mothers. The participants in this study shared concerns around this, and raised it as a reason for not engaging in FASD diagnosis. Many participants themselves stated that this was a concern for them prior to their participant in the training project, as articulated by one:

> My comfortableness with suggesting it's a good way to go for a family, you know, it's an ordeal. It's going back years, it's exposing mothers who, who made decisions that they now fully regret and they never, would never consider doing again, you know what I mean? Why take them through that uncomfortable period of their life? (Participant 27, 27/5/2011)

This said, another participant was adamant that this issue was not as problematic as it was often made out to be:

> Lots of parents who come and see me about their kids having difficulties come in and fess up to the glass of wine they had, they're terribly concerned about one glass of wine. You know, 'cause they soul-searched about something that could've gone wrong to damage their child. So it's interesting, they often bring it to you because they kind of know. So it's not quite as difficult as it sounds. I think the wider issue is that we all drink too
much. Ah, but in that sense it takes the sting out of it for parents because it’s not just them, it’s everybody. You know, if we all drink like fish the whole time, then somebody’s going to fall pregnant, aren’t they. That’s what happens. (Participant 28, 30/5/2011)

Other participants proposed that recognizing the issues of guilt, blame and stigma were important when working with FASD, but should not be seen as a reason not to diagnose. Instead they developed ways to talk about alcohol consumption in pregnancy, and to work with families in ways that were supportive and non blaming, as exemplified below:

I think that it’s just important to show them that you’re on their side. With this particular issue there can be a lot of, guilt and I guess the main issue that tends to be negotiated is the issue of blame or guilt for causing a problem, and whether that might affect... her willingness to come in and get the assistance or to acknowledge that she drank during pregnancy. I think most women, probably are willing if, if they recognize there’s a problem to do what’s right. In that case, if they’re willing, you have to be supportive and really show them that you’re on their side, that it’s not a matter of blaming them but about working with them, and helping them. So, that’s with this particular disorder, that gets in the way, and it gets in the way of physicians and other people, even broaching the issue, because they don’t want to feel like, they’re putting a burden or blame or something onto the parent, but that is, I’ve been convinced since working in this area, that’s something you have to get past. (Participant 29, 1/6/2011)

Regardless of the professionals’ own sensitivities to the problem of blame and stigmatization, they also recognized that in many cases parents were already stigmatized due to their child’s behavioural symptoms, and this stigma and blame has manifested in other negative perceptions of ‘bad parenting’ and ‘disobedient’ children. Indeed, in some cases it was the parents themselves actively seeking out information and diagnoses for FASD.
The unknown prevalence of FASD

New Zealand does not collect health data on FASD. As previously noted, there has been little research on FASD in general and no prevalence studies and so this makes FASD an easy condition to dismiss on the basis of inadequate statistical data. In the context of the training, one participant alluded to this by revealing that some of his colleagues argued against providing diagnosis for FASD because of the dearth of prevalence studies for FASD in New Zealand. Another participant noted:

People don’t see it as a problem, it’s been under diagnosed so the prevalence rates aren’t there for us to actually [see that] this is a very significant problem... I think that until it gets acknowledged, it sort of feels like a chicken and egg, until we do the diagnosis and have got the figures we can’t really go back and say we need to get services in place for these kids or we need extra funding for diagnosis, and we need to have the time and resources to do the diagnosis to... ...feed back figures. So it’s good the push is actually coming from justice... ...and they say these are the kids ending up in the courts and these are the actual figures, and these are how many we are diagnosing, and we need to diagnose them earlier. (Participant 30, 21/6/2011)

Many participants suggested that the under-diagnosis of FASD, in conjunction with the lack of prevalence studies and insufficient health documentation all generate the perception that FASD is a non-issue in New Zealand. Even where FASD is acknowledged as a recognized condition, the general lack of infrastructure for FASD results in health professionals being unable or unwilling to engage with it, thus rendering it a marginal field:

...It is not mainstream in this country so all of us have inertia, resistance to change, so that means to say there is something new, there's [a] suspicion of, like are you sure? And even if you are sure, I don't really want to change what I am doing because I have just gotten comfortable and now you are telling me there is something new and new services and I'm busy enough as it is and where is the money going to come from? And actually that is
someone else’s problem, that is not my problem, can’t the disability community deal with that? (Participant 33, 20/6/2011)

**Comparing alcohol damage with illicit drugs**

Even in circumstances where FASD is recognized as a health concern, some participants talked about how illicit drug use was often perceived by colleagues as a more serious issue than alcohol use in pregnancy. For two of the participants, this issue came up when providing training to colleagues subsequent to their involvement in the original training project. One paediatrician gave an example of such questioning, and her response:

He said: “Well, what about other drug use, surely that’s worse?” And I was a bit gob smacked really, and I said: “Well, what is worse? Nothing's worse than alcohol, really”. Heroin's not worse, you know, and actually that concept is there, which I think is why the midwives always write down, oh, smoking cannabis and gloss over the alcohol because they get totally hung up on the drugs people are using and don’t think of alcohol as a drug in itself. (Participant 28, 30/5/2011)

This said, they also acknowledged that their colleagues were generally receptive to understanding the extent of alcohol damage when presented with appropriate information:

Once you get people understanding that actually it’s a bigger problem than P [methamphetamine], you know, first we get everybody saying: “But what about the P babies?” and we're saying “Well, you know the numbers are smaller and actually the methamphetamine and cocaine studies aren’t showing the same level of, I guess, dysfunction or impairment than alcohol”, and once you get them past that, then they’re like: “Oh yeah, yeah.” (Participant 26, 26/5/2011)
Reflective critiques of diagnostic practice

The third key domain of discussion with diagnosticians was the reflective critique by participants of their own professional practice. In most cases, participants identified past cases in their professional experience that might have benefited from the incorporation of FASD assessment, and they also reflected at length on their past handling of broader alcohol-related issues with patients. In particular, participants identified asking about alcohol use and documenting maternal alcohol consumption as practice gaps on the one hand, and simply talking about FASD with patients and families on the other. They also singled out their practices in liaising with other professionals for reflective critique.

Asking about alcohol use

Asking about alcohol consumption during pregnancy is a necessary part of an FASD assessment. Without confirmed material alcohol consumption, it is not possible to make a diagnosis under most of the fetal alcohol spectrum. How professionals ask about alcohol consumption can, however, affect how women report their consumption, how they feel about themselves, the assessment experience, and FASD. A number participants in this research said that asking about prenatal alcohol consumption was a key area of their practice that had changed as a result of undertaking the FASD training: “I'm aware of it, I'm thinking... [and] I'm checking that I've actually asked parents... whether they drank in their pregnancy. I'm making sure that question is asked” (Participant 27, 27/5/2011). Some participants had routinely asked about alcohol consumption during pregnancy as a part of their assessments, however most had not. All of the participants now routinely ask about alcohol consumption in their assessments but, more interestingly, a number noted that they have also changed how they ask. For example, one participant explained:

I used to ask: “Did you drink any alcohol when you were pregnant?” That was my question, but now I break it down to, when did you find out you were pregnant? Before you knew you were pregnant, what were your drinking habits like? ...It starts the conversation in a different way, because
immediately it’s the bit when you didn’t know, so it’s not blaming.
(Participant 28, 30/5/2011)

In many cases participants said that, when asked respectfully, parents were often open to discussing their alcohol use. In some cases, participants reported that families felt relieved when presented with a potential explanation for their child’s behaviour, and in some cases families raised their alcohol consumption voluntarily: “Quite a lot of people will talk about their drinking anyway. And, you know, some are probably still on their own journeys” (Participant 28, 30/5/2011). Despite this, most participants acknowledged asking about alcohol use can be a challenging part of the diagnostic process for both clinicians and families. Clinicians talked about the importance of asking and about alcohol use in ways that were sensitive and respectful. This included allowing time to build rapport with families and in some cases asking about it more than once, to give families an opportunity to process and think about their experiences. Two psychologists and a paediatrician said that, in some cases, birth mothers have changed their answers about alcohol consumption later on in the assessment process:

When it’s the birth mum, it’s tricky and in a way, that’s one thing, if the assessments take longer, we find that that is helpful because we can ask again, and sometimes all of a sudden, the answers are different, when they know that we’re not judging, when they know that is the best for the child, that’s been quite useful. (Participant 25, 26/5/2011)

A central tenet of this approach was articulating the importance of parents understanding clearly why questions about alcohol consumption in pregnancy were being asked, especially birth mothers. However, this was something for which limited training had previously been available, particularly in terms of explaining in how to ask, and why to ask about alcohol use:

I think there is certainly a reluctance, and myself included at times, and certainly initially [to ask about alcohol consumption]. Much like when I first started psychiatry, and I used to get anxious about asking whether someone
had thoughts of suicide, or killing themselves, or about their sexuality. People tend to kind of avoid the topic because they are worried [about] what other people think. For me, the reasons I have been uncomfortable is the blaming nature of ‘you messed up your kid’, or... asking it in a way that leads to denial, so I am not collecting valid information. But all that I have gotten to with it, much like the suicide and sexuality questions, is to [find] better ways of kind of asking the question so that valid information can be obtained without blaming and without causing harm to usually the mother. I think it is quite possible to train people to do that... ...you just role play it and get people to use their own words and have the experience of [it], so you can kind of desensitize them. (Participant 33, 20/6/2011)

In contrast to this observation, however, other participants noted that an additional barrier to documenting or discussing alcohol use is that some health professionals don’t see it as their role, as one participant asserted:

I guess for me, I don’t know if I didn’t see it as my role... it’s one of those kind of taboo things in some ways, so it was always designated as a social work issue, and so you don’t talk about it. Whereas now, for example, I even will record any mental health issues or anything that has been disclosed or stuff like that. So definitely it has changed how I write notes. (Participant 31, 7/6/2011)

In one case a participant said that she was surprised to see that alcohol use during pregnancy was recorded on one of her patient’s files however there was no record as to where this information was from:

I got a referral and it says “alcohol use during pregnancy”, that is what a paediatrician wrote and I went “Oh!” But then again he didn’t say who reported it. I will go back and ask him... So people are becoming more aware and they are asking. (Participant 31, 7/6/2011)
In answer to this, participants felt that asking about alcohol consumption should be made a part of primary health care assessments by “Getting primary health care workers including GPs and midwives and nurses in emergencies departments and anyone else having initial face to face contact with the client group to ask kind of basic screening questions [about alcohol use]” (Participant 33, 20/6/2011). Furthermore, screening for prenatal alcohol exposure was seen as especially important in the cases of children who were likely to have diagnosis that co-exist with FASD or symptoms similar to FASD.

Despite the interpersonal challenges it poses, asking about alcohol use was seen as a positive intervention in primary health care because it has a two-fold effect of raising awareness of the risks of prenatal alcohol exposure, which can be seen as part of the prevention of FASD, and identifying potential risk factors for FASD through this screening:

I talk about alcohol and community alcohol use in a much more flexible way, so that I try at my very best to make it non-judgemental. I like a glass of wine myself, so I'm not blaming anybody else for liking one too, and, because a third of pregnancies, people don't even know they're pregnant, you know, I mean some people know exactly when they have sex and got themselves pregnant, but many people don't. (Participant 28, 30/5/2011)

Ultimately, participants saw these discussions as necessary, and often cited cases in which their concerns about the possible negative impact of alcohol-related discussions actually turned out to be far less problematic than anticipated, as in the following example:

We've found it for people to be potentially a more empowering thing which is really interesting, 'cause when I thought about it in the past before I had experience in it, I thought oh imagine talking with a mum about the fact that their alcohol intake has caused this huge area of difficulty for their child. I think it's about making the environment safe enough that they can talk
Talking about FASD

A second area of concern in participants’ professional practice was the challenge of simply talking about FASD with clients and their families, especially considering the extent to which information about FASD is couched in specialist or scientific language:

I think, um, helping people get their heads around some of the deficit can be difficult, because [for] a large sector of the group I work with the concept of executive functioning, or even the term impulsivity is a word people don’t know. So you’re trying to get them to think about things or sensory processing, that are really outside their experience and therefore very hard for them to take in and then do something about, so it’s a bit of a journey really. (Participant 28, 30/5/2011)

Meanwhile, some participants talked about how they have tried to make their reports user-friendly and accessible not only to families, but also other professionals who may have limited understandings of FASD, “which can be quite tricky when you’re talking about quite complex things” (Participant 26, 26/5/2011).

Three of the participants talked specifically about the challenges of talking to individuals affected by FASD about their diagnosis. As mentioned above, a key challenge was explaining FASD in a way that is understandable, or in the words on one participant, “How do you explain the language to someone who’s got a language disorder?” (Participant 25, 26/5/2011). A psychologist highlighted the complexity of this challenge with an example of how one patient had feelings of anger about her diagnosis: “My girl got quite angry with me which was good, [she] had to direct it somewhere… she said you know, you had to put your nose in didn’t you…now look what you’ve found now” (Participant 25, 26/5/2011).
A couple of participants raised the challenges of working with families where they suspected that the parents themselves were affected by FASD as well. Intergenerational FASD is widely discussed in international literature, however it is not often discussed in the New Zealand context. A few participants said that asking about alcohol use which requires family members to recall information and explaining complex concepts related to FASD can be challenging for birth mothers and families who are likely to be effected by FASD themselves. As an example of this, one participant recalled the case of a birth mother who she thought might be affected by FASD:

One mum gave me a very detailed alcohol history, and then there was something about it I wanted to check. She gave a completely different, very detailed, alcohol history to somebody else, and for a minute we were quite lost on these two histories going, oh, God, which one’s right, which one’s wrong? But in actual fact when we put the whole picture together with other things she was having difficulty with, we realized she was trying to tell us the truth, but wasn’t really certain, you know, it was more of a confabulation issue, trying to give the right answer. And there was no doubt that she drunk heavily during her pregnancy, but when we started to think about her she seemed like she was FASD also. (Participant 28, 30/5/2011)

**Striving for best practice**

Achieving best practice in FASD diagnosis was a constant concern of the diagnosticians involved in this research. Their participation in the Canada-based training, and their immersion in the context of the international conference on FASD gave the New Zealand diagnosticians the ability to compare the New Zealand scenario with international ones, giving them an enhanced awareness of the specific challenges posed by the New Zealand health system’s positioning of FASD. On the one hand, this awareness gave rise to a sense of purpose in their work, as exemplified by the following comment:

I think the conference part gave me a really full picture of what’s involved and how complicated it is… it really introduced the size of the problem to
me. I think if you focus clinically, this is what you do, [and say] why can’t I just go and do that and make this diagnosis, but then what are you going to do with that? I think that is what the conference did really, got across what you are going to do with that. (Participant 27, 27/5/2011)

On the other hand, it also revealed the limitations of the New Zealand system, giving participants the impetus to consider the need for a localized approach to their work. In light of these limitations, the participants’ reflections on best practice coalesced around a few key strategies that could be adapted from international models. Universally, they cited the implementation of multidisciplinary team diagnosis as a key starting point. Doing this required the adaptation of international diagnostic tools and procedures, and the fostering of stronger links with neuropsychology in order to develop a larger cohort of FASD-aware neuropsychologists in New Zealand. Other strategies for overcoming systemic gaps for FASD diagnosis within New Zealand included advancing professional rigour and identifying the most appropriate age for FASD diagnosis. Throughout this discussion, the issue of the cost of FASD assessment was also present, as discussed further below.

**Multidisciplinary team diagnosis**

Participants’ feedback indicated that the Asante Centre component of their training was very useful, and this was probably a factor in their reception of the multidisciplinary team as a functional diagnostic model. Participants found the democratic attention given to each discipline in the multidisciplinary diagnosis team training helpful, including the opportunity to ask questions, discuss diagnostic process and review case examples. On the basis of this training, and reflecting further on the field in general, participants thought that multidisciplinary team assessments were especially important because of the complex profile of FASD:

I just think there’s too many aspects of the brain and too much at stake that we might get it wrong ... there might be cases where it’s really easy, but
we’ve had a lot of cases where to make a differential [diagnosis] was not easy and you spend days and hours on it. (Participant 25, 26/5/2011)

Therefore, a common concern expressed by participants was the lack of multidisciplinary teams in health services throughout New Zealand, reflecting this to other diagnoses as well:

I really feel strongly it should be done in the multidisciplinary [team] approach, so how many of those have you got out there? You know, I mean we have had meetings about autism training just recently with a whole lot of different health professionals from New Zealand and... there are whole teams who haven't got a psychologist, there are psychiatrists out there who have got no access to anyone else in the health system, you know I'm just talking about the DHBs at the moment, so not privately. So it's just a huge problem. (Participant 25, 26/5/2011)

When reflecting on the training, some participants talked about paediatric services that might be able to undertake multidisciplinary autism spectrum disorder assessments, except that they lack access to psychologists (which was exactly the situation for one of the teams that undertook the training but had to recruit a psychologist from another service within the DHB). Others talked about the lack of access to speech and language therapists within mental health services. Ultimately, they all argued that an increase in multidisciplinary teams in New Zealand would benefit a range of patients including those being assessed for autism:

I think it’s comparable to autism because in the guidelines, the golden rule for autism is multidisciplinary assessment, it could not be done by one clinician because, we’ve had cases coming here where they’ve been diagnosed with autism after one hour with a psychologist and they weren't, and it’s very, very hard to try and undo it, you know it’s hard back paddling. (Participant 25, 26/5/2011)
Whilst participants were in agreement that, in ideal circumstances, multidisciplinary team diagnoses were preferable, there was less agreement on whether multidisciplinary team assessment was essential to best practice in the New Zealand context. The most commonly held view was that an interdisciplinary team including medical professional such as a paediatrician or psychiatrist and a psychologist were the minimum needed to make an accurate diagnosis on the FASD spectrum, and this discussion was primarily influenced by participants’ perceptions of what was achievable within New Zealand health services. One participant termed this as ‘gold standard vs. what is practical’:

I think it’s a gold standard vs. what is practical, that is my feeling. I think the wealth of information that you get from a multidisciplinary team cannot be compared, but I think sometimes practically if you have got someone who is able to understand the diagnosis and do a good diagnosis that is better than having no diagnosis at all. I mean, I think it needs a medical professional and a psychologist at the very minimum like we have got here. That is what I call basic, you know, I think having speech and language and OT is amazing, I think that is the gold standard and that is what we all should be working towards. (Participant 30, 21/5/2011)

In an ideal team, according to participants, the health professionals involved would include a medical professional (paediatrician or psychiatrist), a psychologist (with neuropsychology assessment skills) and a speech and language therapist. A social worker or clinical coordinator and an occupational therapist were also considered useful. However, in relation to arguments around what is likely to be achievable in New Zealand, the participants had differing views. One participant believed that it is possible to provide an FAS diagnosis (not FASD) as an individual doctor, though she also acknowledged the limitations of this:

I think if they had full fetal alcohol and facial features and a full alcohol history, I think I would [be comfortable diagnosing individually]. But I suppose it is how helpful is that, I think the neuropsych part is very helpful in the treatment and the management, so I can give the diagnosis and I
would say this person needs a neuropsych in order to help them. And probably speak to a language therapist to assess their communication difficulties. I think you can make the diagnosis but how helpful? I think it’s a little bit helpful to help people understand that this kid does not have normal brain function and that they need to be doing things differently and a better understanding that none of this is deliberate and I think that is helpful... ...but I think helping with strategies and identifying strengths and weaknesses, because they are so different, they need a full neuropsych and speech and language assessment to really help them. (Participant 30, 21/5/2011)

Another participant thought that, on top of the basic interdisciplinary model consisting of a medical professional and a psychologist, there also needed to be a high and complex needs coordinator to coordinate referrals, gather further information, and liaise with the family and professionals in the community, as these are time-consuming tasks. Beyond this, the most commonly requested addition to an ideal multidisciplinary team was a speech and language therapist – a role seen by many as being essential to the team. Indeed, most professionals considered a standard multidisciplinary team to include a medical professional, a psychologist, a speech and language therapist and a clinical coordinator or social worker. This is a common model employed in FASD diagnostic clinics (and autism clinics) internationally, and (as noted) is also the model used at the Asante Centre for FAS in Canada. However, participants in this research differed in their views on when and how speech and language assessments were most useful.

One psychologist was adamant that a speech and language therapist’s assessment is a vital component of diagnosis: “We’ve only got one speech language therapist and she only works part time, that’s a really huge problem and so you know, we’ve actually been saying do we really need to have a speech language assessment with every single case” (Participant 25, 26/5/2011). Another psychologist stated that “…It’s nice to have the speech language therapist, or other professionals, but, but that’s not critical because it can be done with um, a paediatrician and a neurophysiologist, if they have the time to do it” (Participant 29, 1/6/2011).
Meanwhile, two participants viewed speech and language therapist involvement as most useful for children under age eight, arguing that a speech and language assessment helped to provide greater insight into impairments at a time when many psychological assessments were not able to be undertaken due to the child’s developmental stage:

I think often in FASD kids, it is the early language acquisition that is abnormal... The younger the child, the more that becomes more [important in] the diagnosis, because executive function is not developed, so other aspects of cognitive function haven’t emerged, therefore language becomes much more a part of the diagnosis and much more a part of what is important in that child’s life. (Participant 32, 20/6/2011)

Some participants perceived an overlap in speech and language assessment and psychological assessment in older children, especially past age eight, when psychometric testing that includes executive functioning tests are employed:

As a neuropsychologist, although I don’t do as much language evaluation as they [speech and language therapists] do, I still do a lot of language evaluation. What is really noticeable in the older kids, is in terms of their communication, is this kind of verbal reasoning, so that they take language literally and it’s almost like language and executive functioning intercorrelate, so that they have poor vocabularies. I assess those, but they also can’t use language to socialize and to reciprocate and to be spontaneous. I know that a speech therapist would be able to evaluate that better than me but I pick it up in talking with them. (Participant 32, 20/6/2011)

While this participant viewed a speech and language assessment as unnecessary in older children, another felt that it was helpful to cross-compare psychological assessment and speech and language assessment results, especially in cases where the psychological assessment might be borderline:
In cases where I can’t get into the, the details of their language and speech in depth, there is a lot of impairment there, and she [the speech and language therapist] can do it in more depth than I can, and also she’s... excellent in terms of making recommendation for interventions in the school... And it is also helpful um, where you have people who are sort of on the border because the speech-language therapist flushes out areas of impairment and disabilities that are specific to verbal abilities. (Participant 29, 1/6/2011))

A speech and language therapist agreed that collaboration can be helpful, and evidenced one case in her experience where the speech and language assessment made the difference between diagnosis and non-diagnosis. Another participant felt that a speech and language assessment could also be very useful in older children. Her concern was that speech and language therapy assessment and intervention services tend to drop off just when some children need them most:

It's very easy to miss things and the speech angle on it would be the biggest one of those, that, because of the increasing complexity in how we use language past the age of five. Easily miss kids who had had normal speech language assessments at the age of the five and been kind of cast aside from speech language services, and they won’t get anything. The way that it's funded it, once you’re over the age of eight there is no speech language therapy within the health or education systems for you. (Participant 28, 30/5/2011)

Another concern raised regarding multidisciplinary team FASD diagnosis in New Zealand was a lack of suitably trained neuropsychologists in New Zealand. Neuropsychological assessment is essential to FASD diagnosis, however according to many of the participants, the number of psychologists who have the skills to undertake neuropsychological assessments for FASD in New Zealand is insufficient. The four psychologists undertaking training as part of the pilot project were clinical psychologists. All had experience in developmental psychology and had worked with autism and ADHD, and all had an interest in neuropsychology.
Three considered their general level of experience to be high, however none felt they had the skills or confidence to undertake the specific neuropsychological testing needed for FASD assessment prior to their training. The psychologists all suggested that extra training is needed for clinical psychologists to undertake FASD neuropsychological assessments, as articulated by the neuropsychologist:

In New Zealand we should have proper neuropsychologists. I mean there aren’t any, so we have got to take people who’ve got not the right background to do it and put into practice something that is specialized. I mean it’s almost a bit like, taking a general doctor and all of a sudden turning them into a psychiatrist and they haven’t done the psychiatry training. You know it’s hardly ideal, but it’s not impossible if people are willing to specialize in that and go on. (Participant 32, 20/6/2011)

One of the trainers for the project was concerned about a shortage of neuropsychologists in New Zealand, but raised further concerns around training clinical psychologists to do neuropsychological evaluations:

I think... [The neuropsychologist trainer] has had a hard time of it because there is a shortage of neuropsych[ologists] globally, but especially New Zealand. I think the... ...depth and breadth of what she has needed to convey to them is big even for trained neuropsych[ologists] but she has had people who are not trained neuropsyc[ology], so it’s been this massive up skilling and I think that’s been a really, really hard part of the project. And I am concerned for future projects in that I strongly disagree with the view that this is something that any psychologist can learn quickly and easily. (Participant 33, 20/6/2011)

The neuropsychologist trainer agreed that providing training to psychologists with no neuropsychology training could be challenging. However, she thought it was possible but that certain psychologists were more suited than others to undertaking training for FASD assessments:
So you have got to have the neuro[logical] and the developmental [work experience]. So if you get people who are working those areas as a clinical psychologist start to get a feel for different neurodevelopmental disorders... ...where they are used to autism they are used to ADHD and they are used to perhaps kids with intellectual disability, then they sort of understand their needs. Those sorts of people have got potential to go on and do this work. Ideally there should be programs training people in this! I mean this should be an important part of training for some psychologists who want to specialize. (Participant 32, 20/6/2011)

Ultimately, participants views on multidisciplinary team diagnosis and the roles of particular professions within this were largely influenced by their awareness of the current state of the New Zealand health system, and what might reasonably be achieved within this. While participants generally thought that something is better than nothing in circumstances where certain multidisciplinary team components may be missing, they nevertheless expressed concern about how the variability of multidisciplinary team makeup might impact on the rigour or perceived rigour of FASD diagnosis nationally, particularly in an environment that was already sceptical of the relevance or even the very existence of FASD.

**Diagnostic rigour**

In view of the difficulties expressed above, participants talked about the need for a high level of rigour when dealing with FASD diagnosis. As the first cohort to undergo this training, they felt that they were under strong pressure to ‘get it right’, as conveyed by one participant: “…whilst I am learning, it’s not that I am a perfectionist but I want to get it right because it is going to be the basis for the future. You want to get those first few reports and actually sit down and think and do them properly” (Participant 30, 21/6/2011).

Professionals talked about having to have high thresholds of evidence in their assessments. With regard to getting confirmed evidence of maternal alcohol consumption, one participant said:
I don’t think we can jump to conclusions that it was there because that would be quite an easy explanation for why I’m not getting the clinical outcomes I want from the kid I’m dealing with. I think we’ve gotta make sure that we definitely have the evidence. (Participant 27, 27/5/2011)

Another talked about having high levels of screening for assessments:

One of the other things we got from the conference if you like was about where we were gonna draw our line, about, it’s always a risk, but we’re not going to assess everybody who ever had a glass of wine, you know. We’re going to make it a little bit higher than that. [The trainer] gave us some advice about two binge-drinking sessions in a first trimester being a big risk factor. So we’ve kind of used that as a benchmark, so we’re trying to help people think about their drinking and then having those conversations you’re giving them some information too. (Participant 28, 30/5/2011)

As if to reinforce the perception of diagnostic rigour, many participants were quick to point out that they often ruled out FASD as a diagnosis, even in circumstances where prenatal alcohol consumption was a confirmed factor. For example when I asked one participant about whether there had been any suspected cases of FASD referred to her where she did not make a diagnosis she responded:

Oh yeah, heaps, heaps. The court referrals I get, I mean for instance, I have just done two recently... these are both teenage boys offending, presenting with learning problems with behaviour problems, long histories..., both of them were confirmed alcohol exposed and both of them didn’t reach the diagnosis. (Participant 32, 20/6/2011)

Another participant said:

There’s actually been a couple where we decided it wasn’t FASD, which is good as well ’cause we were a bit worried we were gonna get over, over
keen about it and suddenly give it to, make the diagnosis a choice for everybody. (Participant 28, 30/5/2011)

Another psychiatrist who was particularly aware of this issue, stressing the importance of rigour when making an FASD diagnosis:

...a lot of things look like a nail if you have got a hammer. Psychiatry is notorious for fads, Edward Moniz’s got the Nobel prize, he is the only psychiatrist to get the Nobel prize, for inventing [the] lobotomy.... so I’m not comparing diagnosis of FAS to that but I think there is a risk of not being specific and thinking well it sort of is [FASD]. (Participant 33, 20/6/2011)

Diagnostic tools and resources
Currently, New Zealand diagnosticians work in the absence of New Zealand specific standardized diagnostic tools or resources for FASD diagnosis, so participants in this project used the Canadian harmonization (Chudley et al. 2005) of the Washington 4-Digit Diagnostic Code (or the ‘Washington Code’) in their diagnoses. While participants thought it would be very helpful to have New Zealand-specific resources for FASD intervention and information for families and professionals, almost all professionals felt that utilizing Canadian and American diagnostic tools was appropriate practice for New Zealand:

I think it’s fine, the New Zealand population is polymorphous and so it the Canadian and so is the American... For me the most important thing is the brain function and the presence or absence of physical features is merely just telling you more about which days they were drinking on and maybe whether they were drinking all the way through, but it, it's not the brain. There’s a degree of brain dysfunction, which is really what the speech language therapist and the neuropsych are evaluating, are what tells you about the function of the child, And I think you can get too absorbed and stressed about physical features that actually aren’t going to take you any further. So that's why I sort of shift the focus on to function. (Participant 28, 30/5/2011)
One participant did not agree with the others on this point, however, and raised concerns as to whether the standardized norms for measuring facial dysmorphology, in particular the lip and philtrum scale and palpebral fissure length, were appropriate for the New Zealand context, especially where Māori and Pacific Islander populations are concerned:

It’s one of the four digits, so it’s got a twenty-five per cent loading, which I don’t consider small ... If we are dealing with our New Zealand population, how are we going to accurately define that digit? Because if you are going to measure that digit loosely or without adequate rigour then why have it? You are going to get false positives or false negatives. (Participant 33, 20/6/2011)

**Age for diagnosis**

International literature asserts that, ideally, children with suspected FASD should be initially assessed when they first present to a service and that further assessments should then be ongoing throughout a lifetime to capture strengths and challenges at different stages of development. Many training participants argued that, in practice, this was not realistic within New Zealand health settings and, in some cases, not particularly useful. On the one hand, this view reflected an awareness of resourcing issues:

What we can't afford to do is what they do in Canada, is to be reassessing everybody. We’ve looked at it and we just can't do that, we'll be struggling to see everybody once. So we had to pick an age at which we could do the executive functioning testing and eight, eight’s the best time, well, it’s the earliest time you could really do that while the child is still at a point at school where it'll make a difference when we say what we've found. (Participant 28, 30/5/2011)
On the other hand, participants also expressed the concern that, if the child was assessed too early, then health professionals might not pick up the potential issues. One participant used an international example to illustrate this concern:

It was really interesting looking at the Manitoba [Canada] experience seeing one of their, you know presentations at the conference and they talked about you know when they assessed at pre-school children, yes there were some things that highlighted that they may be more likely to get an FASD diagnosis, but they had to defer for most of them until they're older. So you just don’t get the executive functioning and the social [skills], you know all those issues don’t come on board really till later... ...I think the problem or the difficulty if you're assessed too early, potentially you won't highlight the difficulties. (Participant 26, 26/5/2011)

Given these issues, age eight was identified by most participants as an optimum time to undertake an FASD assessment for children who present to services at a young age. Age eight was primarily chosen because, at this age, most executive functioning tests within the neuropsychological assessment for FASD can be undertaken. These tests constitute an important part of an FASD neuropsychological assessment. This discussion was framed under the assumption that children are likely to present prior to age eight to services due to learning or behaviour concerns. Thus, while age eight was seen as an optimum time to assess, this also included children older than age eight. One of the trainers who worked in private practice acknowledged participants reasoning behind age eight but disagreed with the idea of limiting diagnosis to an age group:

I think we should be diagnosing kids whenever they present with a problem, whatever age. The university of Washington clinics run from 0–89 years of age, they have got no aged limits in acknowledgement that it is a problem that is life long and it is present from birth and goes through to old age... ...Eight is just the time executive functioning tests start. Really, when you think about it, children should be diagnosed before they start school, because it is so important. (Participant 32, 20/6/2011)
This participant further emphasized the importance of early diagnosis, using a case from her own practice to illustrate the benefits:

The boy was four and the mum confirmed that she drank heavily and you just needed to look at him, I don’t remember what his face was like but he was definitely leaping around and his language was way behind. We made a clear diagnosis even though he was only four, because his problems were that extreme, we knew that was the nature of the problem and that was important for her that she got that diagnosis then and she acknowledged that she knew that it was her drinking and that she sort of thanked us to be so frank and she said ‘now I know what to do’, you know and it was important. So I don’t know that there is any ideal age [for diagnosis]. (Participant 32, 20/6/2011)

However, she also acknowledged that, when diagnosing under age five, much caution must be taken due to the different developmental pathways children take.

One group of professionals from a particular team stated that they would aim to assess children for FASD at age eight, however they flagged children with suspected FASD at whatever age they presented to the team, and linked the child and family into various services until reaching the age for diagnosis. They said that within their local area there is not a need for a diagnosis to access services until age eight, so this worked well. A paediatrician from this team described a range of interventions available to her regardless of diagnosis:

Well generally speaking if you’ve been referred to me you’re, there’s a problem with your learning or behaviour or both, and if I feel that’s true and alcohol has been a ... factor in the history, then I will refer you in for an assessment at the age of eight, which means you might not get it straight away... ...In the meantime ... we’ll flag it as a contributing concern to [and] give them information about handling the child differently. They could see an OT through the Child Development Unit in the interim, they could maybe
get speech language support through special education [and] we talk to the schools, give the schools some information. (Participant 28, 30/5/2011)

Another participant within this team talked about how, in some cases, the team identifies suspected FASD part way through an assessment process. This most commonly occurred with children who had suspected ADHD, and there is a need for “making it clear that they've got both, rather than just one” (Participant 28, 30/5/2011).

A different team assessed children as young as four years old, however their process did take the age of the child, amongst other issues, into consideration when deciding on when an assessment is appropriate:

We look at, of course, whether or not there’s an acknowledgment or strong suspicion of alcohol, during pregnancy, that has to be present, and there had to be disabilities that or impartment’s that are evidenced that are consistent with what we would think would FASD. And so there has to be a genuine, suspicion that they might have it, and then also we look at their age... ...we’re just finishing up a five year old now. It's a little young, sometimes to, unless the symptoms are pretty profound, which in her case they are, so she's actually the one we've diagnosed with a partial, and that’s because she has physical symptoms. But often times we might, just screen them, at a younger age and then they come back for another assessment, so, the, the age is relevant. (Participant 29, 1/6/2011)

Participants raised some concerns about the drawbacks of limiting a diagnosis to age eight and above. One particularly strong concern was that speech and language therapy services often stop at age eight, making it difficult to obtain a speech and language therapy assessment and then intervention as part of an FASD assessment and intervention plan. The speech and language therapist who participated in the training was unclear as to why speech and language therapy services often stopped at age eight, but said the implication were huge for children with FASD or suspected FASD:
The special education speech and language speech therapists are going towards a zero to eight main emphasis... I don't know [why] and there is no research to say specifically eight... They are not even looking at the FASD kids or the kids that are older than eight and so for me the implications are huge. It is about teaching the teachers...because they are not actually going to get the speech therapy support they need and for us recently one of the children has come out developmentally very low and he is seven. What I am hoping is that one of the speech language therapists is going to go in and just provide strategies for the teacher. And just help her for the next twelve months hopefully a little bit more, to get something on file that says this is the way you need to talk to him this is the concrete level that he needs to work at and provide them with this sort of information. But I mean huge implications particularly in terms of transitioning, so going from primary school to intermediate, intermediate to high. (Participant 31, 7/6/2011)

The cost of FASD

The prior discussions of multidisciplinary team diagnosis and diagnosis age reflect limitations largely imposed by financial cost. There is a lot of international research that examines the cost of FASD, and most of these studies talk about the cost of FASD across an individual’s lifetime, or the overall cost to the health system. However, diagnostician participants in this research also framed the cost of FASD assessment in New Zealand in terms of its cost-saving ability within health, community service, education systems and justice systems. Participants believed that FASD diagnosis is a cost-effective way of dealing with FASD for two reasons. First, a proper FASD assessment that leads to diagnosis can prevent multiple assessments for a patient. As one participant explained:

There would be these kids that just kept coming back and back and back and the families were desperate, they don’t know what to do, their behaviour is off the wall, they are about to get expelled from school, you know and they would be seeing them from the age of four through to fourteen and nobody figured out what was going on. And when you look at
how many clinics those kids present at and how many doctors’ visits, doctor's visits are expensive, medical specialists visits. [If] we can try and iron out those problems, figure out what is going on, intensively at one point in time and manage that so that everyone knows what to do, it’s not out of control, and sure they are still going to have problems, there is no getting away from it but if people know how to manage them, then it’s going to be saving hugely. (Participant 32, 20/6/2011)

In addition, diagnosis is cost-effective because it identifies appropriate interventions to meet needs, thereby decreasing the likelihood of the client using resources in the health, community service, education and justice sectors because of secondary disabilities. Some participants also talked about how an incorrect assessment can contribute to the development of behaviour problems leading to secondary disability and that, given this, assessing and making an FASD diagnosis is potentially cost saving.

In terms of the cost of their own assessments, many participants acknowledged that FASD assessments, which require the skills of a number of health professionals, can be expensive. However, some said that it was not more costly than other diagnostic processes, such as autism diagnosis:

Well they are not actually [more time consuming than other assessments], if you do an ADHD or autism assessments right. These assessments can also be streamlined, the more I do of them, the better I get. One of things that [a trainer] from the Seattle-based group said to me is: “How many notes do you need to hear before you recognize the tune?” Now I can be kind of a little more crisp in sort of looking for it and recognizing parts of it and then being able to draw down quite quickly. (Participant 33, 20/6/2011)

Some participants thought that FASD assessments were more time-consuming than autism, ADHD and other assessments, while others did not. A number saw the reason for this as their own limited experience undertaking FASD assessments and thought that as they gained experience in FASD assessments the time it took to
undertake them would decrease. Views on this issue also differed depending on discipline. Whilst the medical professionals (paediatricians, psychiatrists) did not find the assessment process overly time-consuming, the psychologists did see an increase in their workloads as did speech and language therapists. Despite this, as stated above, participants agreed that the time taken to complete a comprehensive FASD assessment was time well spent and could also be seen to decrease the number of assessments for that patient overall.

Interestingly, participants said that improved access to FASD diagnostic services did not necessarily mean an increase in the number of patients seen by professionals. Indeed, a key finding from the pilot project was that improved access to FASD diagnosis had not necessarily meant an increase in children being seen by teams. It simply meant that the assessments carried out were more relevant to the presenting problems and the child’s immediate needs.

**Conclusion**

All of this discussion around FASD and diagnosis reveals the inherent complexity in approaching FASD in clinical practice, within social and biomedical systems that are not set up to address it. Many of the diagnosticians’ concerns here relate not to their own practice, but to how their findings might be viewed or interpreted by others, thus foregrounding the important role of the social construction of FASD. Participants expressed clear concerns about the place, resourcing and support for FASD diagnostic services in New Zealand, however, it is also clear that they consider FASD to be a significant health issue – so much so that they were willing to devote their own time and energy outside of normal work contexts into addressing it. Despite their concerns, practitioners developed a range of innovative responses to address barriers that they encountered in coming to terms with FASD diagnosis. While many of these innovations were considered by the participants to be pragmatic and not ideal, they have nevertheless helped to contribute to the development of diagnostic capacity in New Zealand.

Overall, the diagnosticians were clear about the benefits and challenges for FASD diagnosis, and demonstrated insight into the social complexity of the disorder. This
insight has left them feeling pressured to do diagnosis as correctly as possible, and they have been largely reliant on Canadian and US models for achieving this. Their work, in this regard, has been innovative, but also pragmatic, and many revealed compromises that they had faced in order to continue pursuing FASD within their existing work contexts. All of them, however, considered the development of diagnostic expertise for FASD in New Zealand to be essential.
Chapter 9: FASD intervention

This chapter explores the professional practice of intervention workers from a range of professions and service provision contexts in New Zealand, who participated in FASD training and who have since continued to play a role in working with suspected cases of FASD. I use the term ‘suspected’ because, at the time of writing, only one of the participants had ever worked with a client with a confirmed FASD diagnosis. All had worked with clients whom they suspected were affected by FASD, and some participants said that it was likely that a large number of their clients were affected by FASD amongst other alcohol-related health impacts. This chapter is intended as a counterpart to the previous chapter focusing on FASD Diagnosis, and follows a similar line of enquiry. It differs, however, in the particular experiences of intervention workers and how they compare to the experiences of diagnosticians.

This chapter is organized according to the four main themes arising from interviews with interventionists: the impact of diagnosis on intervention work, the barriers that exist with regard to intervention for FASD, the strategies deployed by intervention workers to overcome these barriers, and the specific challenges of working with families on the issue of FASD. While these themes overlap to some extent with the issues raised by the diagnosticians, they are also different in that they reflect the different professional services that intervention workers are required to provide, and the greater degree of contact that intervention workers have with clients and their families.

The impact of diagnosis on intervention

An underlying issue for the intervention and management of FASD is that work in this area is impacted directly by the availability of FASD diagnosis. At the time of writing, there is currently no access to best practice multidisciplinary FASD diagnostic services in the South Island of New Zealand, and, according to many participants, no access to FASD diagnosis of any kind in their region. The research participants were, however, unified in their conviction that there were clear
benefits to confirming suspected FASD through a diagnosis, despite also acknowledging some potential challenges.

Participants reported that they had, in the past, made various referrals to paediatric departments, Child and Family Mental Health Services, Youth Mental Health Services, disability assessment services and private health providers documenting prenatal alcohol exposure and/or suspected FASD. However, in most of these cases, FASD was either not considered within a differential diagnosis or dismissed following a physical examination that ruled out physical symptoms associated only with fetal alcohol syndrome. A number of participants had discussed their concerns about FASD with health professionals such as paediatricians, psychologists and psychiatrists in their area, with varied levels of responsiveness. While participants acknowledge systematic barriers to FASD diagnosis such as a lack of profile at official, governmental levels, they are also acutely aware of gaps and barriers that exist at the local or grassroots level as well. In many cases, FASD is simply not considered as a potential diagnosis because it falls outside the training and experience of diagnosticians, rendering it effectively invisible.

The perceived resistance amongst health professionals to diagnose FASD was also attributed by some participants to health professionals themselves not having sufficient training, knowledge or information concerning FASD to be able to make an informed contribution in this area. Those participants who expressed this view did so as a result of interactions with health professionals in which they realized that their own knowledge of FASD was greater than that of their health-sector colleagues. A number of professionals said that in some cases FASD was dismissed as a potential diagnosis due to the lack of physical facial features associated with FAS. Some postulated that other diagnoses on the spectrum were not considered because the health professional’s awareness of diagnosis options was limited to FAS:

What they get stuck with is if there's no dysmorphic features then it's not there, and I think they don't have an understanding of spectrum... I think
they’re obviously thinking about it, I think they know it exists and they’re thinking about it, but, you [don’t] know if it can’t be seen. (Participant 16, 31/1/2011)

Another participant said that, while some professionals acknowledge FASD, their lack of understanding of FASD coupled with a view that nothing could be done to medically treat the client made them reluctant to identify FASD as a potential issue worth further assessment:

I think it’s because they haven’t really understood it enough and they don’t want to say, they don’t want to deny it, but it’s like anything – when you become aware of the disabilities that some of these children have, a lot of people feel so overwhelmed... And then the fear is, if we open up, “Oh there’s more!” But there’s no treatment for it [which] leaves people vulnerable as well... they go well how can we help them. I mean I don’t get a sense that people don’t want to help these children at all, but I think it’s just, still a lot to be understood about it. (Participant 16, 31/1/2011)

Almost all of the participants considered diagnosis to be an important first step in providing informed and appropriate intervention and management services for those affected with FASD. They believed that diagnosis has positive repercussions for individuals with FASD, their families and the community, as well as positive practice implications for professionals working in allied health and social services with clients or patients who are affected. The reasons given for this were that diagnosis makes FASD visible and that it fosters understanding, by all parties, of the issues involved in an individual’s circumstances.

**Diagnosis makes FASD visible**
Research participants were adamant that diagnosis leads to enhancing the visibility of FASD in a range of settings: in the community, in the health system, amongst professionals and within families. Participants viewed diagnosis as a form of prevention, as a way of increasing awareness and providing evidence to the broader community of the risks of alcohol consumption during pregnancy. Greater
community awareness would, in turn, make it easier for professionals to talk to clients about both the risks of alcohol consumption during pregnancy and their alcohol use pre, post and during pregnancy. Diagnosis of FASD also legitimizes FASD as a diagnosis. According to some professionals, until FASD is more regularly diagnosed in New Zealand, other professionals in the health, allied health and social and community services sector will dismiss it. As one social worker said:

It's sad to say that it is actually quite important because until it becomes a recognized diagnosis, it's not something anybody's going to pay attention to. It'll be kind of like witchcraft, it'll just be gobbledygook to a lot of people and they'll just say well, that's just nonsense, you know. What proof have you got, there's no such thing; no doctor would say that. There's people out there who put a lot of weight on what the medical people recognize as a problem, if you like. So until it has that mana that comes with being an accepted diagnosis, it's going to be just, you know, 'bad parenting'.

(Participant 2, 18/11/2010)

Participants also said that diagnosis could lead to greater insight into the incidence of FASD in New Zealand, which can have positive implications for how FASD is resourced and managed. FASD diagnosis provides an explanation for behavioural symptoms and learning difficulties, making the brain damage visible. This, in turn, enhances the understanding of the specific issues faced by an FASD-affected person, as much for themselves as for their families and the health and allied-health sector professionals with whom they liaise. One participant explained why this was important:

There was a child who went through school with my son, who looked really different, behaved really different[ly]. And so, therefore, in some ways it was easier for her because support was put in place and people understood that she was different. But for people who might only look a little bit different and may only have some challenges, then for me that's harder, and I think society doesn't understand the impact for those children.

(Participant 18, 11/2/2011)
Diagnosis reveals challenges and fosters understanding

Participants in this research stressed that another key benefit of diagnosis is that it could help to reframe negative perceptions of people affected by FASD (often caused by a lack of understanding of their condition). According to some participants, this was seen as a useful intervention in and of itself. A social worker from Child Youth and Family explained, for example, how a shift in perception and understanding can have a positive impact on both the family and the individual affected:

I think somewhere in a lot of people's minds, if you've got a diagnosis then you've got justification for the behaviour; whereas, if there's not a diagnosis then there's the possibility that you're just not managing the child, [that] you're not an adequate caregiver; you don't have the right parenting skills. (Participant 2, 18/11/2010)

This shift in perception can impact on how a health or social service sector professional might view and manage the child, and also helps allow parents and caregivers to externalize issues, instead of internalizing negative perceptions of their own ability to manage their child, as articulated by one participant:

For a caregiver or a parent, when they've got a child that's difficult, you spend a lot of time thinking, “okay, what have I done wrong?”, or “is it the child that's wrong?”. But if you've got this thing over here that's called ‘whatever', then that's where you can put that and then work with it. It makes it easier to work with the problem if the problem sits somewhere over here and it's got a name which isn't your name or the child's name. (Participant 2, 18/11/2010)

Reframing also assists professionals and parents/carers to adjust and develop more realistic expectations of FASD-affected children, which in turn shifts focus from the things the individual cannot do well to things that they can do well. A diagnosis also gives parents information (and evidence) to be better advocates for
their children said some participants. This was seen as particularly important in the current climate where there is a lack of recognition in the professional and general community of FASD.

Participants further stated that, within the health, allied-health and social service delivery sectors, diagnosis holds a lot of symbolic power and can determine how the client is perceived and how they are treated by other professionals. The notion of diagnosis as ‘proof’ was raised by a child and adolescent counsellor who emphasized the importance of diagnosis as a way of legitimizing the client’s challenges:

Everyone who comes up and has contact with these young people forms their own opinion about them, and often, by the time that diagnosis is actually given, they have already been labelled as ‘bad’ or having an attitude that is difficult, and [that] the young person is actually the problem, and it takes a lot to sometimes shift other workers or professionals or parents away from blaming the young person. So I think sometimes you actually need authority with some clout to actually go in there and say “No, it is actually this, you are wrong”. I have sat in a meeting where I have had a Deputy Principal say “Where is your proof?” to a mother. (Participant 11, 27/1/2011)

Effective early intervention necessitates a diagnosis, according to some participants. Understanding and providing appropriate interventions early on can prevent problems in later life including disengagement with education and involvement in Juvenile Justice. For example, one participant said that, following a diagnosis, there is likely to be earlier intervention “rather than us ending up with a parent who is coming us saying ‘I’ve got this teenager whose completely out of control and I don’t know what to do’” (Participant 18, 11/2/2011) and this in turn is more likely to prevent secondary disabilities.
Diagnosis: A pathway to resources

One of the other main benefits of diagnosis, according to professionals, was access to resources and funding to support management and intervention. Whilst there is currently no systematic funding for FASD support and management in New Zealand, participants said that generally, a health or mental health diagnosis would allow for at least some sort of resourcing. The absence of a diagnosis has an impact on some professionals who rely on it in order to justify working with and resourcing a client. This was explained by a mental health nurse who said:

[A diagnosis is needed] in New Zealand for getting services... because all of our services [and] funding is driven through diagnostic criteria, one would say that we would be getting our hands slapped by funding and planning if we had hundreds of kids that had no criteria in services. (Participant 14, 22/10/2010)

The lack of resourcing is further reflected in the perception that there are not enough psychologists with the specific training required to undertake psychometric testing and assessments within paediatrics departments and child and adolescent mental health services, according to participants. This issue is not limited to clients with suspected FASD however some participants believed that given limited services and heavy demand for these services, clients with FASD would be more likely to be deprioritized due to disagreements by professionals about which service area is the most appropriate service for the client. A mental health nurse discussed an example of what sometimes happens given this situation:

We do not have enough clinical psychs [psychologists] attached to peds [paediatrics] and to YSS [Youth Specialist Services] and to CAFS [Child and Family Mental Health Services] and to services that really require them, and so what is happening is that of course we assess kids and we look at them and we go: “gosh something is not right” and psychometric testing will find out, and so we advocate strongly and make referrals, and this gatekeeping effect occurs... one [service] will say “no”, so I will go to another and they
say “is that a mental health issue?” And I go “no, not really”, but the kid is distressed because she’s struggling at school and she wants to keep up with her peers and she can’t and so I tried to sell it to CAFS in that way but “no”, so I wrote to peds [paediatrics] and gate-keeping occurred. (Participant 14, 22/10/2010)

While most participants saw resourcing as one of the most important reasons for diagnosis they also raised concerns about the lack of resources and funding that would be available to clients if they were diagnosed with FASD in the current system, as also discussed by diagnosticians in this research. However, this is a ‘chicken and egg’ argument said many, as future resources are unlikely to be made available in the absence of the very diagnosis practice that would otherwise provide an evidence base for that resourcing.

Some participants observed that there was no point in diagnosing FASD if there are no services to meet the client’s needs, arguing that a diagnosis without access to appropriate support and intervention is simply a label. A couple of participants took this view further stating that a diagnosis could in fact further limit access to services for clients with FASD because the diagnosis may prevent clients from accessing services that they no longer meet criteria for. For example, a number of participants from a child and adolescent counselling service said that while they currently work with clients whom have suspected FASD, it would be likely that the service would not accept a referral for a client with diagnosed FASD because providing services for FASD is not within the service’s remit. Some argued that counselling is not an effective intervention for FASD, so such a referral would not be in the best interests of the client anyway.

**Barriers to intervention**

A lack of diagnosis options was a substantial barrier to providing intervention for FASD, however there were also a range of other barriers impacting on participants’ ability to provide appropriate management and support. Participants identified four particular barriers in the context of this research: the comparison of FASD to ADHD, access to training and gaps in prior knowledge amongst intervention
workers, workplace support, and the overarching question of where FASD fits within social and health sector services.

**Comparisons to ADHD**

One key complicating factor, and barrier, for intervention work with FASD is the extent to which FASD overlaps (or might be co-diagnosed) with ADHD. In some circumstances a diagnosis of ADHD might even be preferred over FASD in order to ensure that a client has access to ADHD-specified services (for which an FASD diagnosis could result in exclusion). There was a strong view amongst many participants that health professionals misdiagnose FASD as other conditions, most commonly as ADHD. In many cases of ADHD, the client’s history of prenatal alcohol exposure is not taken into consideration, according many participants, including a drug and alcohol counsellor who said:

...It's really important to have an accurate and true diagnosis for ADHD before you go on to providing any intervention for it... ...More often than not it's never even taken into account that there has been a history of alcohol use in utero. The oversight of that being a presenting factor is just all too common. I was very vocal in the early days around actually insisting “you know this child is a child in a family where there's significant alcohol and other drug use occurring”. And yet we're treating them for ADHD when that in itself is enough of a presenting issue to be creating behavioural issues for that child, let alone considering that there might have been alcohol use in utero. (Participant 13, 31/1/2011)

A senior social worker in CYF, said that ADHD is a common diagnosis amongst CYF clients, many of whom have a history of prenatal alcohol exposure, leading to the suspicion of misdiagnosis:

Personally, I think diagnosis has not been done as well as it could have – I'll be careful what I say because I'm not in the health field and it's not for me to say what is and isn't being done there. But in terms of where I do work, from what I'm seeing, every second kid – and that might be a bit of an
exaggeration – has got ADHD, and I suspect that many of those are children who have either been formally identified or are only identified by their parents who perhaps can’t cope with their behaviour, could be fetal alcohol spectrum disorder. But there could be this great big question mark, because there are a whole lot of other factors too. (Participant 22, 24/5/2011)

In some cases, health professionals viewed FASD and ADHD treatment as the same, so given the stigma and complexity of FASD diagnosis, they choose to diagnose ADHD, according to participants. One participant postulated that health professionals diagnose ADHD in suspected cases of FASD “because it gives people a feeling that they at least help these children” (Participant 16, 31/1/2011).

Prior knowledge and training
Another significant barrier for most participants was their lack of formal education or training on FASD. FASD was not covered in their undergraduate training, postgraduate training or professional development prior to attending the training. One participant said it might have been covered in her occupational therapy training, but not in any depth that she remembers. A drug and alcohol worker who considered FASD presentations likely to be common amongst her clients said that, despite her experience working in the field for nearly twelve years, she knew little about it:

I did four years of training at the National Addiction Centre in New Zealand just recently. Not once, did I hear a reference to FASD... This is the training that's equipping people to be competent drug and alcohol counsellors. That's the registration body. If they don't see it as important, why should I? (Participant 15, 14/4/2011)

The lack of formal training and opportunities means that many interventionists felt limited by their own sense of competence in dealing with an unfamiliar issue. As a result, the participants’ perceived ability to screen for FASD varied. Few felt they had the skills and knowledge to screen for FASD, however most said they had the skills to screen for prenatal alcohol exposure. Most participants had a general
understanding of the presenting symptoms of FASD however these symptoms, which primarily included behavioural and learning problems, overlapped with other common diagnoses, especially ADHD (as mentioned above), Reactive Attachment Disorder or Oppositional Defiant Disorder.

In light of these limitations, a number of participants said that access to a screening tool for FASD would be helpful because it would give them a greater understanding of the challenges the client is facing, and clearer guidelines on when and when not to refer to a health provider for an assessment. However, some other professionals questioned whose role it was to screen for potential cases of FASD. A social worker said:

I think it is more the role of health professionals who have knowledge of that. I feel like we do not have enough knowledge and we usually rely on health professionals to pick up stuff like that... but definitely if we had more knowledge around it we could say: “look, we think there is something not right here, can there be an assessment done for this?” (Participant 23, 23/5/2011)

Workplace support and funding
The cumulative effect of gaps in training and diagnosis provision is that intervention workers feel unsupported in handling suspected cases of FASD. This is exacerbated by other workplace-related factors concerning professional support and funding. The majority of professionals felt that FASD intervention only partially fit into their professional role. Only a couple of participants felt equipped with the basic knowledge and skills required to work with clients diagnosed with FASD, however they did not believe that they had the resources to do so. Time was a key factor in integrating some skills developed in training into practice. Participants felt that they did not have adequate time to appropriately support families with high and complex needs, and there was little or no allowance within their service to adapt their workload to meet the needs of families presenting with cases of suspected FASD.
A number of participants from one particular mental health service said they did feel supported by management, however they did not see FASD intervention work fitting in their role as counsellors in any case. Despite this, they continued to work with clients and families with suspected FASD in advocacy and support roles because they acknowledged that there were no other services in their area to provide such support. They also said that their skills and the structure of their work, which involved brief weekly contact, not casework or intensive work, placed many limits on the effectiveness of their work with families. A manager in the service stated that there was a gap in services for FASD affected families and FASD work was limited within the service but said a cross over between suspected FASD and mental health issues justified such work in the current system. She acknowledged the good work that some staff were doing with suspected FASD but said that the confidence of her staff in this area was varied. A key concern for her was the lack of appropriate supervision for staff working with suspected FASD because she thought her staff, who all attended the FASD training, were likely to have had more training and developed more skills in dealing with FASD than their supervisors.

Where FASD fits
For some of the participants in this research, these barriers have resulted in them avoiding FASD or deliberately pursuing intervention strategies for their clients’ other coexisting diagnoses. Seeking an assessment or diagnosis for clients with suspected FASD was dismissed by some participants, who saw referrals as ‘pointless’ given the lack of diagnostic services. Others chose not to refer for an assessment because of the lack of resources and services available to the client if they were indeed diagnosed. Some participants were not sure what to do when they suspected FASD. When a CYF social work participant was asked what she would do if she suspected FASD she said:

[I’d] come back to work and say: “wouldn't be surprised if that kid hasn't got fetal alcohol”, and that's about it you know. Because I really don't know what to do if that is the case. What can be done? I mean, is it just child behaviour management that works with any other thing that works with
FAS? I don't know. I don't think any of us really have enough training on it. (Participant 2, 18/11/2010)

This does not, however, mean that FASD is not an issue in practice, and these professionals experienced continued interaction with clients who appeared to be FASD-affected. The question, for them, was what to do about it. For some, this meant that they would often discuss their suspicions of FASD with colleagues, referrers, educators and others but would not take it any further.

Some participants were willing to pursue FASD diagnosis, however were unsure where to refer to because they were unclear where FASD might fit in health service provision, health, mental health or disability support:

There are young people that we do definitely question. There was a young girl... who we had questions about, and when we put two and two together we probably had a strong idea that, yes, she would meet that criteria, to be on the spectrum, but then what do we do with that? We queried it as a team, but I don't have that experience. I don't know where to go or what things there are to do with that... (Participant 8, 14/1/2011)

Compounding this frustration, a number of participants had been involved in multiple referrals where FASD was suspected and expressed their frustration about this situation:

It's a bit sad to say: "look, this is my recommendation", and to have to quantify yourself as a professional again and again and again to other professionals who are asking your professional opinion and then don't follow through on your recommendation. (Participant 14, 22/10/2010)

Some participants continued to document prenatal alcohol exposure or suspected FASD in referrals, despite their experience of an FASD assessment being dismissed, with the hope that identifying suspected FASD in referrals might lead to changes in diagnostic services for FASD in the long term. However, a couple of social work
participants from Child, Youth and Family said that, if they suspected FASD, they would suggest to the family to go to a GP to get a referral for an assessment because they do not believe that their formulations would be taken seriously by health professionals: “I don’t think they recognize us as the experts or having knowledge around this…they generally think it is behavioural when it’s from Child, Youth and Family” (Participant 23, 23/5/2011).

A number of interventionists further described an experience of ‘gatekeeping’ where services would deny access because they did not see FASD as fitting within their remit, or because the professional had already engaged with or made an alternative referral to another service, even if the service did not agree to see the client. In some cases other more specialist services refused to accept the referral because the client was engaged with the referring service already, and they did not see how they could further assist in cases of suspected FASD. A number of participants from one specific region talked about how this issue commonly played out in their region. They said that the paediatricians they had contact with were resistant to considering FASD, and suggested that patients, who often had coexisting mental health issues, should instead access mental health services. Ultimately, these experiences reflect a health system in which the ‘place’ of FASD remains unclear, resulting in haphazard, contradictory or simply wary or disengaged responses to FASD from professionals across the sector.

**Strategies for intervention**

The barriers to intervention discussed here reflect the difficulties faced by intervention workers when approaching FASD. Despite their clear limitations, intervention workers have often been adept at finding strategies to overcome or circumvent some of these barriers. In the course of this research, six types of strategies emerged from discussions with intervention workers: referring for alternative diagnoses, providing interventions for alternative diagnoses, addressing family members’ and individuals’ expectations, adopting a strengths-based approach to the client, actively advocating for clients when working with other sectors and systems, and focusing on prevention education as a means to
reduce future impacts of alcohol consumption within the pool of clients seen by intervention workers.

Referrals for alternative diagnoses

In cases where interventionists have been uncertain about the usefulness of an FASD diagnosis or have suspected that they would not get an FASD assessment regardless of their suspicions, they have instead opted to make referrals documenting alternative suspicions. Some participants made referrals to health providers for ADHD assessments when they suspected FASD. Participants said they would be a more likely to get an ADHD diagnosis and would gain more support services for their clients this way. One mental health nurse explained:

We can sometimes say to a doctor, “Please can we just get a diagnosis then we can get a funding stream for this kid even though we think it might be FASD... can we get the ADD or the ADHD part funded? (Participant 14, 22/10/2010)

She also said, in suspected cases of FASD, she would not necessarily refer for a FASD assessment if she thought there would be no chance of an assessment/diagnosis but would 'shop around' for an alternative diagnosis that would get her client support:

Sometimes I’ll say to a paediatrician or psychiatrist, just give me a diagnosis because I need something to attach some funding to. I can get a needs-based assessment if they have a diagnosis and if they don't, I can't. And if they get a diagnosis, I can get... respite for this family and get carer support provision for them and get funding for programs for the holidays. So I actually don't [care] if you don't want to diagnose FASD just diagnose something so I can get them help! (Participant 14, 22/10/2010)

Professionals who made referrals for psychometric and mental health assessments when they suspected FASD were often proactive about it, approaching a range of health services including hospital paediatric departments, youth mental health
services, university-based psychology services, disability services, education-based psychology services, and in some cases private psychologists. While these approaches might not result in any direct intervention for FASD, some participants said that their clients had some benefit from receiving an alternative diagnosis such as ADHD, Global Developmental Delay or Reactive Attachment Disorder, mainly in the form of access to funding for services such as respite care.

Working with an alternative diagnosis to FASD presented challenges for professionals who recognized that obtaining an FASD diagnosis in the health system was unlikely, but valued the importance of working in ways that were evidence-based. Some participants said their job was to identify concerns and formulate possible diagnosis, however, once assessed, they would only work with the diagnosis given. A social worker in child protection said that despite suspicions that up to a quarter of her caseload was likely to be affected by FASD she would only work with the diagnosis given because:

[A diagnosis] kind of predetermines what you’re going to do, yeah. So, if they had a diagnosis of FAS and we knew what to do about that, then that’s what you would work with, yeah. If a child’s diagnosed with dyspraxia or dyslexia then you go looking for information on that and that’s what you work on. So yeah, you do tailor your responses, I think, to whatever diagnosis sits with the child, whether that’s right or wrong. (Participant 2, 18/11/2010)

While this situation did not sit well with her, she did not see any alternatives. She said she would be reluctant to talk to caregivers about FASD without a diagnosis and given that she believed few CYF-appointed caregivers have an adequate understanding of FASD, this situation was likely to impacted negatively on the young person and the placement and could contribute to placement breakdowns.

A child and adolescent counsellor shared a similar view initially: “I can't diagnose for fetal alcohol, so I work with what the young person’s already been diagnosed
with, which is the ADHD, and put those strategies in place” (Participant 10, 27/1/2010). However, she later added:

There’s such similarity between the ADHD and fetal alcohol, I think that works okay. So it’s ADHD, they get the diagnosis of ADHD, but it may be fetal alcohol, it’s what’s going to work really is the key thing. What’s going to help the young person? What’s going to help the family? That’s what’s really important. It’s not so much the label that’s put on the child; it’s more, what are we doing to make life more manageable? What other supports do we need to put in place to help this young person? That’s the key, because as I said, it’s a name, isn’t it, and you can try different strategies. (Participant 10, 27/1/2010)

Some professionals discussed FASD with clients and families prior referring for a FASD assessment, and put in place strategies related to FASD. One mental health nurse expressed this as follows:

I say: “well there is fetal alcohol spectrum disorders”, I will say this to parents: “It’s not well recognized in New Zealand”, but I said some of the symptoms or parts of the disorder are like ADHD and intellectual disability and all of those developmental issues can [potentially be] attributed to the disorder. I often tell them there aren’t many people who will actually diagnose it. I’m actually honest about it because you have to be, it’s not fair to them otherwise. (Participant 14, 22/10/2010)

**Interventions for alternative diagnoses**

One outcome of seeking alternative diagnoses is that this leads to specified interventions for alternative diagnoses that might also prove useful for FASD-related issues. A number of participants talked about working with ‘parts of FASD’, for example, the ‘ADHD components’, and some talked about working with just those ‘parts’ that have been diagnosed, whilst advocating for further support. A large number of participants pursued behaviour management techniques and other interventions they found useful for ADHD management to manage suspected
FASD. Some participants said that they understood that ADHD interventions had limitations with FASD, but many could not explain why, while others thought that ADHD and FASD interventions were essentially the same.

A mental health nurse with extensive experience working with ADHD in child and adolescent mental health services said that she had tried ADHD interventions with children with suspected FASD with mixed results. She said that while some ADHD interventions were appropriate for FASD, she saw some key differences in how children with ADHD and those with suspected FASD (but diagnosed ADHD) responded to behaviour modification interventions. She noticed that the children with ADHD who were medicated often engaged well with behavioural interventions that assisted them to manage their behaviour, self-regulate and be more flexible in their thinking. This, in turn, had a positive effect on learning and participation in school. However this was not the case with clients with suspected FASD. She thought that their ability to benefit from behavioural management was limited by their ability to apply these approaches in different settings, their memory, and their poor understanding of abstract concepts: “even if they are medicated, their sense of justice and fairness won’t change... ...they don’t have the ability to be more flexible, so you almost feel like everything’s here and now, how it is today”. (Participant 16, 31/1/2011)

One participant said she had employed strategies related to FASD with one family who had a child diagnosed with ADHD, while continuing to liaise with health professionals about her suspicions of FASD. In this case the family had agreed with her assessment of suspected FASD and were agreeable to proceeding with FASD education and strategies. The professional said she was able to do this because the family, who had tried a range of ADHD interventions without any improvement, wanted to try something different and because she was experienced with ADHD and felt equipped enough to talk about alternative management strategies with the family. Other professionals tailored their work to models of practice more suited to FASD management without explicitly stating so to families or other professionals, or by applying interventions that they described as tailored to the client and the circumstances, without mentioning FASD as a possible factor.
Addressing the expectations of families and individuals

Some participants’ engagement with families centred on developing realistic expectations, taking into account the child’s strengths and challenges. In some cases, this work was compromised due to an inability to access psychometric testing for the client. However, participants generally said that this approach helped to reframe negative perceptions of the client bought about as a result of some of the behavioural symptoms of suspected FASD, and assisted families and professionals to employ strategies that considered the client’s actual level of functioning:

I think that one of the key things, that people have got really good about, is considering what expectations are put on that child... It’s really unfair to be expecting them to be the same as their peers when they are clearly, you know, are suspected to have that diagnosis... Often, interventions are similar in terms of getting some structure in place, getting some regular patterns in place for, you know, basics happening at home, and ensuring that the family’s aware of what the needs of that child are. Leaving this child to their own devices is not going to work very well. You need to be actively alongside them in what they’re doing, or be clear about what you’re asking them. So you know even those basic [things such as] keeping directions very brief and direct rather than giving them three things to do at once and knowing that they’re not going to get any done. (Participant 13, 31/1/2011)

Developing realistic expectations of the client was seen as an effective strategy that could be employed regardless of whether the child had a diagnosis or not. A community-based social worker pointed to an example she had heard from a foster parent that she had subsequently used to help explain and reframe perceptions to others:

I was speaking to a foster parent who’s got a child in her care with significant issues around attachment and, you know, just constantly dealing with it. And she said: “I have to remind myself that, if she had lost a leg, I
 wouldn’t be making her run up the stairs”. And I thought that was a really good one. And she said: “you know, because we cannot see it, we are expecting huge things of these kids and forgetting that we need to adjust life accordingly”. She said: “Because, if the disability was really obvious, then we would have that constant visual reminder that we need to make adjustments”. But she said: “You forget that it’s not going to... the leg won’t suddenly grow back”, and I thought that was a really good way of putting it. (Participant 18, 11/2/2011)

**Employing a strengths-based approach**

Interventions that sought to support the client and considered challenges such as memory deficits and poor executive functioning were seen to be more beneficial by some participants than behaviour-based strategies. All too often, participants noted that it was easy to focus on clients’ deficits while overlooking their strengths. Interventions that focused on providing structure, routines, clear boundaries, repetition, simple instructions and support aids were identified as helpful, as well as strategies that fell within the compass of a ‘strengths-based’ approach to intervention.

A strength-based approach was seen as important by some participants because it maximized the positive aspects of the client’s abilities and the family’s capacity to support them. One participant stressed the importance of recognizing the useful knowledge that parents have about their children, while another, who valued strengths-based work, cautioned that care must be taken to make sure that challenges and deficits were also considered within a strengths-based approach. She shared an example of where a strengths-based approach that did not also consider the client’s deficits impacted negatively on the client:

Her school was very much aware that she struggled academically, and as with a lot of these children, everybody tries. I think they feel that when they say there’s some deficits, that they try to outweigh it with piling all these positives, you know like she’s really bright, she’s really loving, whatever... but she also is, you know, has trouble self soothing, [has a] temper, she can’t
read situations, she feels very unloved, she doesn’t feel like she belongs. (Participant 16, 31/1/2011)

Research participants from a child and adolescent drug and alcohol program said that their ability to work intensively with clients, tailoring their work to meet the client’s needs, was very beneficial. One pointed to an example of why this works:

Often in schools the young people that come here, they don’t get that one-on-one attention to help explain things in a different way, maybe, if that is how they learn... Of course they are going to act out if they don’t understand and they are finding it too hard. And then you see them come here and with a little bit of extra support they can do really well. So it’s just about understanding and supporting them and providing them with the tools to really be able to feel success. (Participant 9, 14/1/2011)

However, participants from this service said the limitation of this work was that it was short term and clients were sometimes discharged back into community based services that lacked the resources to continue to support them in this way, with negative consequences for the client.

**Providing advocacy**

As participants said that clients with complex needs, such as those with suspected FASD, required intensive support and expertise that could not be provided by themselves alone, they placed a high premium on working effectively with other professionals across sectors. Participants had varied views on which system was most appropriate to address the needs of FASD, with many agreeing that clients with FASD needed support across systems including support services in education and in some cases drug and alcohol and juvenile justice services:

They are multi-factorial kids, so you have got to have a multi-systemic approach to it. They need special ed[ucation], they need special needs, they need special medication, they need special assessment, they need this and that, and it’s all scattered across services. So everybody does a little bit of
gate-keeping to a point, because these are our criteria and this is what we will do and not do. If there was a little bit of creativity and flexibility about bringing a multi-systemic approach to some of these kids their needs would be so much better met. Its chicken and egg stuff, so let's not fight it, let's just get on with it and decide who is doing what, and do it. (Participant 14, 22/10/2010)

Participants also saw their own advocacy through other services on behalf of clients as an important part of intervention. Some commented on how it was a challenge to engage a range of services with a single client, even if each different service was needed to address a range of needs. As one participant said:

The perception [by some professionals] is once they're in our service that they're going to be all okay and we can attend to all of that. But that's not the reality, and we know that, so advocacy, I think, is the key thing, and that we're not doing anybody any service if we're just allowing them into the service and they're not going to get any progress. (Participant 13, 31/1/2011)

On the other hand, some participants said that discussion of diagnosis and the most appropriate management strategies for clients with suspected FASD was often complicated by the range of professionals involved with the client and their understanding of FASD. Many said it was common for clients with suspected FASD to have engaged with a wide range of professionals and service providers. However, professionals did not always agree on the best way to progress when FASD was raised, especially if the client had an alternate diagnosis offered, making it difficult for professionals to work effectively together. Putting in place strategies related to suspected FASD was challenging for participants in situations where their colleagues had no or little understanding of FASD. Getting professionals ‘on the same page’ was seen as important, but challenging, by participants:

It's about 'more information is better'; getting people to understand what that diagnosis is and what it means for that child, and what things could
certainly help for that child in certain settings. But what I know is when people are on the same page, whether or not the diagnosis has been made by the required professional, that people can get on and implement things anyway. (Participant 13, 31/1/2011)

Often, when a range of services were engaged with a client, some would attempt to remove their service, citing that the client was being ‘taken care of’ by the other services, thus demonstrating the need for continued advocacy. For many participants, integration of services was seen as a deciding factor in the provision of effective intervention:

In an ideal world, you'd be able to take all the compartments [and] integrate them all, whereas if they're presenting at different services at different times, different focuses are gonna be in, and families often feel like, you know, it’s just one thing after another, after another, because they don’t feel integrated, or everything doesn’t feel integrated for them. (Participant 16, 31/1/2011)

**Focusing on prevention**

On top of all of these strategies, many interventionists framed their role in relation to FASD as one of prevention. Though professionals had varied understandings, skills and experience of FASD, and approached the management of suspected cases in different ways, most saw their role in prevention education as important. A number of professionals had spoken to young people and their families about the risks of alcohol consumption during pregnancy:

There is a high percentage of young people that come through here with whanau [extended family] history of alcoholism, and the young people here who are using, because that is the thing for us, is the preventative and we work on a risk minimization strategy... ...if we can stop them doing it, and we can educate them, then I think that training has done that for us... ...I have had four young ladies who are mothers now that have gone through
this program and we've had a young father who has gone through this program. So that would be valuable to them... (Participant 8, 14/1/2011)

**Working with families**

Managing suspected FASD was understood by all participants as being a challenge for professionals and families alike. To this end, research participants spoke at length about their strategies for working with families as a way of handling FASD. In this regard, the experiences of the intervention workers differed substantially from that of the diagnosticians, who are less likely to have extensive dealings with family members in their professional practice. For the interventionists, families fall directly within their professional practice as family support and preparedness constitutes one of the key determinants of success or failure in intervention strategies.

**Talking about FASD**

Participants have had mixed responses from clients when raising and discussing suspected FASD. One participant talked about how her clients felt anxious and concerned about the possible effects of prenatal alcohol exposure. Another said “I can’t say it’s been positive ... some of them have felt a bit guilty but they have been, ‘well it was a long time ago and I did drink and I am aware now’” (Participant 14, 22/10/2010). Nevertheless, a number of participants said that their clients raised questions about alcohol use themselves, or responded receptively when probed about prenatal alcohol consumption.

Some participants had worked with foster carers and adoptive parents who had looked into FASD or who were told by Child, Youth and Family services that the child might be affected by prenatal alcohol exposure. In some cases, parents suspected something was wrong but didn’t know what the problem was, and in other cases professionals raised FASD as a concern with parents and families. In others, participants said that their clients felt relieved to have a possible explanation for the challenges their child was facing, for example: “[The] mum was starting to say, ‘you know we, we don’t know what it is’, and so I showed her some of the information we had [on] fetal alcohol after doing the training, and we sat
together and went through it, she said ‘that’s my child… it explains it all’.

(Participant 16, 31/1/2011)

Clients with suspected FASD and their families had a range of things in common. Intervention workers often suspected that FASD may have been an issue in some families that were repeat clients at their services. Most often this was because their needs had not been met, interventions pursued had not worked, and the client and family had continued to face challenges. Sometimes, families returned to the service despite the service not meeting their needs because of a positive experience with a professional in that service. For some clients, the suspected FASD was identified because the client had returned to the same service many times, as explained by a mental health nurse with regard to a client:

I read all her presentations, her whole file here and it was [presentation] number three or four that caught [my] attention and got her really pinned down for assessment… It was like [hearing a repeated recording playing] each time she presented, but if you read it in its entirety, as a story across a continuum, you can see that there was disability just screaming out and possibly FASD in the picture. (Participant 14, 22/10/2010)

Participants said that while clients with suspected FASD were unlikely to be assessed by health professionals for FASD, they often undergo a range of assessments by a range of different services. A social worker from Child, Youth and Family said that children in child protection care in particular are tested over and over again:

We might get an assessment for a young person for example, and, you know the assessment came back with a... IQ of 68, therefore mild mental retardation, you know, something along those lines. Then we refer them to a service and that service says, “Oh, look, [we] don’t believe you”, so you go back and get another assessment... you keep going round and round... Now as a seventeen year old they’re questioning that diagnoses... we’re sort of looking at [it] going: “Oh gosh, you know, in some aspects he is managing
quite well, in other aspects he’s not, yes he certainly has some learning disorders, oh I wonder if he’s got fetal alcohol in him?”. (Participant 19, 29/4/2011)

**Pressure on families**

The challenge to families who repeatedly access a range of services without success, or in the hope of achieving a better outcome, was acknowledged by intervention workers, as articulated by one drug and alcohol counsellor:

> It can be fairly hard work for parents having to seek that assistance and maybe work through different professional settings and services to try and get an answer that they pretty much know already, but they aren’t getting that acknowledgement for it, and then they become seen as being ‘difficult’, so get themselves a bit off-side with professionals. Then they can be caught in the middle of differing views, so that’s pretty tough for them as well, ‘cause they’re hearing mixed messages about what’s going on. And it can be terribly frustrating depending on what’s actually happening, but there can be quite a few demands on having to attend different appointments or school meetings or health, whatever. There’s a whole range of things that can be a challenge. (Participant 13, 31/1/2011)

It is not uncommon for families to get mixed messages from professionals about the child’s presentation and the best intervention strategies or pathways to pursue. This places greater stress on families who are often struggling to manage the challenging behaviours of the child:

> I think families, depending on their own personal resources... find it really tiring trying to manage a child that has FASD as well. Often it’s not understood why that child needs so much more attention than the others. Often they’re misdiagnosed and, you know, ADHD is given as a diagnosis when it’s not that. So I think it’s tiring for families and it’s challenging to try and get some answers about what’s going on. And they feel that sense of failure, that their child isn’t doing well enough, they’re not performing well
enough at school, that it’s a struggle to get them to school. It’s a struggle to get them to eat their lunch. You know there’s a whole range of things that can occur. (Participant 13, 31/1/2011)

Parents who accessed a range of services without satisfactory outcomes often felt blamed, according to some participants. When multiple interventions from a range of services were not effective, professionals often looked to parenting issues as a potential cause of the problems, and parents were offered parenting courses. This can further a parent’s sense of frustration and failure said some participants. Children also can internalize the perception of failure according to one participant who said: “these children are so [guarded] and get so angry because they know, a part of them is aware that they can’t do things that other children do, so they do have an awareness” (Participant 16, 31/1/2011). Parents who felt disempowered because they lacked support and acknowledgement sometimes found it challenging to advocate for their child, resulting in further a lack of support for the family.

**Intergenerational FASD**

In some cases, participants mentioned working with families where they thought intergenerational FASD was likely to be an issue. Where parents’ own exposure to prenatal alcohol was possibly affecting their functioning, the parenting of the child was also a complicating factor for all concerned. A senior social worker from CYF who convenes family group conferences said that she often asked herself whether FASD was a factor for many of the parents that she saw. She said that this issue has ramifications for how vulnerable children are cared for in the New Zealand system, which has a current focus on keeping children in families or placing children with extended family:

In this country now, we’re looking to families to care for their own children, and not the state. I don’t have a problem with that. I totally support that where it’s appropriate, however, it’s the appropriateness. If that child is likely to have fetal alcohol spectrum disorder, then they’re going to require a lot of hard work in terms of parenting, probably. They’re probably not
going to cope well in school. They're going to quite possibly present some challenging behaviours. If the parent is affected by fetal alcohol spectrum disorder, then they're unlikely, without a heap of support, and even with that, to be able to offer that child what they need. It can even go back a generation or even more... If alcohol is sort of normalized, then they're unlikely to recognize that child's needs. (Participant 22, 24/5/2011)

Possible intergenerational FASD can also impact on a family's ability to advocate for the child, according to a drug and alcohol worker who compared them to parents of children with other disabilities:

Parents of children with disabilities are often quite militant and they're often quite used to battling the system and there's quite a lot of support around for them... In terms of that mother with FASD having a child with FASD [or] having a grandchild - they are victims doubly over. (Participant 15, 14/4/2011)

A commonality in these experiences according to a child and adolescent counsellor is that families and children with suspected FASD are not being acknowledged or understood:

[I think about] the meaning of fetal alcohol syndrome from the perspective of people who live with it, experience it. Today I have been thinking about how I know it is not diagnosed in Dunedin. You know the anecdotal kind of aspect as well and what it is like for those families who actually experience it or those young people who actually live it... the invisibility of that... I think one of the most awful experiences people can have is not actually being understood and actually how frustrating that actually is and there is an injustice in that, because I think there is enough information here to offer understanding. (Participant 11, 27/1/2011)
**Asking about alcohol**

Participants had mixed views and experiences of asking about prenatal alcohol consumption with their clients’ families. While all of the participants saw the value of screening for prenatal alcohol exposure, many felt uncomfortable and some not at all confident in asking about alcohol use. Prior to attending the FASD training, few of the research participants routinely asked clients about their alcohol consumption, and when they did this was most often related to safety concerns for the child and centred on how alcohol consumption may be impacting the family and parenting of the children, not prenatal alcohol use.

A Plunket nurse clinical leader who did report frequently asking about prenatal exposure prior to training said she had very little understanding of why she was asking or what to do if a client reported prenatal alcohol consumption:

> One of the questions that we ask, our first visit to all Plunket clients is, did you consume alcohol in your pregnancy and to be very honest, I just ask the question. Most people would say no. If they said yes, it was very rare or they’d say, oh maybe I did in the first couple of weeks before I knew I was pregnant. But to be honest after that, okay, I noted it. It didn’t ring any alarm bells, it didn’t do anything else. Unless they’d say, well yes I was a binge drinker and yes, I took drugs as well. So that would set off an alarm there, but that’s all I knew. (Participant 21, 23/5/2011)

The participants’ level of understanding of the potential risks of prenatal alcohol exposure and FASD, and their experience in asking questions around alcohol use, also influenced whether they asked about prenatal alcohol use. Other factors included their relationship with the client and their perception of risk for that client. The threshold for what was considered risk varied greatly between participants. Some considered risk to be a family history of alcohol consumption, others focused on binge drinking, while others considered ADHD symptoms as a risk factor.
A manager of a mental health service said that while she thought her staff were more confident about considering prenatal alcohol exposure as a factor in some presentations, she thought that some staff were more likely to ask about prenatal alcohol use than others, stating that: “non alcohol and drug staff are less likely to ask about alcohol and drug issues, so that’s going to be down in the hierarchy of questions” (Participant 13, 31/1/2011).

In relation to asking birth mothers, participants felt more comfortable about asking if they approached it from a perspective of ‘not knowing that they were pregnant’, as evidenced by a youth drug and alcohol worker who said:

> I suppose, if I was going to raise it with the mother, I would have felt a bit more confident... because... often people are drinking and they still don’t know they’re pregnant, that the crucial day fourteen to eighteen, or whatever, they still don’t know – and so I thought well actually it’s not about blame or guilt. (Participant 15, 14/4/2011)

Participants affirmed that building rapport with clients prior to discussing alcohol use was important in order to minimize feelings of blame and judgment and foster an environment where alcohol use was reported accurately. Many said that, post training, they had changed how they asked about alcohol use in order to fit it within a broader context of conversations about health and family:

> So, learning ways to talk about it with parents and being so careful about that no-blame way [is important]. Taking it slowly and gently, but having those conversations, so not making it clinical, just having conversations and, and asking what they thought or felt... slowly bringing them that way and then within that, being about to talk about their family of origin, and brother and sisters and aunties and uncles, and grandparents and all those... their attitudes to alcohol... and then starting to talk about, you know the child's learning, and, and then when, you're confident [it’s] the right time, or whatever, to bring in some of the [Canadian FASD] resources. (Participant 16, 31/1/2011)
One participant said that changing the way she asked about alcohol use resulted in changes in how her clients reported their use:

We used to ask if there was any... alcohol consumed during pregnancy? People would say “no”. Most of them say “no”. So now I say: “Can you think of any time that you may have had alcohol during all your pregnancy?” Because most people will say, “Oh probably those first few weeks before I didn’t know”, a majority of people say that... Then I’ll ask how much, “So was that a lot of alcohol, a glass maybe once a week or was that binge drinking? What would you assess that as?” So it’s a lot more intense now, what I do ask. (Participant 21, 23/5/2011)

However, social workers working in child protection who suspected high levels of FASD amongst their clients said that child protection social workers were more likely to ask promptly and directly about alcohol use because building rapport was challenging due to limited time and high workloads. A child protection manager said that she was concerned that analytical skills and skills in establishing rapport are being lost in such services, impacting the collection of accurate information including alcohol use and exposure:

I don’t think now we are focused on establishing a rapport. Without sort of establishing that rapport, and bit of respect, it is hard when you work for a child protection agency like Child Youth and Family – I mean, there are going to be people who just hate you or something because you work for child protection. But I believe there are skills to establishing rapport and being able to ask people those questions, and let them know you’re asking them for some very good reasons, and collecting the right data and then analysing what that means – historical stuff and current stuff. I’m just all the time blown away by our lack of analysis of what all that is telling us... I think history can inform what’s happening now, and it’s not about being judgmental, it’s about making judgments. (Participant 22, 24/5/2011)
Mother blaming, judging, creating unnecessary stigma and creating feelings of guilt were concerns amongst participants when discussing alcohol use. Some participants said this deterred them from asking at all:

I guess asking someone that I don't know, I feel uncomfortable doing that. Because I guess it can be seen as possibly passing judgment and then therefore if someone answers yes, they may think I might judge them differently. And I don't want people to feel like I am doing that because that's not the case. (Participant 9, 14/1/2011)

A couple of participants also reported that some parents became anxious and worried about their child as a result of discussing prenatal alcohol consumption and that they did not feel like they were equipped with adequate skills and knowledge to address these issues:

My problem is that when you get all this information, some of them get really concerned, they get really worried because they'll do a little bit of education. I say, well you know it is best practice to have none. We don't know how much is not enough so we say that no alcohol is the best way to go. They go, “Well how do you know that when you don't know you're pregnant?” and that's really difficult to answer, and “Do you think I've done any damage to my baby?” That's what I'm finding probably, lately, as being the problem: “What do I say to them now?” I have referred a few people to websites for information. The others, I sort of ask them how much and how often? I'm not sure exactly what I'm talking about. I'm just actually trying to get their fears down because I've sort of opened up a can of worms and they're going, “Do you think I've actually done my baby damage?” (Participant 21, 23/5/2011)

However, most participants said that these were not good enough reasons not to ask. Some participants said that while it made them uncomfortable, it ensured that their asking process was thoughtful. Greater community awareness of the risks of
alcohol consumption during pregnancy and FASD would make talking about alcohol use during pregnancy easier according to participants:

... being able to talk to them about, “Have you seen that ad? What do you think that is about?”. It could mean a talking point... I suppose in a way of not normalizing the situation but normalizing being able to talk about it and I suppose that campaign around family and partner violence and those things, talking about that has been normalized. I think the same maybe approach around fetal alcohol could be beneficial as well (Participant 12, 9/2/2011).

A number of participants said it would also be helpful if they were given some sort of mandate to ask about alcohol use during pregnancy. Participants pointed out that many allied health professionals are required to ask about certain health issues such as smoking or domestic violence, however this is not the case with alcohol. Mandating professionals to ask about alcohol consumption would ensure that professionals engage with the issue. It would also normalize the question for patients and clients, who become aware that this is a standard health question and not a value judgment by the professional:

[Asking about alcohol], I think it should [be mandated] because – maybe it’s kind of like family violence. It wasn’t fashionable to [ask about] that kind of stuff but then children were dying, people were getting injured and all that kind of stuff. That was brought to the public’s attention. Now we’re routinely supposed to ask [about family violence] – well, CDHB are supposed to. We’re getting better at it. (Participant 18, 11/2/2011)

**Conclusion**

FASD training gave participants a greater understanding of fetal alcohol spectrum disorders and, as a result, participants were more likely to consider FASD as a factor in client presentation, especially where maternal alcohol consumption was evident. Participants also took on a greater role in FASD prevention following the training, with many participants discussing the risks of alcohol consumption
during pregnancy to clients. Many participants, however, did not change their practice with regard to management strategies and interventions as a result of the training. This was due to a combination of systematic barriers impacting on gaining an FASD assessment, a lack of funding and services for clients with suspected FASD and a lack of knowledge and skills in how to best deal with FASD. Most participants said further training on how to identify FASD and provide appropriate intervention and support for FASD would be helpful.

Participants highlighted the lack of diagnostic services as a barrier to intervention however there was a perception amongst many that, similar to ADHD, FASD is likely to become more recognized in the future, especially considering New Zealand’s culture of alcohol consumption. Participants expressed an interest to learn more about FASD management and intervention strategies that could be applied in practice with clients who they suspect may be affected by FASD or who may gain a diagnosis in the future. Working across systems was seen as a challenge to effective service provision given varied views on FASD, expertise, gatekeeping and the general challenges of working with professionals across services and disciplines. However, by far the most common challenge articulated by this group was that the ‘invisibility’ of FASD in New Zealand impacts negatively on their work. According to the participants, this issue extends into the general community where there is a lack of public health information or awareness of FASD, into policy and planning where is no guidance underpinning professional practice in any sectors, in service provision and support where there is no funding, and in the health system where there is virtually no access to FASD assessment and diagnosis.

The lack of access to diagnosis was raised as a key concern by the participants, who explained that diagnosis informs their intervention. Working in the absence of confirmed diagnosis presents unique challenges for intervention where FASD is suspected, and participants in this research revealed a wide range of strategies for approaching the problems that this presents. Indeed, the overwhelming picture presented here is that of the sheer flexibility demanded of intervention workers in undertaking their professional practice in circumstances where FASD is a suspected issue.
Chapter 10: Discussion

This research has engaged with New Zealand health, allied health and social service professionals across a range of local and international settings, and has thus far revealed the breadth of their engagement with FASD, providing a number of key points for discussion. This chapter consolidates and expands on these key points, with a view to synthesizing the information gleaned through the research process. While some issues are more prominent than others in different professional contexts, two overarching themes carried through the experiences of most of the research participants: the shared challenges that FASD poses for professional practice in New Zealand, and the realization that social and cultural factors strongly influence professional practice for FASD. These themes provide the basic structure for this chapter, which will unpack each of them in turn. With regard to professional practice, the two most prominent discussion themes that emanated from the interviews were the invisibility of FASD, and the overall importance of diagnosis in the management of the condition. Where social and cultural factors are concerned, the two key areas of discussion were the question of where FASD fits within service contexts, and the framing of FASD in discourses of disability, stigma and blame.

Part 1: The circumstances surrounding professional practice in New Zealand

FASD is often described as an invisible disability in advocacy discourses, symbolically situating it alongside other ‘invisible’ disabilities such as autism or ADHD, which have moved from positions of general ignorance to widespread acceptance in society over the last two decades. A primary reason for this is that most people with FASD have no visible physical features, rendering it physically unseen. Greater awareness of FASD, including enhanced services for diagnosis, not only impacts on how the individual is treated, but also on how FASD is dealt with at a policy and service system level. Many of the participants in my research revealed an awareness of this invisibility issue. From a professional perspective, given that instances of physically recognizable FAS constitute a minority of cases,
and that they are more likely to be engaging with individuals with PAE or even just suspicions of FASD, invisibility is a cause for concern.

In New Zealand, the invisibility of FASD affects professionals across the health sector, social service system, disability sector, education sector, juvenile justice sectors and those working in the wider community. Existing New Zealand research has demonstrated that birth mothers and individuals with FASD feel marginalized and lack access to assessment and diagnosis services and support (Salmon, 2008), and that professionals often lack the skills or knowledge to provide effective services for these individuals. Participants in my research have confirmed these concerns, and have also identified a range of factors that exacerbate the invisibility of the condition, including general awareness, specific knowledge gaps, mixed messages concerning FASD, difficulties asking about alcohol consumption, the normalization of alcohol, and the absence of prevalence studies to help confirm the extent of FASD’s impact in society.

A repeatedly voiced perception of research participants in this project was that there is a distinct lack of awareness and understanding of FASD amongst professionals and the broader community. This aligns with the findings of research conducted internationally, which I introduced in Chapter two (cf. Tough, Clarke & Hicks 2003, Payne 2005, Cox, Clairmont & Cox 2008). In my research, the participants self-identified a lack of knowledge and understanding of FASD prior to engaging in FASD training, and further identified a lack of awareness amongst many of their professional colleagues. FASD was not addressed adequately in any of the participants’ formal training or professional development training prior to undertaking FASD-specific training. Participants were more likely to have had some awareness of FAS, however this awareness would not have been sufficient for most of them to feel confident about diagnosing or providing intervention services for FAS. Participants identified that the lack of awareness of FASD can extend to misunderstandings amongst professionals, which can impact negatively on clients and patients. Indeed, the participants themselves provided examples of their own experiences as patients, where health professionals had given them
misinformation or incorrect information regarding alcohol use during pregnancy or FASD.

Misinformation, coupled with inadequate information regarding alcohol consumption in pregnancy, was another reason for the perceived lack of understanding of FASD in the general New Zealand community. A key concern in this was that, without accurate information, people fill in the gaps in their own ways, or simply disregard the risk. This broader lack of recognition of FASD as a health concern in New Zealand impacted on professionals’ confidence and willingness to ask about alcohol use in pregnancy with their clients and patients. This aligns with Woudes’ findings of inconsistencies in how New Zealand health professionals ask about alcohol in their practice (2009). In my research, participants articulated clear concern that their clients may not have been aware of the risks, may not have heard of FASD and may feel singled out or stigmatized as a result of such questions, within a culture where discussion of alcohol use during pregnancy is subject to conflicting and often inaccurate information.

Participants in this research confirmed that within a range of sectors and in the services within which they operate, including Plunket services, Child, Youth and Family services, paediatric services, mental health services, counselling services, drug and alcohol programs, public health services and family support services, alcohol consumption is not commonly asked about or screened for. This issue presents a barrier to FASD diagnosis in New Zealand. Ideally, a birth mother would self-report her alcohol use during an FASD assessment, however often this is not possible, especially in cases where the child is no longer in contact with the birth mother. In cases where professionals do ask, they often do not understand why they are asking, cannot explain the risks to patients or allay concerns and have no referral options for diagnosis or intervention.

Another factor identified by participants as contributing to FASD’s invisibility was the lack of funding and support available for FASD-related needs. There is no targeted funding for FASD services, and there are no national policies regarding FASD in New Zealand. Therefore, there are no specific FASD-funded services
available to address FASD or provide specialist training and information to professionals in the general health system. These issues are manifested in the fact that there are no best practice multidisciplinary team diagnostic services for FASD in the South Island, and limited best practice diagnostic services for FASD in the North Island (and those that do exist have been developed as a result of the pilot project discussed in this thesis). Given the specialist skills needed to undertake an FASD diagnosis, it is unlikely that there are any publicly funded services undertaking best practice multidisciplinary team diagnosis in New Zealand other than those included in this research. My discussions with FASD experts from Canada during the course of this research revealed that some of their best progress on FASD diagnosis and intervention had been reliant on direct government support. This was especially the case in British Columbia, where the government developed a comprehensive strategic plan to address FASD (Government of British Columbia 2003, Rutman, Hubberstey & Hume 2011).

In New Zealand, in the absence of these services, suspected FASD cases are often given an alternative diagnosis, the most common of which is for ADHD, which has many behavioural similarities to FASD. This similarity was raised as an issue discussed by all of the research participants. ADHD symptomatology can mirror that of FASD, and in many cases ADHD may be a coexisting condition, even though the overall management of these two conditions is considerably different. On the positive side, research participants noted that a co-diagnosis or alternative diagnosis of ADHD could lead to quicker access to intervention services. However, on the negative side, it has the potential to lead to the implementation of intervention services that are not going to be successful (thus contributing to the individual’s sense of helplessness or possibly to their disengagement from interventions) and contributes to ensuring that FASD remains invisible. This is an area that might benefit from the development of clearer guidelines for differentiating between ADHD and FASD, as acknowledged in international research (Peadon & Elliot 2010).

Given the lack of specialist skills and understanding of FASD amongst professionals in the allied health and social service sectors, and the assertion by many
participants from those fields that they are not equipped to deal with FASD, it is likely that the needs of those with FASD are not currently being addressed appropriately. This conclusion resonates with the work of Salmon (2008) and Symes (2004), who both assert that families and individuals with FASD do not feel supported by the health and allied health systems in New Zealand. Whilst the participants in this study have made great progress in the development of services to address FASD, it is clear that FASD remains under recognized, under resourced and largely invisible. While this is a concern in itself, it also has further implications for professionals and their practice, which will now be discussed.

**The importance of diagnosis**

In light of the above discussion, diagnosis services are especially important as a mechanism for increasing the visibility of FASD. According to the research participants, diagnosis is a starting point for identifying and understanding FASD, preventing secondary disabilities, and informing appropriate and effective interventions. Participants asserted that this was of benefit to the individual affected, their family and professionals. Prior to a diagnosis, it is common for individuals with FASD to develop a collection of negative associations as a result of challenging behaviours related to or caused by their underlying FASD. This is a concern often articulated internationally by professionals and by individuals affected by FASD and their families (cf. Malbin 2011, Himmelreich 2011).

A diagnosis helps to reframe these negative perceptions of the individual, as it acknowledges that FASD is, first and foremost, a brain-based physical disability, and that the individual's behaviours are symptoms of brain differences. Diagnosis allows individuals to gain insight into what they do well, why they may be different to their peers in some ways, and help them plan for the future. For families, diagnosis may help them to understand why their child’s brain may work differently to others, how to support their child’s strengths, how to develop realistic expectations, and how to make changes within the family to support the child's development.
Diagnosis also helps others to develop realistic expectations for the individual, making them more likely to succeed and have positive experiences and provides families and individuals with information to advocate for the child. It also provides an explanation for the behaviours and the reasons that chemical or behaviour modification-based strategies for managing them may not have been effective. In some cases this recognition also provides validation for parents who may have been previously labelled as having poor parenting skills. This is a factor that was also observed by Salmon (2005).

A key benefit described by almost all the participants was that best practice multidisciplinary team diagnosis, which includes a comprehensive report to professionals and families, informs appropriate intervention. Specifically, best practice multidisciplinary team diagnosis provides professionals not only information about the clients strengths, deficits and needs, but also includes recommendations for management, intervention strategies and resources to best support and educate individuals, families and other professionals about the condition. From this base, professionals can develop tailored interventions that maximize strengths, minimize deficits, and ensure appropriate environmental accommodations and resourcing.

Without a diagnosis, professionals in the allied health and social and community services can only speculate on the cause of the presenting issues and employ strategies related to the client’s presentation. In the case of FASD, professionals often employ strategies related to addressing the behavioural symptoms that are commonly present cases of FASD. This was the experience of many of the interventionists within this research, who, without access to a diagnosis, commonly employed behavioural learning-based interventions with clients. As noted in Chapter five, Diane Malbin (2011) asserts that whilst these types of interventions are not necessarily good or bad, they often do not consider the neurological root of the behaviour, and therefore may not be effective.

A diagnosis that informs appropriate and effective intervention strategies is not only of benefit to the individual and family but also to the service system because it
helps to ensure services and resources are used effectively, reducing the risk of duplication of costly ineffective services and reducing the likelihood of the development of secondary disabilities. Another service system benefit of increased FASD diagnosis is that it inherently leads to greater awareness of the condition, thus helping to promote FASD awareness. This was demonstrated quite clearly in the results of the Alcohol Healthwatch pilot project discussed in Chapter six. Participants in this research repeatedly asserted that this could have important flow on effects in terms of access to recourses for intervention, and that diagnosis could help explain (and justify) why a child with FASD might need more resources than another with a similarly debilitating but less complex condition. Meanwhile, there is a degree of moral or ethical expectation that the health system should provide targeted resources for FASD where it is formally diagnosed, and that this is more likely to happen if more formal diagnoses become available.

In the words of a number of the research participants, diagnosis puts professionals ‘on the same page’, all working from the same starting point. Not only does it help to predetermine a lot of interventions strategies, it also helps guide and tailor other responses over the course of an intervention period. While some participants welcomed any kind of diagnosis, most of them advocated specifically for multidisciplinary team diagnosis, which they recognize as being international best practice (as also acknowledged by Peadon et al. 2008). In many ways, participants argued, diagnosis is also a form of prevention because it raises awareness of the condition, and diagnosis can also be seen as an intervention because the understanding and insight gained as a result of a multidisciplinary team diagnosis reframes understandings and perceptions of the person that can result on how the individual is treated and supported.

**Diagnosis, intervention and ethical responsibility**

As this discussion reveals, there is a close relationship between diagnosis and intervention, and in many ways, effective intervention relies on the availability of best practice diagnostic services. Diagnosticians viewed their own roles in this way, as part of a continuum of service in which their reports and findings were providing intervention services with a pathway for action. This does, however,
reveal the necessity for intervention services to actually be available. Some of the
diagnosticians who participated in this research expressed an awareness of an
ethical dilemma in their work, and questioned whether it was ethically justifiable
to provide an FASD diagnosis in cases where appropriate intervention services
may not be available. Indeed, participants pointed to a number of areas in which
support is either lacking or non-existent. Intervention workers also identified a
range of barriers to effective professional practice that mirror those of the
diagnosticians, including widespread misinformation, poorly informed practice
bases, and insufficient access to other services, including diagnostic services.

Much of the discourse surrounding FASD diagnosis and intervention, as much in
New Zealand and internationally, revolves around children and young people,
meaning that adults with FASD are often left outside of the frame of service
provision priorities. However, it is generally agreed that FASD is a lifelong
condition. Therefore, some participants argued, adults could require just as much
attention as children in the FASD service provision context, and FASD service
provision should therefore be seen as a long term intervention process.

Meanwhile, participants also acknowledged that FASD impacts on the family as
well as the individual, and that the needs of families do not always figure in
intervention strategies that focus on the needs of the individual. This impact can
relate specifically to diagnosis: on the one hand, in the absence of a diagnosis,
intervention workers might perceive a child’s behaviour as stemming from a
parenting problem, and therefore work on developing parenting skills. On the
other hand, parents feel blamed, as ‘poor’ parents, and in these circumstances, a
diagnosis can actually improve their self-view and confidence as parents. In the
worst of cases, families are disadvantaged by professionals who aren’t aware, are
not trained, or are limited in their ability to act. They are limited by a system that
does not have provisions to support them. Whilst many professionals are aware
and willing to or see a need for work in this area, they do not have the resources or
skills to do so.
This understanding of diagnosis as something that can be both empowering and disempowering aligns strongly with the writing of sociologist Annemarie Jutel, whose recent work (2011a, 2011b, 2011c) provides a critical deconstruction of medical diagnosis, examining the potentially beneficial and potentially harmful effects that diagnosis can have. As Jutel explains, while diagnosis organises and interprets disorder, it does do from a position that is itself socially constructed and prone to socially or culturally guided responses. While diagnosis validates, offers explanations, opportunities for increased agency and access to services, it also has the potential to create stigma, concern for the future and limit access to services and opportunities. Most importantly, and with particular relevance to the FASD context, Jutel’s discussion of ADHD asserts that diagnosis needs to take both individual and environmental factors into account because “the disorder resides not in the child or the environment but somewhere in the nexus of the two” (2011a, p. 797).

In every health, allied-health and social service profession, intervention workers are trained to work with the given diagnoses of their clients. They are trained to formulate, refer for assessment and then provide interventions based on recommendations from that assessment. However with FASD this is a challenge because, while they are aware that it exists and that it could be affecting clients with whom they work, they also know it is not often diagnosed, which means that some of their clients are likely to be undiagnosed or misdiagnosed. This creates a dilemma. Working to a diagnosis constitutes best practice, and working without a diagnosis has the potential to cause harm. But if the diagnosis itself is contributing to harm in the sense that it is not addressing the underlying cause of a condition, then the intervention worker is put in a difficult position. As indicated in Chapter nine, a number of the intervention workers interviewed had developed innovative strategies for working around diagnostic advice, or adapting intervention practices to go beyond what might be normally expected in a given diagnosis. In many cases, however, intervention workers who knew of FASD and were aware of systemic shortcomings in approaching it felt morally obliged to go beyond their roles in dealing with it. Others were happy to screen for or suggest FASD, and to provide prevention information, but did not incorporate FASD-related strategies into their
professional practice as they did not consider that they had the necessary skills or did not believe that their respective services would support intervention intended for FASD.

A number of participants said that they would not make a referral to a health provider outlining suspected FASD because of their lack of FASD knowledge. They felt that, in order for such a referral to be considered, they would have to make a strong case for an FASD assessment and many did not feel they had the skills to do so. Some also said that they would not know where to refer a client who had suspected FASD. In some cases this related to their confusion as to where FASD ‘fits’, whether it was considered a mental health issue, a health issue or a disability and thus which service was more appropriate. In many cases, participants did not feel confident that a referral would be accepted by any service because FASD was not recognized in their area. Others were concerned about the circumstances of the referral possibly leading to unproductive labelling (of the client, or of the ‘alcoholic’ mother), and questioned the usefulness of having an FASD diagnosis if dedicated services were not available to respond to this.

The outcome of all this was that intervention workers often felt insecure about handling suspected FASD. Raising the potential risks of alcohol consumption during pregnancy and talking about FASD with parents or caregivers was identified as a particularly challenging task. Participants simply felt unequipped to take it on in many cases. Some participants who worked with young people said that the FASD training had given them confidence to talk to their clients about the potential risk of alcohol consumption during pregnancy, a number saying this was the main practice change following their attendance at the training, however many felt that they could give no more than basic information on this issue. Overall, these concerns reflect not only the knowledge base of practitioners, but also the pervasiveness of the ‘soft’ complexities associated with FASD, and illustrate the need for practitioners in this area to be equipped to deal with such complexities.
Summarizing practice-based experiences

In summary, the experiences of health and allied health practitioners in coming to terms with FASD in their professional practice reveal a balance of positive and negative forces surrounding the condition. On the negative side, FASD appears to exist in a kind of ‘catch 22’ situation. Intervention workers often see it as pointless to refer for a FASD diagnosis because they will not get an assessment, and diagnosticians see it as pointless to diagnose because there are no intervention services. Both groups do, however, perceive the greater individual and social benefits of recognising FASD in relevant cases, and therefore strive to overcome the limitations of the systems in which they work.

On the positive side, this same discussion reveals that professionals in both of these areas view each other as complementary parts of health service provision, and indeed regard each other as essential to achieving a continuum of practice. Both groups also saw prevention and education as essential parts of the continuum because of how they contribute to making FASD visible. Interestingly, many of the research participants saw their own work as contributing in some way to FASD prevention in the big picture. This notion of a continuum of practice was articulated by quite a few of the research participants, and is probably the most constructive force currently at play across service provision contexts for FASD. It relies on a great deal of personal interest and goodwill, and depends also on the goodwill of service managers in allowing staff to make space for time consuming activities such as multidisciplinary team consultations, but is nevertheless a strong thread running through diverse practice contexts.

Part 2: Contextualizing FASD

Many of the challenges identified by diagnosticians and intervention workers regarding their professional practice relate to broader cultural and contextual issues that deserve detailed discussion in their own right. As I established in Chapter seven, the social conditions surrounding alcohol consumption in New Zealand are a particular challenge, directly affecting people’s attitudes towards FASD. However, the particular workplace and sector structures in which they are located also contribute to the scope and limitations of what can be done with FASD
in a given context. This section seeks to examine this further, by problematizing the question of where FASD ‘fits’ (or indeed, doesn’t fit) in health, allied health and social service sectors, and then by returning to the broader question of FASD in sociocultural context and revisiting the key themes that influence how FASD is conceptualized in public and professional discourses in New Zealand.

**Making FASD fit within current service systems**

In her influential work, Diane Malbin has proffered that one of the key challenges to FASD service provision in the USA is ‘silo thinking’ – characterized by professionals working separately within their own fields of reference and not engaging sufficiently with each other across different services and sectors (2011). A similar issue exists in the New Zealand context, revolving around the question of where FASD fits in relation to existing service structures. The issue is complex because, in the absence of an FASD-specific funding stream and without clear health sector recognition of FASD as a disorder or disability, professionals within many existing services, even those sympathetic to the recognition of FASD, point to practical barriers of funding and service scope to claim that FASD doesn’t fit within their service, occasionally accompanied by assumptions that ‘someone else’ (another service) must be better equipped for handling it. This was driven home during the interview process with intervention workers in one New Zealand city, where a social worker assumed that Plunket must be routinely picking up FASD in their assessments, while a Plunket nurse assumed that this was something being investigated by social workers. Even though their respective services were in constant communication, neither saw FASD as really ‘fitting’ within their mandate. When pursued on this point, they added that their lack of knowledge of FASD made them concerned about how to approach it.

Whilst most participants saw FASD fitting into their professional role in some capacity, they questioned where FASD fits in health and social service systems in terms of service provision and funding in both diagnosis and intervention. This was based on two main factors: the nature of the symptoms and underlying cause, or a perception of which service system area were best equipped to deal with FASD in the current system. For example one participant said that whilst he
considered FASD within a disability framework he would place FASD within mental health services because these services are more likely to have access to psychologists who would be more equipped to provide appropriate assessment and intervention services. The discussion on where FASD fits was important to intervention workers because it also links into funding structures and the issue of gatekeeping.

‘Gatekeeping’, in the words of the research participants who mentioned this, describes the process by which a service declines a referral of a client based on the clients ineligibility to meet the services criteria, the view that the client is better suited to access other services, or is already accessing other services therefore does not need to access another service. Some participants indicated that their own services would often decline referrals if they suspected FASD because they did not believe that their service was the best service to address the client’s needs. Despite this, participants said that clients with suspected FASD often accessed a range of services individually resulting in service duplication and sometimes mixed messages from professionals. A number of participants raised concern of the cost of such duplication, arguing the money could be better spent addressing the clients’ needs in more efficient ways.

With regard to this conundrum, research participants universally acknowledged the need for a multi-systemic approach including case management for clients with FASD. I provided an international example of this kind of program, the Canadian Key Worker Program, in Chapter five, which I regard as an example of how this might be enacted in New Zealand. This program involves a central contact person (akin to a ‘Key Worker’) who not only provides family and individual support on the best way to manage FASD but also links the individual to professionals in the health, allied health and social service fields, thus being able to target specific individual needs from a range of specialist services more efficiently and economically. Indeed, many participants were of the opinion that FASD fits within a range of systems and could not be isolated to one service system area.
FASD is variously conceptualized as a health issue, a mental health issue, and/or a disability, depending on the perspective of the professionals involved and their perceptions about which services will best serve the client. While the first time inclusion of ‘neurobehavioral disorder associated with prenatal alcohol exposure’ (ND-PAE) as a category in the forthcoming DSM 5 manual for mental health diagnosis might suggest that this area is being presented as a mental health concern, the wide range of presentations that accompany the condition prevent it from being limited to just this domain. Therefore, FASD diagnosis and intervention remains complex and multi-systemic. Where disability is concerned, FASD is rarely positioned as a disability in New Zealand, partly because FASD cases usually involve IQ levels that are low, but still often above the threshold for intellectual disability. However, FASD clearly fits within Beatson’s definition of disability, which I discussed in Chapter four, as it encompasses all four of Beatson’s dimensions of disability (Beatson 2004, p. 23).

A further concern raised by participants in relation to this confusion is that, given the very strict parameters guiding access to specific fields of intervention, an FASD diagnosis within the current constraints of the service system might actually restrict a client’s access to particular services. As some participants pointed out, within the current system it may be more strategic and advantageous for their clients to gain an alternative diagnosis such as ADHD, despite the potential for FASD purely in order to gain access to services. As there are no services specific to FASD in New Zealand, a diagnosis could in fact limit access to services that may assist children and families affected. For example, an FASD diagnosis could prevent children accessing disability services because it is not a recognized disability in New Zealand. Similarly, despite the inclusion of ND-PAE in the DSM 5, the various diagnoses encompassed within FASD are not recognized in this manual for mental health service provision, and may or may not attract support in this domain. In response to these issues, as in the earlier discussion concerning professional approaches to diagnosis and intervention, the participants in this research strongly advocated for the potential of multi-systemic practice as the starting point for approaching FASD in New Zealand. This was especially true of those who had
participated in the training exercises in Canada, where they had seen multidisciplinary teams in action.

Finally, there was an overwhelming view by participants that, in order to achieve positive change in regards to FASD, the New Zealand Government needs to take a greater role in FASD planning, policy and funding. One participant went as far as to argue that the government needs to address the whole culture of alcohol consumption in New Zealand in order to tackle FASD. This final comment brings the discussion back to the examination of FASD in its social and cultural contexts, which I will now interrogate.

FASD in social and cultural context
When planning the lines of enquiry for my interview process, I initially glossed over the issues associated with FASD in social and cultural context, believing that this would be of little interest to professionals who were being asked about their work practices. However, as I engaged more in the field and spoke to people with a range of different perspectives internationally and in New Zealand, it became evident that the sociocultural context of FASD was the elephant in the room – discussed rarely, but clearly impacting on professionals’ conceptualizations of FASD and their practice experience. The extent of their interest in this issue is reflected in my inclusion of a chapter devoted to professionals’ perceptions of FASD, where much of what was discussed was raised during interviews without prompting.

The reasons for this are complex and overlapping, and all reveal that practice cannot be easily separated from the social contexts. Moral and ethical decisions have implications for practice, especially with regard to how clients and birth mothers, as well as their broader families are perceived in the practice context. However, professionals also recognized that the FASD field is dominated by the bio-medical definitions and that research of FASD and engagements related to the social-moral issues are largely absent within the field. Approaches of those in the field may not intentionally aim to create stigma, however the largely absent inclusion of fathers and an a broader analysis of alcohol consumption in society
alongside well meaning but potentially stigmatizing images and language do this themselves. It is likely that these kinds of things impact not only on individuals, birth mothers, families and women in general, but also contribute to a reluctance by professionals to become engaged with this field in the first place. Whilst the answers to many of the moral complexities that face the field of FASD fall outside of what is possible in this thesis, the issues must be discussed in order to not only ensure that professionals are approaching the issue in ways that minimize blame, but also to demonstrate to those outside (but relevant to) the field that these issues are not ignored.

**Alcohol, stigma and blame**

Some participants thought the personal views and experiences of health professionals and other intervention workers contributed to their reluctance to engage with FASD in their professional practice. In some cases, participants speculated that some health professionals were unwilling to consider FASD because it is too controversial, or that professionals in general were reluctant to engage with FASD because of the normalization of alcohol in New Zealand society. This, combined with the research participants’ own personal experiences of alcohol, and in some cases alcohol consumption during their own pregnancies, may have contributed to a reluctance to consider FASD in their professional practice. This is manifested, as discussed earlier, in some professionals’ reluctance to ask clients about alcohol use – a reluctance not unique to the New Zealand context, as noted by Dorothy Badry:

> There is often discomfort on the part of health or social service professionals around asking about alcohol use in pregnancy. Although information about consumption of alcohol use during pregnancy is a critical part of a diagnostic assessment for FASD, this is an extremely sensitive issue that must be cautiously addressed. Asking the question of alcohol use during pregnancy in a child protection investigation can traumatize women and further research on this topic is required. (Badry 2009, p. 49)
While diagnosis can cause stigma to the individual and mother, it is likely that these people already face stigma due to the presentations of FASD, which often limit the person’s ability to fit into socially constructed behavioural norms. Other more obvious or easily diagnosed conditions – such as physically demarked cases where a person has down syndrome or is blind, or missing a limb – there is little discussion in the medical world around whether it is appropriate to diagnose. All those conditions face social stigma and structural inequity. It is the moral aspect, the nature of alcohol, and the construction of the mother as the ‘cause’ of the disability that makes FASD different to other disabilities. When this is contextualized the burden is not on the mother but on society.

FASD is also difficult to talk about in broader contests, such as family meetings, because of family dynamics and other complexities. Where children and young people are concerned, it is often the case that foster carers or adoptive parents are involved, possibly alongside a birth parent’s input. In some cases, elements of the juvenile justice system or child protection systems may also have a role to play in family discussions. Indeed, health professionals feel more comfortable broaching FASD if it is framed in ‘not knowing’ way, that assumes the woman did not know she has pregnant when drinking. This idea that women do not know they are pregnant and may drink was raised over and over as both a concern and to be used as a strategy when asking about alcohol use to minimize stigma.

This concern by professionals should not be minimized, indeed FASD is a stigmatizing issue and professionals must develop ways to minimize this stigma. However there are studies of birth mothers that indicate that regardless of the diagnosis they face stigma anyway (Salmon 2005). Further to this, there are many examples of birth mothers being active in seeking out a diagnosis of FASD, thus acknowledging the cause of the disability, but many have faced barriers to obtaining assessments because of the reluctance of health professionals, often ironically justified by a concern around ‘stigma’ for the birth mother. This does not detract from the need to consider the stigmatization of mothers and moral constructions of women, but it adds another important dimension, which demonstrates that mothers of children with FASD have varied experiences, views,
and feelings about FASD and themselves and many different ways of engaging with it. They cannot be lumped in together purely because they are women who consumed alcohol during their pregnancy and had a child with FASD. Thus, ways of engaging with birth mothers and conceptualizing the issue cannot be formulaic, but must consider the broader moral discourses and potential issues that contribute to FASD and also not make presumptions and pre-judgments about what is best for women, what women may want or how women may feel about the issue.

**Conclusion**

This discussion raises multiple issues that need to be considered where FASD is concerned. While these issues can be conceptualised as belonging to either professional practice or socio-cultural domains, they are in fact interrelated. Overwhelmingly, four issues predominate in this discussion: the invisibility of FASD as a recognized condition, the importance of diagnosis in the overall management of FASD, where FASD fits in service provision, and how FASD is situated in relation to discourses of disability and stigma.

The social construction of FASD, and social context within which FASD sits, is the elephant in the room. It is an obvious factor in the construction and understanding of FASD, yet is largely ignored or disengaged with as professionals attempt to legitimize FASD as a medical condition. This is a particular problem in the decontextualized application of evidence-based practice in FASD research and service provision, as I proposed in Chapter four. Clinical research grounded in evidence-based practice may attempt to circumvent social discourses by measuring and objectifying the physiological aspects of FASD and normalizing it as a medical condition, possibly in order to neutralize issues of stigma and blame. However, my research demonstrates that FASD cannot be disentangled from these discourses.

Health professionals' own perspectives on alcohol consumption and FASD impact on their practice - they cannot be separated. Meanwhile, families and individuals affected by FASD cannot be separated from their lived experiences. In order to
engage with FASD in ways that are meaningful, respectful and helpful, professionals need to consider FASD from multiple perspectives, including the perspectives of individuals, parents, carers and families, as well as the other professionals who might engage with their client, in a range of practice, policy and research areas. An effective approach to FASD therefore requires critical reflexive practice that can accommodate these positions and contextualize their associated moral discourses around alcohol consumption.
Conclusion

In the last four years, small number of health, allied health and social service professionals engaging with FASD have made great headway in developing a response to FASD in New Zealand, especially in diagnosis. This is reflected specifically in the progress achieved as a result of the *Fetal Alcohol Spectrum Disorder Multidisciplinary Diagnostic Services Training Project*, which I discussed at length in Chapter six, and the capacity building that has eventuated through the development of new teams with FASD diagnostic capacity since the pilot project was undertaken. At the time of writing there are now seven of these teams in operation in the North Island of New Zealand.

Given the barriers to diagnosis – structural and social barriers, as well as colleagues who still deny the existence of FASD despite international bodies of evidence – this is a remarkable achievement. In the field of intervention, the barriers to service provision have prevented practitioners from engaging with FASD in ways they consider effective and appropriate, however this research has demonstrated that interventionists are both motivated to address FASD and creative in their approaches to dealing with PAE within the current practice areas. This research has demonstrated that these professionals do come into contact with clients who have PEA and suspected FASD, and based on the frequency of these interactions, that FASD is likely to be a significant health concern in New Zealand. Participants were unanimous in their view that FASD does not receive adequate attention in the New Zealand health system, and even where it is acknowledged, FASD service provision is hampered by ineffective service duplication, inconsistent understandings of the condition, and other factors. Overall, the professional climate is not conducive to providing the best outcomes for people with suspected FASD.

There is nothing straightforward about FASD. There is currently no biomarker to definitively determine its existence, and each individual’s presentation is unique because the damage to the brain is dependent on a range of factors. This means that suggested ways for handling FASD vary from person to person and professional to professional. On top of this, FASD sits within complex social and
moral contexts. While a biomedical model defines the cause of FASD as prenatal exposure to alcohol, sociocultural analysis reveals the cause of FASD is much more complicated, implicating wider society’s attitude to alcohol consumption, and receptiveness to public education messages that might counter commonly-held understandings of risk and danger. Any response to addressing FASD, including an investigation such as this one, must consider both the biomedical and sociocultural implications of the condition and its place in health and wellbeing discourses.

Across diagnosis and intervention, many professionals view FASD as a ‘can of worms’ that might be better left alone. However, there is sufficient research, and documented accounts of lived experience of FASD, to show that it should not be ignored. It impacts on how individuals live their lives, how families function and feel about themselves and their loved ones, and how others view them. It impacts on professionals who come into contact with clients with PAE and suspected FASD, who must deal with this regardless of whether they have access to appropriate resources to do so. And increasingly, as people become more aware of FASD, it will impact on how we conceptualize and respond to alcohol consumption in our communities. Whilst I do not claim to provide the all of answers on how to address FASD in New Zealand, my starting point has been to take on board this complexity and tension, to be mindful of the broader socio-political and moral issues, and receptive to reflexive critical practice, information and knowledge shared by other professionals. It is possible to do this, it is necessary to do this and this research has demonstrated that the New Zealand practitioners who have now engaged with FASD themselves are strongly motivated to do so.

In an attempt to address these complexities, I have offered a surgical slice into health, allied health and social service provision for FASD, engaging specifically with professionals who received training on FASD between 2009 and 2012, and examining how this training has influenced their professional practice. This approach required multiple short instances of multi-site fieldwork, and participant-observation in the training programs themselves, including exercises based overseas in Australia, Canada and the USA. This fieldwork was conducted in
an applied anthropology setting, informed by my own professional practice as a child and adolescent counsellor, and my prior academic training in social work.

My engagement with twelve professionals trained for FASD diagnosis exposed me to an echelon of medical practice that I had previously only experienced from the outside, as an allied-health professional largely reliant on medical practitioners for certain functions, but not a participant in their professional processes. My access to this group was a product of the goodwill and inclusive attitudes of the professionals who underpin Alcohol Healthwatch, who were one of my first points of contact in initiating this research project. Despite the professional distance between myself and my research collaborators, I was unquestioningly included into their learning processes as they (and I) underwent the training and shared numerous revelatory experiences. My research questions and feedback gave many of them a sounding board for experiences that were, in many cases, new to them, and the nuances of these experiences are borne out in Chapter six, seven and eight of this thesis, in which their personal perspectives and professional initiatives in relation to FASD are revealed.

My engagement with eighteen allied-health professional in allied health and social services around New Zealand was also facilitated by co-participation in training exercises, but in these instances, I was often talking to people of the same or similar professional background to myself, and in some of the Dunedin-based examples, with people who were current and former colleagues. Because of my close professional association with these participants, I intimately understood the pressures of their work environments and could empathize with the frustration that they often expressed about the lack of resourcing available to them for approaching an issue such as FASD. Where the diagnosticians’ training experiences became a catalyst for action, the intervention workers’ training often ended in exasperation, as they would invariably not have access to any extra resources to help them come to terms with the (in most cases) new awareness of the problems posed by FASD. Like the diagnosticians, their personal and professional perspectives both had roles to play in how they synthesized and managed issues relating to FASD.
I have scaffolded these participants’ contributions to this research with substantive background information relating not only to FASD as understood internationally, but also in the New Zealand context. I have endeavoured to provide useful and relevant international reference points to demonstrate how best practice might be conceived in this field, and I have provided a theory-informed commentary problematizing how one might come to conclusions about ‘best’ practice in the first place. All of this underpins an analytical approach grounded in thematic analysis, which I have applied to my ethnographic findings and from which I have rendered the discussion that precedes this conclusion.

Having applied critical reflective and reflexive lenses to my examination of these others’ practices, I now turn the reflexive gaze towards myself, to consider where the value of this research ultimately lies, and what conclusions and recommendations can be drawn out of my research process. One of the clear challenges in initiating and developing this research project was the question of where to situate it in relation to professional practice frameworks. I am a social worker and have spent much of my career in the field of mental health and community service intervention, so my initial plan was to focus on the intervention side of FASD and the experience of professionals like myself. However, in my preliminary fieldwork, I became more aware that my lack of knowledge of FASD was something that I had in common with many professionals.

None of my colleagues had any experience of working with individuals with a diagnosis, which was a major barrier to them, and it became clear to me that diagnosis and intervention are so inextricably linked that and understanding of the current state of FASD diagnosis in New Zealand would be necessarily if I was to also understand intervention contexts. However, engaging professionals who felt confident to talk about FASD proved to be a challenge because of the general lack of knowledge about the condition in all practice medicine fields. The decision to build the research from the basis of training exercises was, in the first instance, an answer to this, as it meant that all of the participants had at least a similar level of post-training knowledge.
When I began to write up the results of my interviews with professionals working in the field of intervention, I initially thought it would be easy: partly because this was my own broad area of practice, and partly because most of the participants had similar things to say about their views and experiences of FASD. However, as I analysed the data, it became clear not only how diverse the group of professionals was, but also how complex working in support and intervention can be. The participants from this group had different professions and varied knowledge, training and general levels of experience. They all worked in different ways and had different ways of managing suspected FASD, yet they were confronting a shared set of issues. Meanwhile, the data I gathered from the diagnosticians proved more straightforward, largely because this group was more homogeneous in terms of their professional experience and field of practice.

Over the course of this research project, I have also experienced some changes in how I view my own approach to my work. My training as a social worker and mental health worker, and my use of critical theory in that work, has taught me to consider the broader sociocultural context within which my clients operate. However, my experiences talking to professionals and occasionally families and individuals with FASD throughout the research process have led me to new ways of conceptualizing my practice, especially in considering specifically how FASD is constructed by its sociocultural context, and how this affects individuals and their families. This realization happened slowly, over about three years, and while benefitting from the luxury of being a full-time PhD candidate focused entirely on my research. This contrasts markedly to the experiences of time-poor professionals who must attempt such realizations while managing an unrelenting professional environment.

Overall, my research has revealed some key characteristics of FASD service provision in New Zealand. Firstly, it is clear that health professionals are already working with FASD-affected individuals but due to a lack of recognition across sectors, funding, policy, plans and programs they are not doing it effectively or efficiently. The current system is also resulting in the duplication of these
ineffective services, incurring extra cost for government health budgets and private individuals alike. Professionals are interested in FASD, they see its relevance in their work and want to do more and better things to address it. While there is a lack of FASD-specific knowledge and skills amongst professionals in New Zealand, they are interested to learn more and develop better ways to manage FASD in their practice. They demonstrate an awareness of the sociocultural context for FASD-related work, and are interested in addressing the issues that are raised by its sociocultural complexity. Finally, it must be acknowledged that FASD is a relatively new issue in the New Zealand health system, but this gives New Zealand a unique opportunity to develop and learn from the success and mistakes of other countries.

**Recommendations**

In light of this discussion, and in line with the applied anthropology approach informing this research, it is fitting at this stage, to offer some recommendations for improving, enhancing and sustaining FASD-related health and allied health practice in New Zealand. Fittingly, these recommendations fall into two interconnected areas: social understanding, and professional practice. My first set of recommendations concerns the compromised way in which FASD is understood, socially as well as professionally, and what can be done to change this. Public education, and the erasure of widespread misinformation about prenatal alcohol consumption, are clearly major factors for improving public understanding of FASD, but beyond this, my research indicates that there are two key disjunctures that impact on how FASD is understood.

The first of these disjunctures concerns the ‘fit’ of FASD into health service provision, reflecting the tendency (identified by a number of the research participants) for FASD cases to ‘bounce’ around the health system. As argued in my discussion chapter, the disjuncture lies in that FASD requires inherently multi-service and multi-systemic attention, but is not currently managed in this way. Services refer to each other, but rarely do they collaborate in providing care to a given client. The primary recommendation deriving from my research, therefore, is that the complexity of service provision required for FASD be properly
acknowledged, and that strategies be developed for enabling services to collaborate with each other across service systems, rather than passing clients between them as is currently the case. This includes greater coordination between relevant elements of health, mental health and disability services as well as other areas such as education.

In relation to this first point, the categorization (or miscategorization) of FASD is a further contributing factor in the disjuncture surrounding public and professional understanding of the condition. FASD is frequently under-diagnosed, ignored as an option, or substituted for a more straightforward option such as ADHD and treated accordingly, with widely different consequences and outcomes depending on the individual and the circumstances of their service provision. It is a disorder characterized by cognitive and functional deficits, however, it is currently not considered a disability under New Zealand health service provision frameworks. While FASD has been included as a mental health diagnosis in the forthcoming DSM5, this is unlikely to facilitate access to disability services for people with FASD. Were New Zealand to follow international models and allow FASD to be classified as a disability, this would potentially resolve much of the disjuncture surrounding the condition and the interventions applied to it, resolving a major cause of frustration for many of the research participants in this project. It would also allow for individuals and families and professionals to reframe FASD-related problems as primarily biomedical rather than behavioural problems leading to more appropriate environmental accommodations. A similar process of reframing has accompanied the public and professional perception of autism spectrum disorders, contributing to their destigmatization, and it is likely that people living with FASD would reap similar benefits. The criteria for access to government-funded services, whether in disability or elsewhere, should include the range of behavioural and functional deficits associated with FASD.

Both of these points of disjuncture can be addressed through the development of policy initiatives at a government level, along with a range of other policy-related strategies. For example, while the Ministry of Health has developed excellent and accurate advice regarding alcohol consumption during pregnancy however these
guidelines are not necessarily understood or are not applied by many professionals. More importantly, however, accurate understanding of prenatal alcohol consumption patterns requires that professionals ask their clients about alcohol consumption, and, as identified in this thesis, this can be a very difficult thing for professionals to do. Ministry of Health guidelines for sensitive strategies for asking about prenatal alcohol consumption, and advice on how this should be recorded in medical records, would be a welcome addition to the advice already available.

In order to address these and related issues, I would recommend that a strategic plan for FASD be developed at the national government level in New Zealand, providing guidance that can then be applied systematically throughout the whole country. Such a plan would, however, need to be a cross-ministry initiative, reflecting the range of service areas affected by FASD (including, ultimately, education and justice systems). Amongst other things, this plan could include the formal adoption or creation of a diagnostic tool for FASD in New Zealand, to ensure that the condition is being diagnosed systematically and thereby minimize spurious or questionable diagnoses. The development of a national strategic plan would not only resolve the disjunctures surrounding how FASD is understood, but would also have the effect of making FASD more visible as a known, accepted and legitimate health and social issue.

My second set of recommendations concerns the professional practice context for FASD, and what professionals need in order to support their engagement with FASD. Much of this research project has focuses on training, and it is clear that specialist FASD training can have a beneficial role to play in developing competencies based on understanding. This was especially the case for the diagnosticians I interviewed, though less so for those working in intervention, who often found themselves without access to ongoing FASD-specific support. This was not as much of a problem for diagnosticians, because FASD began to figure as a specialization in their work, something not possible in intervention services. At present, more support is required to allow intervention workers to put the knowledge they gain in FASD training into practice in their work. This support
could come in numerous forms, from dedicated funding to ensuring that FASD can be addressed within current service remits to restructuring workloads in order to allow individuals to form specialist clusters. Indeed, the Key Worker Program from Canada, provides an excellent example of how to generate specialists out of a generalist workforce, and could be used as a model for a similar service provision structure in New Zealand. One way or another, the development of FASD-specific intervention services is not only necessary for the management of FASD cases, but also beneficial to fostering greater diagnostic capacity, as it would neutralize the concerns that many diagnosticians have about providing FASD diagnosis in cases where applicable intervention services are not available.

I would also recommend to all professional services that FASD management be viewed not just in relation to the individual, but also in relation to their family and their support structures over the long term. FASD is a lifelong condition, yet much of the research and professional practice relating to FASD focuses on children and young people. A more holistic perspective, especially in intervention, that takes families and other support structures into account, and does so over the whole life of the individual, would perhaps engender new approaches to managing the condition.

Another practice innovation that was universally commended by the research participants was the advent of multidisciplinary team practice, especially in diagnosis. Given that multidisciplinary team diagnosis is widely used and considered international best practice, it is something that should be a goal of health services in New Zealand as well. Multidisciplinary team models for diagnosis should be integrated into public health services, and where multidisciplinary teams are not possible because of lack of specialists, services should engage with the required specialists remotely through such models as telemedicine, rather than relying on (comparatively) incomplete assessments.

The best way to achieve these practice innovations would be to establish a dedicated FASD service centre in New Zealand, much like the Asante Centre in Canada, in which knowledge concerning the condition could be consolidated,
condensed and nurtured. Such a centre would be able to provide diagnostic services both locally and remotely wherever diagnostic services are absent, and provide supervision and support to developing and established professionals throughout the health and allied health sectors in New Zealand. This centre could play a role in coordinating a type of Key Worker Program, conduct ongoing research, perform outreach and public education services, multidisciplinary team diagnosis training, intervention training, and general knowledge training within and outside of the health system. Multidisciplinary team training has been an important factor in progress made to date in FASD diagnosis in New Zealand, but it could only be conducted overseas, as no local or regional training services for FASD exist. Furthermore the progress that has been made to date relies on the continuing professional practice of the small group of individuals who were trained in the first place. A New Zealand centre would be able to scaffold the substantial investment already made in these individuals by replicating their knowledge and their training experiences more broadly within the health and allied health systems. Until such time as this is realised, practitioners must depend on their own abilities to foster networks with their colleagues in other disciplines, and to appreciate the ‘hard’ and ‘soft’ complexities of FASD side by side.

**Future directions**

This research has demonstrated the presence and relevance of FASD in health and allied health services, and provided an analysis of how professionals work with FASD and how effective they consider their work to be. It has revealed many surprising achievements and a great deal of professional resilience, but also that information concerning FASD in a range of contexts is still severely lacking. There has yet to have been a prevalence study of FASD in New Zealand, and such an undertaking is long overdue – a fact acknowledged by the World Health Organization, which is currently mobilizing an international task force to undertake FASD prevalence studies in a range of countries. It would be a sound investment for New Zealand to capitalize on the opportunity to get involved with this project.
My research has barely touched on other key areas, such as FASD prevention the justice system and the education system in New Zealand. Each of these areas would benefit from dedicated, FASD-focused study, and I hope that my research provides a potential model for this type of engagement. Meanwhile, professionals involved in FASD diagnosis would value the findings of any research into the medium-term and long-term outcomes of FASD diagnosis, especially the opportunity to know how people cope with FASD in adulthood. Underneath all of this, our society’s attitudes towards alcohol consumption are unlikely to change, making research that contributes to awareness-raising, including the amelioration of mother blaming and stigma, very important. Ultimately, professional practice responses to FASD are in some way guided by the cultures, perspectives and attitudes that prevail in wider society, and society therefore has a role to play in coming to terms with FASD.

Returning to the initial research questions underpinning this project, I feel that I can confidently claim to have revealed the practice contexts for FASD diagnosis and intervention in New Zealand and the issues that are associated with these contexts. This research has made clear that FASD is not simply a biomedical condition whose needs must be met within the remit of health services, but that it also sits within a sociocultural context. This influences how people conceptualize and engage with FASD, alcohol consumption and pregnancy. This research has demonstrated that the personal views and experiences of professionals impact on their practice, and that many of the New Zealand practitioners involved in this research have an awareness and analysis that extends beyond the common conceptualization of FASD as a purely biomedical issue.
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Appendix A: 2011 Poster Presentation

FASD Intervention in New Zealand: A Case Study of Lived Experience and Professional Practice
Kerryn Bagley, PhD Candidate, Department of Anthropology, University of Otago

Introduction

New Zealand has a no-construction policy on alcohol, no nationally agreed definitions or diagnostic criteria, and the financial resources for prevention and service provision. In some cases, service providers do not even have an awareness of FASD as a possible diagnosis. Despite this, alcohol and human services professionals continue to come into contact with children who present with FASD symptoms or disabilities.

This research investigates the understanding of FASD in New Zealand by examining and comparing the experiences of health and community service professionals who have provided intervention for children, or suspected cases, of FASD in their work. The study of New Zealand it difficult to obtain an assessment that will even consider FASD as a diagnosis because there are no direct services funded or specifically dedicated to addressing FASD.

The data presented have drawn from two contrasting cases: a case study of my own professional practice as a counsellor for a young person with suspected FASD, and a qualitative study involving interviews with ten professionals from a range of alcohol and community services in the South Island, New Zealand.

Case Study: Working with Helen

Helen responded poorly to three interventions. She eventually dropped out of school as an influence from the juvenile justice system. While HIV may or may not have been a contributing factor; the lack of suitable testing for HIV deprived Helen of an intervention route that may have led to different outcomes.

Case Study: Key Findings

- Helen was able to assume appropriate treatment to either initiate or rule out BVD
- Professionals involved had little or no understanding of BVD and little or no access to training or resources
- Some professionals felt equipped to provide a service that met Helen’s complex needs
- Helen had a number of services engaged in her case which, with differing views on the most helpful intervention and the potential diagnosis
- Behaviour modification programs specific to ADHD were put in place by some professionals for Helen without regard for her cognitive and motor functioning level, and when these interventions did not work Helen was labelled as defiant and troublesome
- Professionals were reluctant to employ interventions more appropriate to BVD as an BVD symptom and diagnosis was not achieved
- Helen’s diagnosis of ADHD and borderline IQ of 70 made her ineligible for intensive behaviour support services

Conclusions

This research reveals that professionals do not consider themselves to possess the education, training and knowledge to provide effective interventions for BVD. It identifies a need for improved screening and intervention for FASD in the South Island of New Zealand, particularly improved access to diagnosis, support and training for professionals. Further research needs to focus on the wider community to make further important contributions to addressing the impact of FASD in New Zealand.
Appendix B: Research questions for interviews

1. General information
   1.1. Tell me about your training, your job and your role
   1.2. How would you describe your level of professional experience?
   1.3. What is your take on FASD?
   1.4. Where does your interest in FASD stem from?

2. The FASD training
   2.1. Why did you attend this FASD training?
   2.2. How would you describe your level of knowledge of FASD? (pre/post training)
   2.3. How many clients have you worked with pre/post training, diagnosed with FASD or suspected FASD?
   2.4. Do you feel better equipped to identify/work with clients with FASD or suspected FASD as a result of the training? How?
   2.5. Have you changed your practice as a result of the training? How?
   2.6. Have you reviewed any pre-existing clients since the training? If so how many? Why?
   2.7. Have you treated any pre-existing/new clients differently as a result of the training?
   2.8. Do you have the necessary tools and resources to assist you in your practice?
   2.9. Are the information/skills you have gained during this training are supported in your work environment?

3. Individual experience
   3.1. What has your experience been of working with suspected FASD/FASD?
   3.2. Are there any challenges of working within the health system on this issue?
   3.3. What are your strategies for working effectively, given the existing circumstances?
   3.4. What are the challenges of working with clients/families on this issue?
4. **Health, allied health and social service system**

4.1. How would you rate the general quality, availability, consistency of resources/training on FASD in New Zealand?

4.2. Are there further training/resources that you can identify that would assist you and other professionals in their practice?

4.3. Is FASD is given adequate attention in the health/allied health and social service system? Why?

4.4. Can you identify any gaps/limitations in FASD prevention/diagnosis/intervention in the NZ?