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**THE LEGACY OF PRENATAL EXPOSURE TO
ALCOHOL: Fetal Alcohol Spectrum Disorder, The
New Zealand Situation.**

**A thesis presented in partial fulfilment of the
requirements for the degree of**

**DOCTOR OF PHILOSOPHY
In
SOCIAL ANTHROPOLOGY**

At Massey University, Albany, New Zealand

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ABSTRACT

‘Alcohol’, the strongest teratogen known to human-kind, is a commonly used legal drug which has the ability to cross the placenta and interfere with the development of the foetus resulting in a birth defect known as Fetal Alcohol Spectrum Disorder (FASD). This thesis looks at the historical knowledge base surrounding prenatal exposure to alcohol and presents the latest biomedical information available on FASD at the time of writing. The sub-discipline of medical anthropology, the associated methodology and its appropriateness for this kind of research is discussed.

A historical look at the introduction and proliferation of alcohol in New Zealand from the macro-micro perspective, and James O’Connors’ (1974) political modes of operation are presented, offering a broad analysis, of a dynamic political process involved with the lack of acknowledgement or action on the part of New Zealand governments. New Zealand specific research on women’s drinking patterns, clinical practise and the experiences of those trying to obtain a diagnosis in regard to FASD within New Zealand are presented. Behavioural profiles pertaining to my participants’ FASD charges are offered to the reader, all of which indicate serious repercussions for New Zealand society as a whole.

Finally the labelling argument relating to the diagnostic terminology surrounding Fetal Alcohol Syndrome is discussed. The original contribution this thesis offers aside from being the first New Zealand anthropological PhD research on the subject of FASD surrounds education and action research. Knowledge creates empowerment and can facilitate individual change. My thesis has been a dialectical process whereby the more I learned from those care-giving for FASD individuals, the more I have been able to feed back to others and act in my capacity as a critical medical anthropologist, using action anthropology as a means to advocate for families affected by FASD, those whose voices of expertise by way of experience, are seldom if ever heard or listened too.

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This thesis has been one long journey, one which would not have been possible if not for the support and help from many persons. I wish to firstly thank all my participants throughout New Zealand for letting me into their lives and sharing their experiences. And special thanks to my chief supervisor Dr Eleanor Rimoldi for the encouragement and belief in my work over the last 10 years and to Dr Kathryn Rountree for your expertise and time. Internationally, I would like to thank the Special Needs Adoptive Parents Resource Centre in Vancouver Canada, who at their own cost allowed me free access to both their resources and the copying machine for a mountain of material and a special thanks to Kristi Colvell from the University of Washington, Fetal Alcohol and Drug Unit for supplying me with a copy of their LHI interview to view and other important research information.

On a local level, I wish to thank Massey University for my PhD scholarship and the University Women's Federation for their grant which was greatly appreciated. I wish to thank Philip Parkinson and Ian McEwan of ALAC who arranged for my airfares to attend an international FASD conference in Canada, enabling me to carry out my Canadian research and my brother Brent for all his computer time to make this thesis. Special thanks to Christine Rogan from Alcohol Health Watch, all those working in past and present FASD advocacy trusts throughout New Zealand and to Shona Davison for being a major player and co-presenter in many seminars carried out throughout New Zealand.

To special people who sadly have passed away during my thesis - Peggy and Dorothy Platt, thanks for your support. Finally, this thesis is dedicated to my mother Margaret, my best friend and proof reader of ten years of my academic journey, who after a short illness passed away one year before the completion of this thesis. An amazing person, whose encouragement and passion for this subject and the positive uses of higher education were the reason for me taking this topic to a doctoral level, this thesis is for you.

INTRODUCTION

‘Alcohol’, or the ethanol contained in it, is the strongest teratogen known to human-kind. A commonly used legal drug, it has the ability when consumed during pregnancy to cross the placenta and interfere with the fetal development resulting in Fetal Alcohol Spectrum Disorder (FASD). Ethanol as a teratogen has the ability to create organ abnormalities and brain damage which last the life time of those directly affected; disabilities that impact seriously on the quality of life experienced by both FASD individual and their caregivers.

My first introduction to FASD occurred in the early eighties while I was residing in Vancouver, Canada. It was during this time that I had the opportunity to understand the full implications of alcohol consumption during pregnancy through my aunt who was employed at that time by special education services in the Burnaby area of Vancouver. Her contract entailed screening suspected cases of FASD, referrals for diagnosis and working with FASD children. On my return to New Zealand several years later, I realised that there was little if any awareness of FASD among the New Zealand population. Even among my women friends, many of whom I considered well educated and switched on, there was a shocking lack of awareness surrounding the risks associated with alcohol consumption and pregnancy, a situation that was totally unacceptable even at that time, given the amount of international literature and credible research on the subject available since this disability and its cause were first identified in 1973.

Around this time there had been minimal New Zealand specific FASD research carried out, mirroring the present research situation in New Zealand, and as far as I am aware, this thesis is the first New Zealand research to address FASD under a non-medical paradigm. I identify myself as a medical anthropologist and have used research methods anthropological by nature and origin. I believe that this thesis is an example of effective action anthropology and advocacy. It was imperative that during my research journey my completed thesis both facilitated a greater understanding of FASD in a daily living context, and the risks associated with alcohol

consumption during pregnancy. Quite simply the more I learned from my participants and other FASD experts, the more I was able to disseminate information regarding FASD to community and professional audiences who attended my numerous nationwide education seminars.

The questions I hoped to find answers for by way of this research were simple:

- 1) What exactly is FASD and do we have a problem here?
- 2) Is 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?
- 3) How difficult is it to obtain diagnosis of FASD in New Zealand and what are the barriers?
- 4) What issues and problems are commonly experienced by FASD caregivers in relation to their FASD charge?

In regard to ethical approval my application was accepted and approval obtained from both the Massey University Human Ethics Committee and the New Zealand Association of Social Anthropologists prior to commencing any contact with prospective participants. The voluntary participants that took part in this research involved 43 active or recent caregivers of a medically diagnosed FASD individual; collectively my participants had 38 FASD individuals in their care. All participants were from varying educational, socio-economic and ethnic backgrounds. All participants received a standardised letter outlining their rights, which highlighted the reality that confidentiality could be offered but not anonymity and prior to the actual interview all signed an official ethical consent form. This research involved family case studies and face to face interviews being arranged and carried out with all my participants in different geographical locations throughout New Zealand. Transcribing tapes, analysing information obtained during the interviews and viewing supporting official documents offered and given freely by a number of participants commenced on my arrival home after my lengthy period of field research.

Chapter one of this thesis, presents a historical account of knowledge related to prenatal exposure to alcohol, predominantly European. Chapter two deals with medical information including the medical diagnosis for the continuum of effects that

is free of medical terminology and jargon. This thesis provides a substantial amount of medical information generally acquired internationally in order for both the reader to understand fully the nature and possible limitations associated with this medical disability, ensuring medical information given out whilst actively carrying out my advocacy and action anthropology, was both accurate and up to date.

Chapter three consists of a story written specifically for my thesis from a grandparent of an FASD individual. A grandmother, who wanted her voice heard, sharing her personal experiences and observations of her grandson's (Neil) struggle to make it through to adulthood. My thesis is not intended to negate the success stories of FASD children obtaining positive outcomes, as Neil is by no means the only success story from within my participant group, but sadly these success stories were in the minority. I felt that it was important that this story be told as all except one success story were I believe due to early diagnosis and knowledge assisted by the implementation of early interventions.

Chapter four describes the sub-discipline of medical anthropology and the associated methodology. This thesis presents the discipline's ability through action anthropology methodology to be a major tool for the collection and dissemination of information gained not only from published documentation but also from personal experiences. Chapter five details my field research journey. My thesis journey has been a dialectical process whereby the more I learned from those caregiving for FASD individuals, the more I have been able to feed back to others and act in my capacity as a medical action anthropologist. Action anthropology as a research tool has enabled me to reveal the political, economic and social contexts for those parenting FASD individuals in a New Zealand context.

In chapter six I offer a historical look at the introduction and proliferation of alcohol in New Zealand from the macro-micro perspective. This is an important chapter as I believe that history is very much part of the present day and to a degree has shaped our attitudes surrounding the consumption of alcohol. Studying early alcohol legislation allows us to obtain a clearer picture of what James O'Connor (1974) terms political modes of operation. By researching a small geographical area where alcohol was first introduced and following historical legislation, manuscripts and archival

material, this chapter presents a possible broader analysis of a dynamic political process that has occurred both in the past and in present New Zealand society surrounding social capital and social expenditure obtained through the proliferation of alcohol. This is a mode of operation that I believe is still active within political arenas today, but one that is not as blatant or obvious as our historical legislation, but rather more covert and disguised.

Chapter seven looks at New Zealand women's drinking patterns and investigates clinical practise and the experiences of those trying to obtain a diagnosis in regard to FASD within New Zealand. I believe my research indicates a possible serious problem within our population of having many individuals affected by prenatal exposure to alcohol. Chapter eight presents the problems experienced by caregivers when trying to obtain diagnosis, investigating the marginalisation of information from caregivers by professionals, a current trend within many professional and governmental service providers. This I believe is possibly due to a lack of knowledge or understanding of the broader implications associated with FASD within our society.

In chapters eight, nine and ten I present issues identified by my participants, collectively, as being of paramount concern. The information obtained from caregivers has enabled me to create a basic profile of information on each FASD individual connected to my participating caregivers. This has given me the opportunity to be able to present to the reader some basic statistical information as well as my participant's descriptions of situations experienced. This statistical data is not intended to prove anything but more to indicate just some of the problems identified by caregivers as affecting their charges, problems that in the broader sense require further investigation and research. Chapter eleven focuses on the labelling argument surrounding FASD terminology presenting different viewpoints surrounding the term Fetal Alcohol Syndrome from both an academic point of view and that of those who have children or adults diagnosed as having FASD. Lastly, chapter twelve presents my reflections and recommendations for future study and issues I believe require attention.

The major original contribution this thesis offers, apart from presenting an alternative broader analysis of past and present New Zealand political process relating to alcohol, relates directly to an education process facilitated by what I believe to be successful action anthropology methodology. Education creates the empowerment of individuals by way of knowledge. Knowledge in turn encourages and instigates action.

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CHAPTER ONE

Pregnancy and Alcohol : A Western Overview

The subject of alcohol consumption during pregnancy has been noted in many different cultural, medical and religious texts over the centuries. Plato and Aristotle describe observations made of what can only be deemed as unflattering references to ‘drunken women’ producing children who were all ‘morose, feeble and misshapen’ (cited Plant 1985:9). It appears that the observations of effects produced through the consumption of alcohol during pregnancy on offspring was discussed and worthy of academic attention. However it is suggested by Ernest Abel (1984:7) that Plato was not overly concerned with pregnant women consuming alcohol but focused his attention on men and alcohol. Plato states that alcohol affects the father by causing ‘bad seed’ to be created. This in turn resulted in any children being produced by that same man, being ‘defective’.

Abel suggests that during that time one person associated the damage to offspring as being caused by the mother consuming alcohol during pregnancy rather than the father; this was in fact Soranus of Ephesus. However he stated that the damage caused by alcohol was not of a physical nature but created damage to the soul of the child.

In order that the offspring may not be rendered misshapen, women must be sober during coitus because in drunkenness the soul becomes the victim of strange phantasies [fantasies]; this furthermore, because the offspring bears some resemblance to the mother as well not only in body but in soul...(Abel 1984:8)

During the time and reign of Cleopatra in Egypt it is documented that the general population knew of and used wine, referred to by the Greeks as the 'Delivery Wine', as a way of terminating unwanted pregnancies. Delivery wine was fermented from cucumbers and is believed to have originated in Egypt (Abel 1984, Plant 1997).

During the Middle Ages popular academic belief surrounding the effects of alcohol were generally associated problems that we would identify this century as promiscuity in women, low sperm count and loss of libido in men. Ernest Abel (1984:11) suggests that the only two writers of note in the Middle Ages to voice concern about alcohol and pregnancy were Robert Burton and Francis Bacon. Francis Bacon's (1625) work is considered by Abel to be more influential and scientific, due to his use of accurate referencing and the fact that his contribution to the body of knowledge was directly associated with pregnancy. For example, when Bacon was dealing with pregnancy and general dietary habits he states:

If the mother eat [much] onions, beans, or such vaporous food; or drink wine or strong drink immoderately;...it endangereth the child to become lunatic, or imperfect memory. (cited Abel 1984:11)

However in the 21st century one could argue the innocence of onions and beans being instrumental in causing brain damage to an unborn child. But not so the consumption of alcohol during pregnancy.

During the eighteenth century Britain was gripped by what was termed the "Gin Epidemic" between 1720 and 1750 (Plant 1997, Abel 1984, Warner & Rosett 1975). The consequences of liquor consumption on the overall British population, (the majority of

whom were referred to as 'the underclass') was becoming seriously problematic. In 1726 the Royal College of Physicians lobbied and demanded that Parliament increase gin taxes in an effort to curb the amount of gin being consumed. The argument - if gin cost more, it would make it less accessible to the majority of poor who were consuming vast amounts regularly. This demand led to a report being submitted to the British Parliament in 1736 concerning the wide spread drunkenness in the majority of the British population. Included in this petition was the mention of the effect alcohol was having on the women and children, identifying it as being instrumental in damaging the unborn child as well as damaging 'British citizenry'.

With regard to the female sex, we find the contagion has spread even among them... Unhappy mothers habituate themselves to these distilled liquors, whose children are born weak and sickly, and often look shrivl'd and old as though they had numbered many years. (cited Abel 1984:11)

In 1751 Henry Fielding supported the petitioners concerns, questioning not only the role of alcohol in crime, but also questioning the predicament of infants who were conceived under the influence of gin. There were large numbers of children who were, in his view, nourished by what he describes as "poisonous distillations" of gin during their fetal development. Children, he said, were being breast fed by what is described by both Abel (1984) and Plant (1997) as intoxicated wet nurses. Abel (1984) suggests that postnatal use of alcohol on infants became a common tool for infanticide often administered by wet nurses. This common practice is suggested to correlate directly with abnormally high mortality rates of infants throughout Britain. Between 1728 and 1757 many reported deaths had a commonality of being reported as caused by 'convulsions'. However one must also acknowledge the appalling poverty endured by the majority of

the British population, particularly the families and children born to the British lower class during that era. These harsh conditions would have had a direct impact on the high infant mortality rate. However Plant and Abel's reference to 'intoxicated wet nurses' to my mind suggests that this was not just a lower class problem but also a problem within the middle and upper classes of British society. No lower class person would have been in a financial situation that would enable them to employ a wet nurse for post-birth care.

Many alcohol researchers identify an illustration drawn in the early 1750's, titled 'Gin Lane', created by British artist William Hogarth as offering insight as to just what life was like for the lower class of English society gripped by the gin epidemic. This picture depicts an unconcerned woman dropping her baby off the top of a flight of steps, in what appears to be a state of intoxication. While in the background, one can see death, hunger, violence and decay amongst an unruly crowd of obviously intoxicated people. In amongst this scene is a female pouring a liquid, presumably gin, into the mouth of a small child that is being held in her arms. It is suggested by Abel (1984) in earlier research that Hogarth created this piece of work out of disgust and dismay at the amount of gin consumed during this time in British history. However Abel (2001) himself retracts his own earlier findings. Abel states that claims surrounding the artists' awareness were unfounded; instead, he was merely painting a street scene that was a common sight in this era.

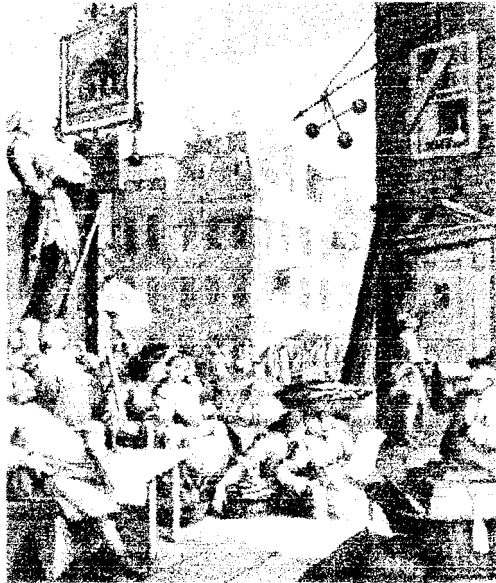


Figure 1. Beer Street -William Hogarth 1751

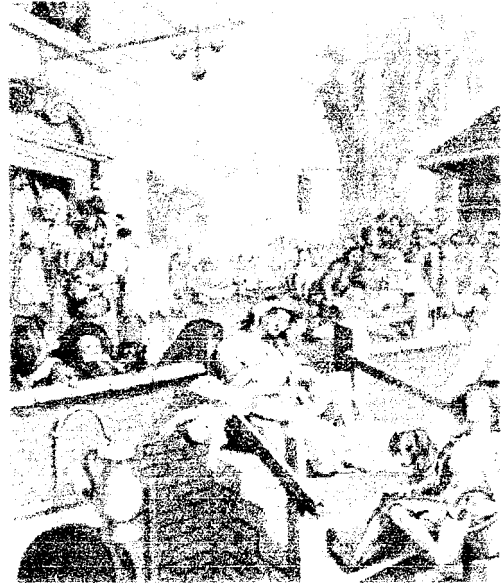


Figure 2. Gin Alley – William Hogarth 1751

However what these researchers seem to ignore is the fact that William Hogarth used his etchings to express a political commentary in a form that did not require the reader to be literate. He has been identified as one of the first graphic artists to investigate the effectiveness of print media as a vehicle to promote a political commentary. Patrick Dillon (2003) author of 'The Much Lamented Death of Madam Geneva', (Gin was nicknamed Madam Geneva in the 1700's) questions the motives behind his depiction of 'Gin Alley'. It is noted that around the same time Hogarth created an etching titled 'Beer Street' (figure 1). This etching depicts a street scene that shows adults consuming beer out of tankards, a direct contrast to the scene captured in 'Gin Alley' (figure:2). Health, happiness and prosperity are all clearly portrayed in this picture suggesting the consumption of beer is associated with a thriving way of life. This artistic commentary

could have been used or even commissioned for the public campaign in the fight to reverse public attitudes towards gin consumption or even promote beer as the healthy alternative. The only person who knows the answer is Horgarth himself or those who did or did not commission him. However, I am sure that the industrialists and politicians of that time who held with a vested interest in the brewing sales and distribution of beer were delighted by his positive etchings.

In the early eighteenth century, the problem of alcohol consumption during pregnancy was intensified by a change in brewing ingredients. Thomas Trotter (1813) documented the rising use of cost-effective opium in the manufacturing of alcohol. It was found that the inclusion of opium in the manufacturing process created a superior brew that contained twice the intoxicating power. This information meant that the foetus was not only being exposed to alcohol but also in all probability, unknowingly, to quantities of opium at the same time (Plant 1997).

The eighteenth century saw a shift in medical paradigms, especially in the area of medical research techniques. This shift was in all probability due to the influence from England's neighbour France, where the French Revolution brought about significant changes in French medical research practices. Medical research was becoming more scientific, breaking away from the traditional medical knowledge base dominated by the clergy. By the mid-eighteenth century, early attempts at epidemiological research were being conducted around health issues. Abel (1984) identifies Samuel Howe as the most

influential researcher of that time, contributing significantly to the subject of effects of prenatal exposure to alcohol.

Howe identified that over half his 300 institutionalised patients, held in an asylum he owned (whom he referred to as “idiots”, terminology perhaps reflective of the attitudes held in those times toward individuals who appeared intellectually challenged), as having a commonality. All had come from families that exhibited parental alcoholism and in one case, seven patients were from the same family. Medical research around this time was by today’s standards most unethical, carried out without permission by the privileged on unfortunate persons more often than not from the lower class, who had been incarcerated in such places as hospitals, jail or simply the poor house. The findings of this research although limited were internationally accepted and touted as evidence, proving that parental alcoholism could damage the children born from such a union.

The first scientific warnings surrounding pregnancy and alcoholism appears to have been published by W.C. Sullivan (1899). His work titled ‘A Note on the Influence of Maternal Inebriety on Offspring’ was published in the Journal of Mental Science. This paper presented his research findings carried out on female inmates of a Liverpool jail. Sullivan found that female “drunkards” (as Sullivan describes them) exhibited two and a half times higher neonatal death rate than non-alcoholics (Sullivan 1899, Abel 1984). This epidemiological research on alcohol was to be the last of its kind until the mid-twentieth century.

The reason for the lack of continued research in the area of maternal drinking patterns was due to two scientists, Elderton and Pearson (1910). As were many researchers of that time, they were involved in the popular eugenics movement, which came to dominate the focus of future alcohol research. They suggested that the ‘defectiveness’ seen in the offspring of alcoholics was due to a ‘defective germ plasma’ (inherited traits). They also identified environmental factors, such as the child’s home life, as being responsible for some of the difficulties observed in children of alcoholics (Elderton, Pearson 1910, Abel 1984). This ‘germ plasma’ theme obtained international recognition and continued to dominate scientific research for many years to come. I suspect that this theory started the ‘Nature Vs Nurture’ debate which is still topical within western societies.

It could be argued that there was merit to some of their hypotheses. Research and common sense would suggest that the home environment would definitely have had an impact on the social development of a child. Some of the difficulties observed may well have been the result of genetic and environmental markers rather than prenatal exposure to alcohol. However with the improvements in medical technology, we can now test the individual for a multitude of genetic causes, a process of elimination that can rule out genetic involvement with the problems being exhibited, particularly with facial characteristics associated with Fetal Alcohol Syndrome.

In other countries, particularly non-western where alcohol is not consumed during pregnancy due to cultural and religious traditions, there appears to be no documented incidents of Fetal Alcohol Spectrum Disorder.

In man, the fetal alcohol-syndrome phenotype has not been documented in malnourished populations in which alcohol is not abused. (Clarren, Smith 1978:1063)

Poverty itself in malnourished populations cannot be held directly responsible for Fetal Alcohol Spectrum. However, in many cultures where alcohol consumption during pregnancy is a cultural factor and a norm coupled with easy accessibility to alcohol, one needs to recognize the possibility that in some cases poverty may well be indirectly responsible. For some individuals alcohol appears to be a temporary escape of sorts from their economic reality.

General medical consensus during the early nineteen hundreds was that alcohol had no effect on the developing foetus (Abel 1984). The study of ethanol on animal offspring had taken place in the early 1900's but declined in popularity as a focus of research after Elderton and Pearson's (1910) theory; it was phased out and considered no longer important after alcohol prohibition in the 1920's (Graham-Clay 1983). The nature versus nurture theory was reinforced in 1942 by researchers Haggard and Jellineck, and again by Keller in 1955.

It was not until 1968 that a French researcher, Paul Lemione and his team, published results of their recent research on alcoholic women and their offspring. This research

challenged the accepted fact that home environments and inherited genetics produced by paternal alcoholism and passed on to the alcoholic's offspring, were largely responsible for difficulties exhibited by these children. Lemoine identified and documented commonalities consisting of growth deficiencies, malformations and behavioural problems exhibited by children born to alcoholic mothers. These results were possibly the most important scientific findings to be presented to the medical profession on the subject of prenatal exposure to alcohol. Unfortunately his work did not receive international recognition and was viewed by peers with scepticism. This scepticism forced this work to be published in a small French medical journal with a small circulation of readers (Lemione, Harousseau, Borteyru & Menuet 1968, Abel 1984, Streissguth & LaDue 1985).

However the importance of this piece of research was not acknowledged within medical circles until after 1973, when American doctors Dave Smith and Ken Jones discovered similar findings with their research participants. Dr Sterling Clarren (1999) who worked under Dave Smith suggests that prior to their research findings Smith himself did not agree that genetics and environments were responsible for all birth anomalies. However, he did believe that environmental agents and other factors were important in so far as understanding people living with any disability.

In 1970 a second year resident student by the name of Christine Ulleland, working in the same hospital as Smith and Jones, noticed a group of four children in her study exhibited familiar facial features. This group of children were completely unrelated, ethnically

different, small for their age, yet looked alike and had similar facial features. One common factor shared by all of these four children, noted in the medical files, was that their mothers had all been alcoholics. Ulleland contacted Dave Smith and suggested that he look at these children, which he did.

Interested in this phenomena, and in agreement that these children did exhibit similar facial features, Smith enlisted the help of Ken Jones and Anne Streissguth to look in depth at this phenomena (Graham-Clay 1983). Photographs of children with an unknown diagnosis that had been seen in the hospital were revisited. Six more similar featured faces were identified. Each of these cases had notes written in the file stating that the mothers of these children had a commonality – in each case they had been an alcoholic (Clarren 1999).

In 1973 Dave Smith and Ken Jones published two articles in the Lancet (Jones, Smith 1973, Jones, Smith , Ulleland & Streissguth 1973) coining the term Fetal Alcohol Syndrome (FAS). FAS was accepted and received international recognition as a diagnosable condition, created by prenatal exposure to alcohol (Plant 1985). It was after these publications that the work published by Lemoine et al. came to light, supporting Smith's and Jones's findings. Smith's and Jones's must be credited with actually naming this syndrome, whereas Lemoine et al and Ulleland must be credited with the discovery of this birth defect (Abel 1984).

Since that time and after the death of Dave Smith, his team of dedicated researchers and other international researchers have continued researching this area. The results have identified alcohol as being a teratogen¹ and the leading cause of mental retardation in the Western world. Alcohol is one of the few substances that can naturally cross the placenta and directly damage the developing foetus prior to birth (Olsen, Burgess, Streissguth 1993, Streissguth 1999).

Since the original identification and naming of Fetal Alcohol Syndrome (FAS) by Jones and Smith in 1973, research has shown that this syndrome is representative of only some effects associated with prenatal exposure to alcohol. It soon became apparent that not all cases seen by researchers and medical professionals exhibited all the same unique cluster of features needed for a diagnosis of this syndrome. On that subject Streissguth and LaDue state that:

All clinicians working with patients having FAS have appreciated the varying degrees of severity in affected patients. Full FAS is recognized as the far end of a continuum of effects and general agreement exists about FAS as a diagnosis entity, at least in the pre-adolescent child. (Streissguth, LaDue Mono 8)

Early on in the research of FAS, other children who exhibited characteristics associated with the other end of the 'continuum' of FAS, generally became known as suffering Fetal Alcohol Effects (FAE). These children were those who failed to exhibit the physical features, yet expressed similar behaviour associated with FAS. The use of diagnostic terminology of FAE has been the centre of much debate in medical circles as

¹ Substances or environmental agents such as, drugs or infections, that can cause malformations or anomalies of the body or the brain during fetal development. (Streissguth 1999)

there appears to have been a tendency for confusion with this term. FAE to some was interpreted as being a less serious condition than the syndrome. This presumption is said to be incorrect by many researchers (Astley, Clarren 1995, Streissguth & Kanter 1999). The cognitive and behavioural characteristics exhibited by FAE individuals has been found to be the same as those diagnosed with FAS. Some researchers recommended that those exhibiting less identifiable facial features associated with the full syndrome be referred to as suffering 'Possible Fetal Alcohol Effects (PFAE)'.

This debate surrounding the use of the term FAE was entered into by the American Institute of Medicine in 1996. They called for the disuse of the term Fetal Alcohol Effects (FAE) in favour of the term Alcohol Related Neurodevelopmental Disorder (ARND). They state that this renaming was an attempt to reduce the clinical confusion surrounding FAE and offered a set of formalized diagnostic criteria covering all effects due to prenatal exposure to alcohol (Stratton, Howe, Battaglia 1996). This will be covered in more depth in chapter two. Streissguth and Kanter (1999:xiii) support this change in terminology by stating that:

The term FAE and PFAE as used in the papers by Clarren and colleagues and Streissguth and colleagues are inter-changeable with ARND.

However to add to this diagnosis terminology debate, it appears that both Fetal Alcohol Syndrome and all Alcohol Related Effects are part of what is now referred to as Fetal Alcohol Spectrum Disorders (FASD) (Barr & Streissguth 2001).

Confused? Well so are many health professionals and associated social agencies within New Zealand who believe that the syndrome (FAS) is more severe than the

effects (FAE). The diagnostic criteria are by no means set in concrete and will no doubt be added to as new research in this area becomes available. Similarly, international trends surrounding the actual name of this medical diagnosis, will alter with time and from country to country. Hopefully, within time, a standardized term such as Fetal Alcohol Spectrum Disorder (FASD) will group all effects of prenatal exposure to alcohol, full facial dysmorphology (FAS), partial facial dysmorphology (PFAS) and those with no or little facial dysmorphology (FAE, ARND) under one diagnostic term. This standardisation of the diagnostic term will in turn place no preconceived notion that any one of these three subtypes on the 'continuum' of effects of prenatal exposure to alcohol is more serious than the other.

CHAPTER TWO

Teratology : Alcohol as a Teratogen

‘Teratology – is the study of malformations of the body.’ (Wolman 1989)

Dr Sterling Clarren (1999) suggests that in the ancient Greek language where the term teratogen originated, TERA meant a thing of wonder - a marvel. However in modern Greek, this term was translated from its original meaning as a ‘wonder’ or ‘marvel’ to mean a ‘monster’. This translation has identified the study of teratology (as it was unfortunately termed in 1935), quite literally as the study of monsters.

What is a teratogen? A teratogen is a term used to identify substances or environmental agents, such as certain types of drugs or infections, that can directly cause malformations or anomalies of the body or brain during fetal development (Olsen et al 1993, Streissguth 1999). When one is discussing the subject of teratogens, it is important to recognize the findings of the American Institute of Medicine - that alcohol (or the ethanol contained in it) is acknowledged as being one of the strongest and most potent teratogens known to mankind.

Alcohol is a recognized human teratogen that produces fetal alcohol syndrome (FAS) and a variety of other alcohol-related effects in children exposed during prenatal life. Of all the substances of abuse, including heroin, cocaine, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus. (Stratton, Howe, Battaglia 1996: 35)

DRUG COMPARISONS

EFFECTS	ALCOHOL	LEAD	OPIOIDS	MARIJUANA	TOBACCO
GROSS NEUROPATHOLOGY	Yellow	Green	Green	Green with black dot	Green
MENTAL RETARDATION	Red	Green	Green	Green	Green
REDUCED IQ SCORES	Red	Red	Green	Blue	Red
HYPERACTIVITY	Red	Blue	Green	Green	Red
ATTENTION DEFICIT	Red	Blue	Blue	Yellow	Yellow
DEVELOPMENTAL DELAYS	Red		Blue	Yellow	Red
GAIT ABNORMALITY	Red	Green	Green	Green	Green
FINE/GROSS CO-ORDINATION	Red	Blue	Blue	Green	Green
SENSORY DEFICITS	Red	Yellow	Green	Green	Red
NEONATAL WITHDRAWAL	Yellow		Red		Red
KEY	<p> Positive findings dose related Positive findings non dose related Suspected (some reports) No effects </p>				

Figure 3. Drug comparisons: impact on newborn. (adapted from Stratton, Howe & Battaglia 1996)

To put this issue into perspective, figure 3 shows observations and differences between the effects of illegal drugs and legal drugs such as alcohol on a newborn. Most would expect alcohol to be the least problematic but in reality, contrary to popular belief, the heroin addict and cigarette smoker is doing less damage to the developing foetus than the consumer of alcohol during pregnancy.

A teratogen can cause four main kinds of problems: death in the form of stillborn babies or miscarriage; functional deficits, expressed in behaviour; growth deficiencies and malformations of body parts or organs (Streissguth 1999). Alcohol as a teratogen quite simply creates what Sterling Clarren (1999) and Anne Streissguth (1999) refer to as 'organic brain damage'. However like all teratogens the actual effects on the foetus

caused by prenatal exposure to alcohol² are dependent on several things. Firstly, the amount or frequency³ the foetus is exposed to while in the uterus - the more the mother drinks the worse the effects can be. Secondly, the timing of the prenatal exposure to alcohol: the more often the mother drinks during her pregnancy, the greater the chances of it coinciding with a fetal developmental stage when the foetus is especially susceptible to ethanol⁴. Lastly, individual factors. The individual differences in genetic makeup of both the mother and foetus⁵ will direct just how the parent and fetal metabolism deals with alcohol (Clarren, Smith 1978; Streissguth 1999; Clarren 1999).

An early study by Christoffel and Salafsky (1975) on dizygotic or non identical twins⁶ who had received prenatal exposure to alcohol found that often one of the twins was born more severely affected than the other. This information was important, as even though they had obviously been subjected to the same amount of alcohol on the same occasions (both at the same developmental stage), the observable effects were different in each child. This particular piece of research illustrates the role played by the foetus by way of 'individual factors' or the individual 'metabolism' in determining just how severe the individual damage can or will be.

This type of information supports research carried out in an attempt to identify certain times during the pregnancy when the foetus is particularly susceptible to damage through exposure to a teratogen. These specific time periods during a pregnancy are

² Prenatal exposure to alcohol is when the baby is exposed to alcohol through the mother's use of alcohol prior to birth.

³ What is known as dose responsiveness.

⁴ What is known as gestational timing.

referred to as a 'critical periods' (Schenker et al 1990). Results from this research and others makes identifying a single critical period for all pregnancies unrealistic. This in part is due to the wide range of effects associated with alcohol as a teratogen. It appears that pregnancies are sensitive to different levels of alcohol at different times, just as the exact developmental timing of the foetus will differ from pregnancy to pregnancy.

Initially researchers such as Scialli (1992) who initially focused on different teratogen effects such as mercury and rubella, focused on the first 3 months (1st trimester) of a pregnancy as being the only period where the teratogen could cause observable birth defects. They suggested that teratogen exposure over the last two trimesters was not dangerous. However these findings have been challenged by many researchers over the years by the use of animal and human studies. Aronson and Olegard (1987) found that 43% of the offspring of their participants who had stopped drinking alcohol by mid pregnancy were intellectually challenged compared to 75% of the children born to mothers who drank alcohol throughout the pregnancy.

Coles (1994), who identifies alcohol as a teratogen, suggests that Scialli might have missed the neurological damage and growth abnormalities due to their invisibility. Researchers simply may not have been aware of the possibility of these abnormalities occurring, consequently not associating these problems with teratogen exposure.

⁵ What is known as individual and fetal responsiveness.

⁶ Results when two eggs are fertilized simultaneously, referred to as fraternal twins - non-identical.

As Sterling Clarren (1981:2436) states:

Phenotypic variability can be extreme in teratogenic conditions where the fetal outcome may be dependent on the dose, the timing and pattern of gestational exposure...

How Alcohol Affects the Unborn Child

The actual mechanisms involved with alcohol affecting the foetus are still not fully understood and there are a number of theories surrounding this subject. Griesbach and Polloway (1990) suggest that the speed and concentration of alcohol getting into the mother's blood stream is the same for the foetus. However, what differs is the length of time ethanol remains in the mother's body; the mother's body will naturally detox itself of ethanol first before removing the waste produced by her foetus. The ethanol level decreases in the mother's bloodstream fairly quickly, while the foetus is exposed to the same level of ethanol often for several hours. Alcohol appears to remain in the amniotic fluid for a longer period – baby is in essence swimming in a concentration of ethanol.

Research published in 2002 gives us further scientific insight as to how alcohol can affect the developing brain. Wilkemeyer, Menkari, Spong, Charness (2002) identified a measurable effect alcohol has on what are termed L1 adhesion molecules. Previous research has identified these molecules as being a naturally occurring compound responsible for helping bring the nervous system and brain cells together during fetal development, central for fetal nervous system and brain development. These molecules have been suspected for several years as playing an important role in Fetal Alcohol

Spectrum Disorder. Results have identified the L1 adhesion molecules as being one of several possible mechanisms targeted by ethanol that can cause birth defects. An understanding of the actual mechanisms involved in ethanol teratogenesis with human development is not fully known. However, research results published by Wilkemeyer et al (2002) suggest that one of these specific mechanisms has to do with ethanol effecting an adhesion molecule⁷ belonging to what is called L1 cell⁸. In essence the ethanol appears to affect the natural glue which enables the L1 cells to bind together, a process that is required for the healthy on-going development of the central nervous system. An appropriate analogy is a tip my mother was given when trying to remove old glue residue left on the floor from lifting previous tiles before laying new ones. By tipping a small amount of turpentine onto the affected area and leaving for a few minutes, the adhesion compound in the glue appears to dissolve, allowing all traces of the old glue to be wiped from the floor with minimal effort. This is a simple explanation of what occurs when the ethanol in alcohol creates teratogenic effects.

It is believed that during the first two weeks after fertilization, the foetus at a cellular stage is generally impervious to harm by a teratogen (Clarren 1999), however termination in the form of miscarriages due to heavy alcohol exposure is not unknown. At this stage, the life form is floating down the fallopian tube referred to as being at the 'Germinal Stage' or the 'predifferentiation period'. During this time the embryonic life form arrives at its destination, the womb⁹, and attaches itself onto the wall creating a

⁷ Known as a Immunoglobulin L1 cell adhesion molecule.

⁸ Plays a critical role in the development of the nervous system and is a transmembrane protein that is multi functional.

⁹ Known as the uterine cavity.

point of origin for the placenta¹⁰ to develop and grow (Roberts & Lowe 1975; Stratton 1996).

The next developmental stage is known as the 'embryonic stage' or what Stratton et al (1996) refer to as the 'period of the embryo'. This stage of development generally ranges from week two until the end of the second month or eighth week (Stratton et al 1996). Both Clarren (1999) and Shepard (1995) suggest that the developing life form is especially susceptible to teratogenic assault during this period. This embryonic development stage is a time when cells are growing, arranging and specializing. A blueprint stage for the growth and development of organs and tissue, particularly the brain and its protective skull. Once the placenta is established, certain substances in the mother's blood system have direct access to the baby (Clarren 1999). Because of this the ethanol in alcohol as a teratogen is able to directly cross the placenta and interfere with the cell specialization process. This interference causes malformations to be made in the structures of forming tissue and organs¹¹. At birth these malformations are generally identified as 'birth defects' (Stratton et al 1996).

Primate studies have shown that the facial cranial anomalies appear to be related to prenatal exposure to alcohol around the 19th and 20th day of pregnancy (Astley et al 1999; Clarren 1999). These animal studies results have had a huge bearing on our knowledge base due to the similarity of primate reproduction to human reproduction and

¹⁰ The placenta grows and surrounds the fetus allowing nutrients and oxygen from the mother's bloodstream to pass onto the developing fetus and for wastes from the fetus to pass to the mother. This keeps both the mother and fetus blood separate.

¹¹ Known as congeembryonic stage is called 'organogenesis' (Stratton 1996 and Clarren 1999.)

for obvious moral and ethical reasons animal studies have been used in this field of research instead of human participants. This concern focuses on the reality that many women have no idea that they are pregnant by the 19th or 20th day after fertilization.

The third and final developmental stage during the pregnancy is known as the 'fetal stage' or the 'period of the foetus'. This period ranges from approximately week eight until birth. This is a time when the foetus is growing rapidly following the growth and structure blueprints (damaged or not) established during the embryonic stage (Clarren 1999).

It is suggested that at this stage of pregnancy physical malformations cannot be caused by exposure to alcohol, however the continual growth of the central nervous system can be disrupted. Figure 4 (p 23) visually shows the approximate timing of fetal development where the foetus appears to be most susceptible to the teratogenic effects of ethanol. This graph identifies the general timing of some of the major structural and minor physiological abnormalities.

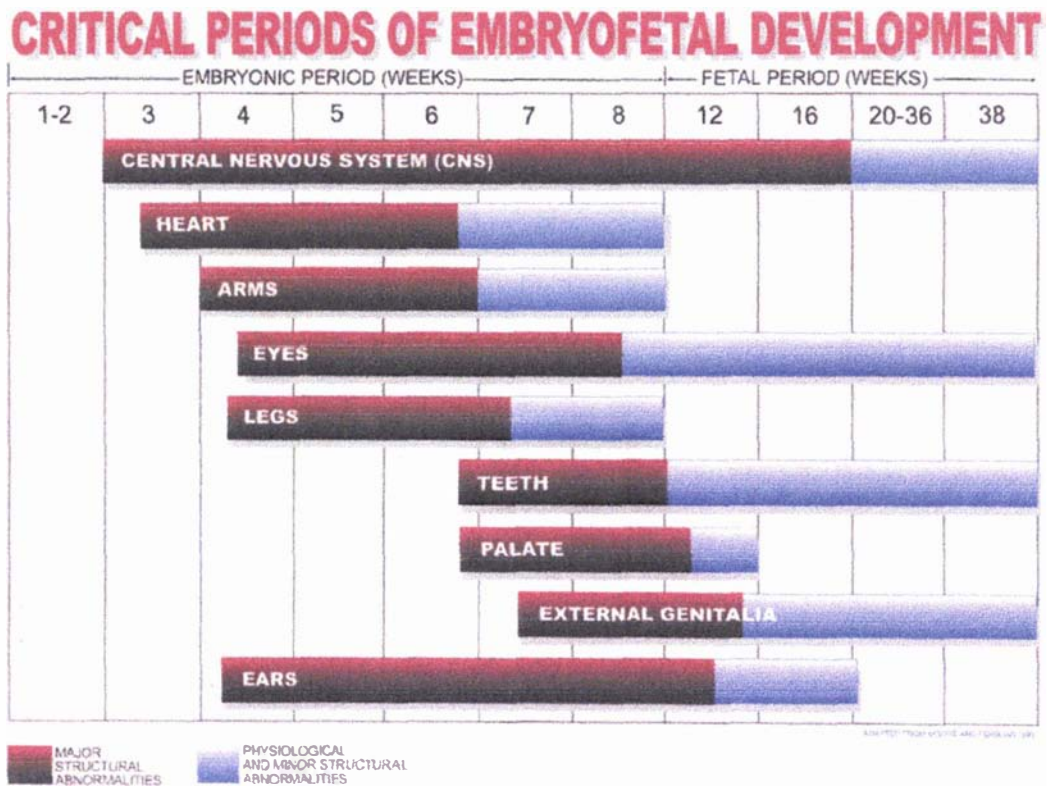


Figure 4: Foetal critical periods (Adapted from Moore & Persuad 1993)

Diagnostic Criteria and Categories

Diagnosis of Fetal Alcohol Syndrome and Alcohol-Related Effects is complicated and must be left to specialised medical professionals to carry out, as there are many disabilities identified by behavioural deficits and physical anomalies. This section is based on the diagnostic criteria for Fetal Alcohol Syndrome and Alcohol-Related Effects set by the American Institute of Medicine surrounding primary disabilities (Stratton et al 1996:4-5).

There are 5 categories in the diagnostic criteria model, and an important thing to note is that no one category is less severe than the other. All categories are considered to represent similar problems and challenges that will be faced by the affected individual across their life span (Streissguth 1997).

CATEGORY ONE

Fetal Alcohol Syndrome

FAS with a known history of maternal drinking¹² involving a regular, heavy or heavy binge type alcohol consumption during pregnancy.

- A. Known history of the above alcohol consumption patterns during pregnancy.
- B. Characteristic facial features¹³ that include features such as short eyelids¹⁴ or eye slits, and irregularities in the two identical bones described by Miller-Keane (1997) as the 'Architectural keys'. These 'Architectural keys' make up the upper jawbone where all the bones in the face except one are connected.¹⁵ This can amongst other things create a thin looking upper lip and a flattening of the mid-facial structures.¹⁶ This flattening of the facial features can result in the vertical ridges situated in the middle of the upper lip stretching to the base of the nose having a flattened appearance.¹⁷
- C. Growth deficiencies, involving one or more of the following
 - low birth weight for developmental age
 - a reduction or below normal weight not due to issues surrounding nutrition.
 - a continued low weight to height ratio.

¹² Maternal alcohol exposure

¹³ Dysmorphic features

¹⁴ Short palpebral fissures

¹⁵ Premaxillary zone

¹⁶ flat mid-face

¹⁷ Flattened philtrum

- D. Examples of Central Nervous System (CNS) developmental anomalies, involving one or more of the following:
- decreased skull size at birth
 - abnormalities in the brain structure – these can include a small head in relation to the rest of the body,¹⁸ part or complete absence of the corpus callosum (the area of the brain that is responsible for communication and information sharing of the right and left side hemispheres of the brain) and/or under-development of the area behind the brain stem that co-ordinates fine muscle movement.¹⁹
 - age appropriate indicators such as: poor eye hand co-ordination, fine motor skills, tandem gait and a loss of sensory information.²⁰

CATEGORY TWO

FAS without a confirmed prenatal exposure to alcohol

This category is used when there is no information concerning the alcohol consumption and is used when the child is exhibiting B,C and D above. This diagnosis is often used when individuals are in foster care or have been adopted.

CATEGORY THREE

Partial FAS with confirmed prenatal exposure to alcohol

A. Known history of prenatal exposure.

B. Some of the characteristic facial features are exhibited as well as either category 1 - C
or D.

or

¹⁸ Microcephaly

¹⁹ Cerebellar hypoplasia

E. The expression of behaviour or thought processing that are below age appropriate.

This process is where one has the knowledge of one's own ability to carry out given tasks involving the process of being able to revise strategies, self regulation, and evaluating development (influences such as environment or family background are not alone responsible for these developmental problems). These can include attention, memory and judgment problems, poor school performance and impulse control, problems involving the acquisition of social perception. Learning disabilities particularly mathematics, poor ability in expressing and understanding language, or problems predicting and monitoring oneself.

Alcohol-Related Effects

Central to the next two categories is once again a history of maternal drinking patterns during pregnancy the same as category 1. However it is noted by Stratton et al (1996) that should future research (either animal or human) indicate that different drinking patterns or lower quantities of alcohol are associated with the next two diagnostic categories, then they need to be included in the diagnostic criteria. If both of these next two sets of diagnostic criteria (ARBD and ARND) are identified in an individual, then both should be used as the medical diagnosis.

CATEGORY FOUR

Alcohol Related Birth Defects (ARBD)

This is when a child presents specific physical anomalies from birth. These include:

Cardiac (Heart):

- problems with the shunt from the left to right part of the heart.²¹

²⁰ Neurosensory hearing loss.

²¹ Atrial septal defects

- defects that disrupts the flow of blood into the heart creating a lack of oxygen.²²
- malformations in the major vessels.²³
- an interference with the blood flow between the heart and lungs.²⁴

Skeletal (Bone structure):

- The incomplete development of finger and toe nails.²⁵
- Shortened fifth fingers.
- An abnormal joining of the two large bones of the forearm.²⁶
- An abnormal shortening of muscle tissue that makes it very resistant to stretching.²⁷
- One or more fingers permanently bent.²⁸
- One or more fingers having permanent deviation or deflection.²⁹ (an inability to place all fingers flat on a flat surface such as a table, often the small finger will stick up).
- Chest abnormalities - where either the sternum is raised interfering with the heart lung action (making the individual prone to lung infections). Or a funnel shaped indent in the wall of the chest is present (which restricts the ability to exercise, makes it difficult to eat a full meal, and can cause heart murmurs).³⁰
- A reduction in the number or a fusion of cervical vertebrae that restricts the amount of movement of the neck, resulting in a shortened neck.³¹
- One side of the vertebrae has not fully developed.³²
- A crooked spine; this is particularly noticeable in adolescents when their bodies are undergoing a growth stage.³³

²² Ventricular septal defects

²³ Aberrant great vessels

²⁴ Tetralogy of Fallot

²⁵ Hypoplastic nails

²⁶ Radioulnar synostosis

²⁷ Flexion contractures

²⁸ Camptodactyly

²⁹ Clinodactyly

³⁰ Pectus excavatum and carinatum

³¹ Klippel-Feil syndrome

Renal (Kidney)

- Not developed properly or abnormal size.³⁴
- Abnormal shape similar to a horseshoe created by fusions.³⁵
- Abnormalities in the tube like part attached to the kidney.³⁶
- Obstructions in the kidney that forms cysts due to a collection of urine.³⁷

Ocular (Eyes or vision)

- Cross-eyed or severe squinting due to a weakness in the eye muscles.³⁸
- Problems with bending light rays to ensure sensory information is transmitted via the optical nerve to other parts of the brain.³⁹
- Problems with the supply of blood.⁴⁰

Auditory (Hearing)

- Problems with the transmission of sound from the ears to the brain.⁴¹
- Sensory information gets lost.⁴²

It is noted by Stratton et al (1996) that some cases of FAS exhibit almost every malformation mentioned above. However studies of the precise causes surrounding each anomaly and maternal alcohol use are not fully understood; only with time and continued research will we achieve a fuller understanding.

³² Hemivertebrae

³³ Scoliosis

³⁴ Aplastic, dysplastic, hypoplastic kidneys

³⁵ Horseshoe kidneys

³⁶ Ureteral duplications

³⁷ Hydronephrosis

³⁸ Strabismus

³⁹ Refractive problems secondary to small globes

⁴⁰ Retinal vascular anomalies

⁴¹ Conductive hearing loss

CATEGORY FIVE

1. Alcohol-Related Neurodevelopmental Disorders (ARND)

This involves the observation of the same Central Nervous System developmental anomalies listed in category one, D on page 24

and/or

The expression of behaviour or thought processing listed in category three – E, page 26.

Diagnosis is still dependent on clinical judgement by medical professionals when identifying these clusters of characteristics. Equally it is important for people to understand that not all health professionals will have the expertise to formally diagnose this condition. Similar to other health problems, there are those who specialise and it is these people who should be central to any referral processes. Diagnostic tools have been created to assist with the diagnosis process. One such tool accompanied with a diagnostic manual is a measuring device used to measure the eye socket size for eye socket malformations associated with FAS. Visually the eyes appear to be closer together, but are in fact housed in eye sockets that are smaller than normal, giving an optical illusion that the eyes are closer together (Clarren 1999). Clarren and his colleagues have been active for the last 25 years in establishing and refining the diagnostic criteria and a comprehensive diagnostic screening manual has been recently published using a 4-Digit Diagnostic Code that is being used effectively (Astley & Clarren 2000). This tool is imperative in the diagnosis of FAS or ARND and has been designed to be very user friendly for medical professionals. A CD Rom tutorial has also been created to accompany this manual to ensure the medical professional uses this

⁴² Neurosensory hearing loss

manual correctly as well as providing a knowledge base to enhance confidence in testing for this disability.

Diagnosis is said to be easiest on young babies due to the situation where facial cranial features pivotal to the diagnosis of Fetal Alcohol Syndrome are more observable. It is noted by researchers that as the child matures, these facial cranial features become less observable (Astley et al 1999; West, Perrotta, Dickson 1998). The following Figure (5), represents the common facial characteristics from Little and Streissguth (1982), where the facial characteristics listed on the right side of this illustration are most often seen in Fetal Alcohol Syndrome, whereas characteristics on the left side of the illustration are not so specific.

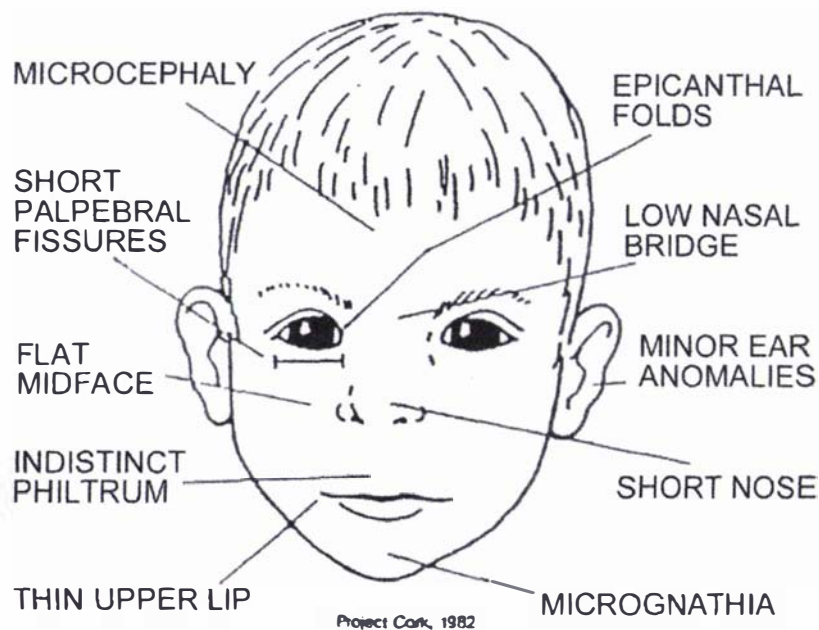


Figure 5. Dysmorphic features associated with FASD (Source: Little & Streissguth 1982)

The Known Effects of Prenatal Exposure to Alcohol

Unlike other major causes of birth defects such as Down's syndrome or Spina bifida, alcohol related birth defects are 100 % preventable if there is no alcohol consumption during pregnancy (McCuen 1994, Streissguth 1999, Clarren 1999). As discussed in previous pages, we know that alcohol as a teratogen has the ability to interfere with the embryonic life form's cell specialization and organization, creating serious life-long consequences for many receiving prenatal exposure to alcohol. However what is of importance is that not every foetus exposed to alcohol is affected.

As with other teratogens – not all exposed offspring are affected. Individual differences occur: Some fetuses are susceptible to the effects of alcohol, whereas others are resilient . (Koper-Frye, Olson and Streissguth 1997:171)

When dealing with the primary central nervous system damage observed in those suffering the Fetal Alcohol Spectrum Disorder, it is, in simple terms, brain damage that has been caused organically. This damage is considered by researchers to be permanent and lasting a lifetime (West, Perrotta, Erickson 1998). It is damage that research has shown does not get any worse or better with age⁴³ - once it has occurred it is permanent.

How does prenatal exposure to alcohol cause the damage and what areas of the brain are susceptible to damage? At a conference held in Calgary Canada in 1999, Sterling Clarren suggested that brain development is a process where neurons are being created and forming pathways extending the brain volume. These neurons all have an encoded address that will dictate where each individual neuron finally rests making up the complex structure of the brain - neurons collectively make up the brain matter. What has

been suggested is that in the brain development of a foetus, that has been exposed to alcohol, these neurons do not form complete pathways. They simply die en-route leaving holes in the brain matter where structures have not formed properly, or migrate past their encoded addresses.

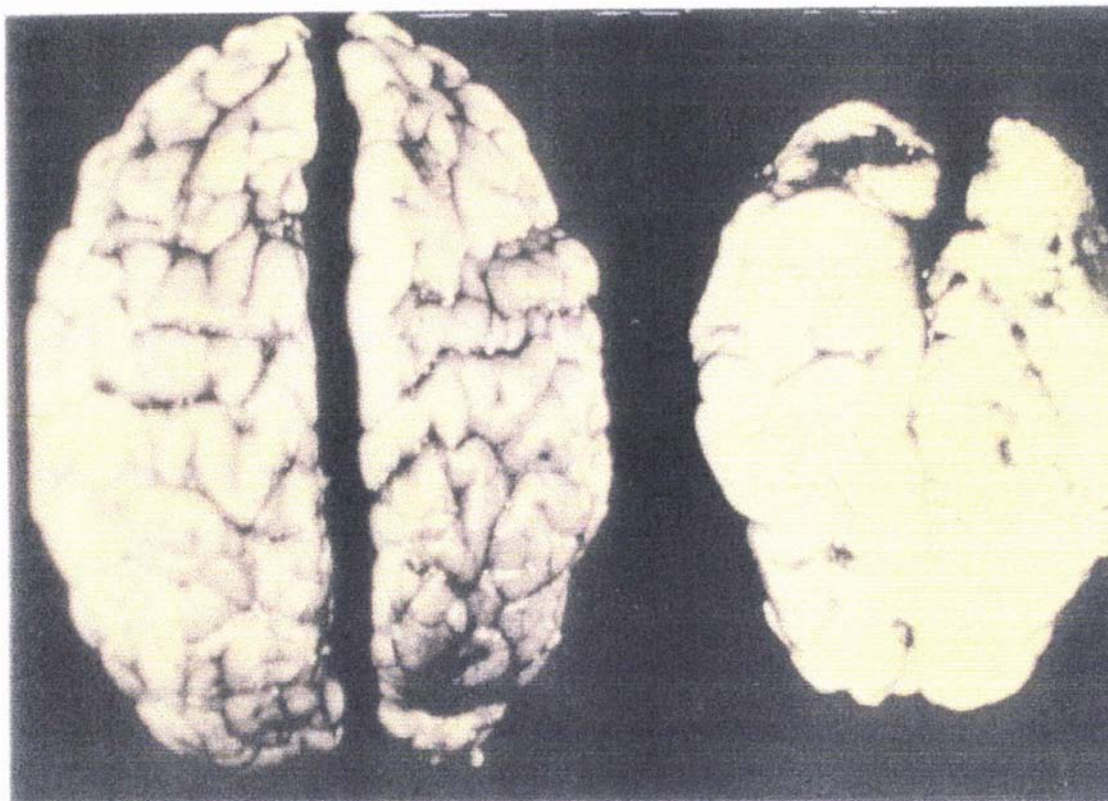


Figure 6. Healthy brain (left) & seriously FASD affected brain (right) (courtesy S. Clarren 1998)

Radiation has been identified as another strong teratogen that is similar in its ability to affect a developing foetus. The difference between the mechanisms associated with damage to the Central Nervous System is that radiation has been identified as causing

⁴³ Known as 'Static Encephalopathy'

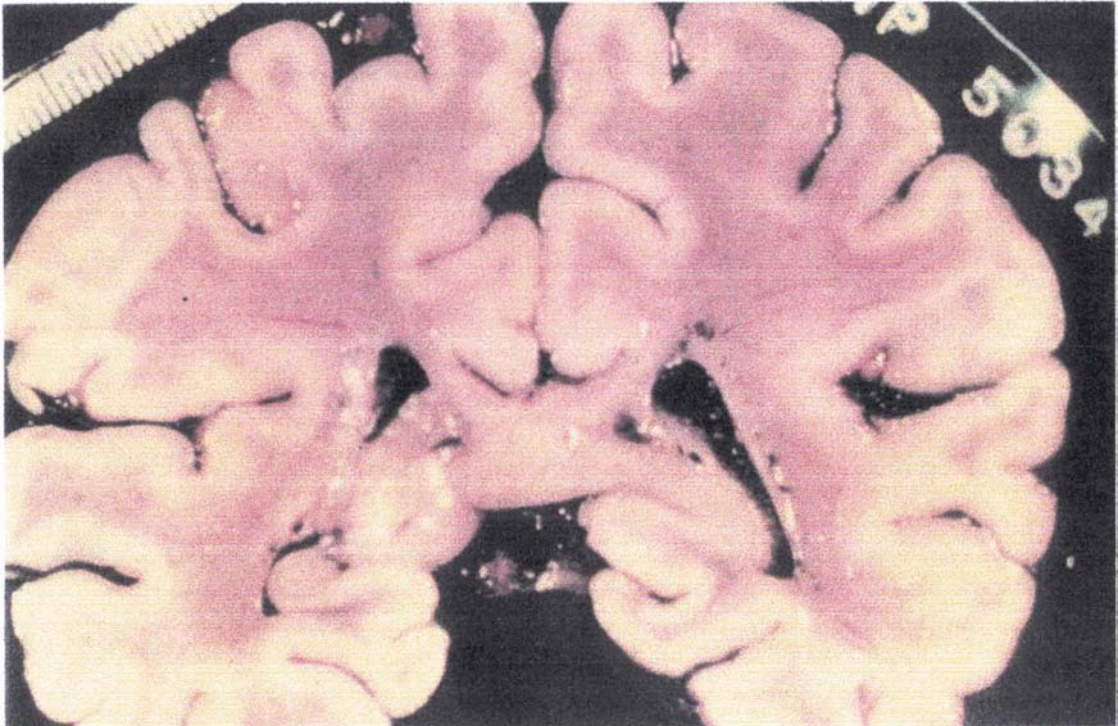


Figure 7. Healthy cross section of infant brain (Courtesy of S. Clarren 1998)

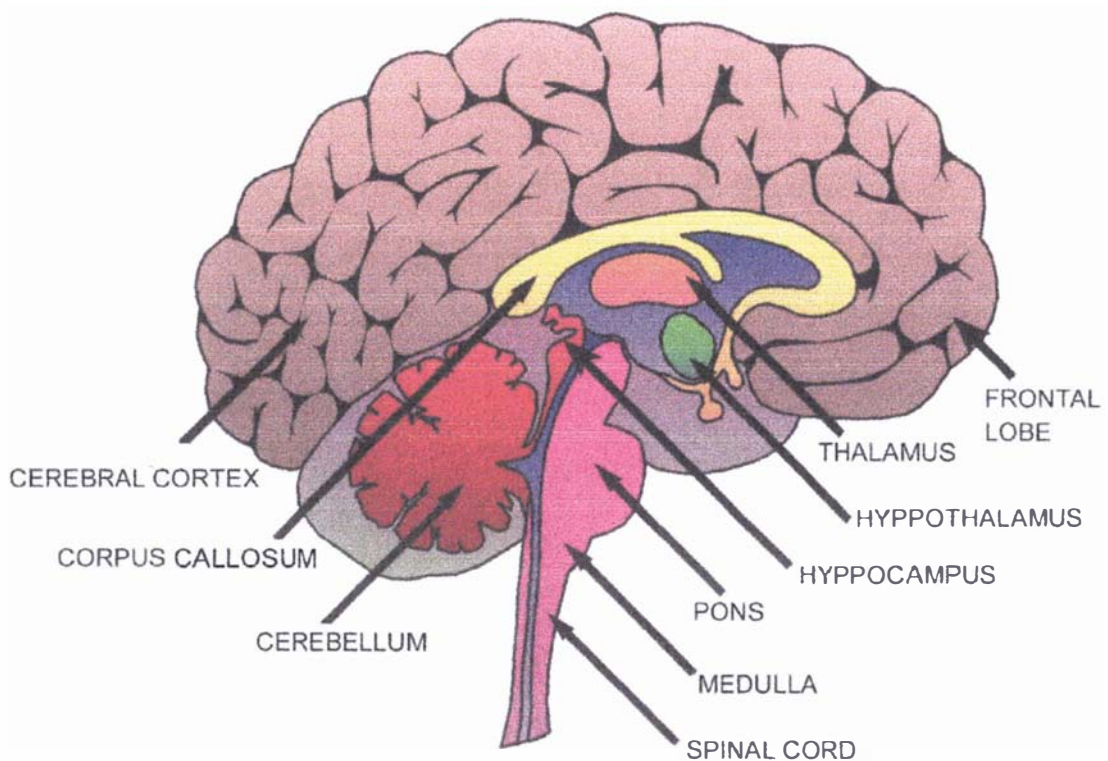
Figure 8. Seriously damaged FASD infant brain (Courtesy S. Clarren 1998)



neurons to stop short of the correct destination address encoded within the neurons. Both alcohol and radiation can create permanent brain damage that will last the life time of those exposed.

With twenty-first century technology there is a lot about the brain we know, but equally, there is also a huge amount that we simply don't know. Research has shown that everyday human actions and thoughts are the result of particular regions of the brain either individually or collectively processing information and responding to external stimuli. Researchers have identified several areas of the brain that appear susceptible to damage from alcohol. Olson, Murse, and Huffine (1998) suggest that some regions of the brain are more vulnerable to damage than others.

Figure 9. The human brain

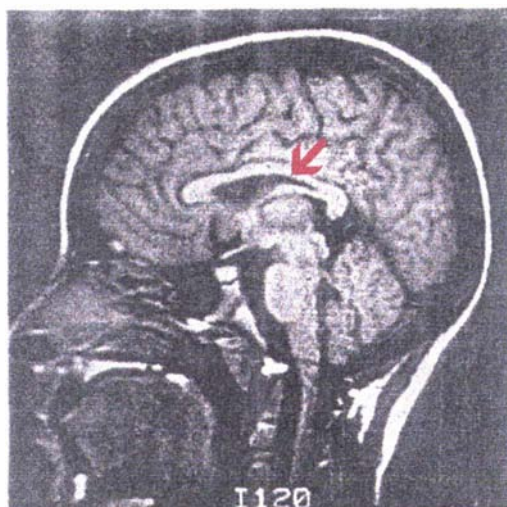


Research has indicated that there are several regions of the brain that appear to be most affected in FASD individuals. These regions or areas of the brain are as follows.

Corpus Callosum. This is the part of the brain that separates the right hemisphere from the left and passes information from one side of the brain to the other – its structure is central to processing information. The importance of this structure is that it provides a communication pathway between the left and right sides of the brain. Some of the tasks associated with the right hemisphere is to control intuition, abstract thought, emotions and feelings. The left hemisphere, amongst other things, appears to control the processing of consequences, orderly sequences, concrete ideas and rules.

If the Corpus Callosum is damaged, doesn't work properly or is missing altogether, information is passed between both sides of the brain ineffectively, very slowly or not at all (Mattson, Jernigan & Ripley 1994).

Figure 10. Left: Corpus Callosum present. Right: Serious FASD no Corpus Callosum. (Source Streissguth & Kanter 1999)



This often results in the affected individual carrying out an action without being able to identify the consequences prior to action or being very slow in processing information or simply unable to process information successfully. It is noted by Hynd et al (1991, cited Streissguth, Kanter 1999:11) that the Corpus Callosum of alcohol exposed children was significantly smaller along with reductions in three of the five callosal regions of the brain. A reduction in these regions has also been observed in children suffering Attention Deficit Hyperactivity Disorder. What Mattson and Kanter (1997) (cited Streissguth, Kanter 1999) found interesting was that there appears to be a high prevalence of similar attention deficits in children suffering Fetal Alcohol Syndrome.

The Cerebellar This is a specialized part of the brain often referred to as the ‘Little Brain’. It is responsible for motor control (Riley1990), and deals with movement coordination, it is also noted as being important for balance and posture (Restak 1995). Initially it was thought that the cerebellum’s only function was associated with movement. New knowledge focused on this area of the brain has been made available through cognitive neuroscience research. The cerebellum has been identified as having an important role to play in other areas of central nervous system function that are involved with timing (Woodruff-Pak 1997). Mattson and Kanter (1997) (cited Streissguth, Kanter 1999) observed a particular section of the cerebellar called the ‘anterior vermal region’ as being smaller in individuals subjected to prenatal exposure to alcohol. Wood-Paks (1997) suggests this timing system is activated every time information is processed that involves perception, learning and action. For example, if a person who has damage in the cerebellum is given a task to identify the longest tone of

a group of administered auditory signals varying in length, they would be very slow in responding or possibly unable to distinguish a difference in length of tone.

The Hippocampus This area has been identified as being involved in learning and memory (Yanni, Lindsay 2000, West, Goodlett & Brandt 1990), expression and experience of emotion (Restak 1995). If damaged, this area has been observed as playing a significant role in creating epilepsy and depression. These problems have been identified as a major disability in some children with fetal alcohol spectrum disorders (Bonthius, Pantazis, Karacay, Bonthius, Taggard & Lothman 2001).

Another important role played by the hippocampal region, in conjunction with the frontal lobe, is that of the working memory. The working memory is a process that allows us to sequence thoughts and ideas and be able to utilize the temporary use of previous learnt knowledge to guide current behaviour including future planning. Individuals with damage in this and the frontal lobe area often find themselves with restricted ability when undertaking problem solving tasks that require a degree of flexibility with the way they should respond to these tasks (Woodruff-Pak 1997).

The Basal Ganglia – This is used for processing memory (Archibald, Fennema-Notestine, Gamst, Riley, Mattson, Jernigan 2001) and appears to play a big part in creation of speeded responses, whether for learning, action or what is known as perception. Although voluntary commands for movement are created in the frontal lobe

(discussed in more detail pg 39) they are sent to the basal ganglia for action (Woodruff-Pak 1997).

Research by Olson et al (1998) and researchers Mattson, Riely, Sowell, Jernigan, Sorbel and Jones (1996) suggest, as with the interior region of the cerebellum, there is a noticeable overall reduction in size of this region in children suffering fetal alcohol syndrome. This region plays a significant role in automatic movements, movements we don't consciously think about while we do them. For example

Turning the pages of a book, ... dancing to the rhythm of a familiar song while thinking of events that occurred earlier in the day – it's the basal ganglia that makes such responses possible. (Restak 1997:16)

Clearly if one has damage in this particular region of the brain it is certainly going to express itself in what most people would term as abnormal behaviour. Mattson et al (1996) indicate those problems in attention and language processing along with memory retrieval and perseverative behaviour.⁴⁴

The Thalamus One of the major roles this area of the brain is involved in is that of passing information between the motor cortex and the cerebellum (Livy, Maier & West, 2001). This region of the brain is part of what we term the limbic system, which consists of a group of brain regions that are connected to each other. Collectively they are involved in memory processing and the expression and experience of emotion.

⁴⁴ Behaviour that is repetitive and often the individual has no idea that they are doing it. Often this behavior is in the form of an idea or solution to a problem that others not affected can see - simply won't work, even with its failings identified by others they will not sway from their original solution.

There are two thalami , one on each side of the brain. Excluding the sensory impulse of smell, these thalami are responsible for the reception of sensory impulses from each side of the body. Their job is to send this information to the appropriate regions within the brain, acting as a messenger service in the process of relaying impulses from one area of the brain to the other a process called a 'feedback arrangement' (Restak 1995:18).

The Frontal Lobe This lobe takes up 50% of the volume of both sides of the brain and is the largest region within the central nervous system (Restak 1995). This area is responsible (in conjunction with other regions) for what is referred to as human 'executive functioning'. This is a region of the brain that is most important as it begins motor activities such as speech and is responsible for transforming thought into action. Due to the activities of this region of the brain, if it is damaged often the individual shows impulsivity. This is a situation where thoughts go directly into action rather than a three step process which involves a gap (reflection) between thought and action. The frontal lobe's major job appears to be that of monitoring the rest of the brain's intentions. The frontal lobe has a major role in forming judgements, inhibitions, regulating sexual urges, regulating emotions and motivation amongst many other roles, consequently those with damage in this area of the brain have a great number of problems including the ability to show and feel remorse (Fasalaska 1997).

Archibald et al (2001) suggest that severe prenatal exposure to alcohol creates a specific pattern of excessive tissue formation⁴⁵ and that similar findings were found in both those diagnosed with FAS and those with no facial cranial features who had been

subjected to prenatal exposure to alcohol. Similarly research by Mattson, Goodman, Caine, Delis and Riley (1999) found that deficits in executive functioning were found in the absence of mental retardation in children subjected to prenatal exposure to alcohol, with or without the medical diagnosis of FAS. These deficits have a huge bearing on the ability of those affected to carry out both adaptive and daily functions. Specific impairments in abstract thinking, thought flexibility, response inhibition and ability to plan were identified along with reductions in the structures within the frontal lobe. Mattson and Riley (1998) report frontal lobe dysfunction in areas of nonverbal problem solving, cognitive estimation and planning ability through tests administered that utilized tasks requiring frontal lobe use. This region of the brain is involved in the planning and thinking process in order to carry out conscious decisions.

Along with being primarily involved in planning, decision making, and purposeful behaviour, there is some evidence that an individual's initial appraisal of whether an event is threatening or dangerous is carried out in the frontal lobe. If the frontal lobe is damaged or destroyed, the individual becomes incapable of planning, carrying out or comprehending complex action or ideas and has an inability to adapt to new situations. Such people are unable to focus attention and are extremely distracted by irrelevant stimuli. Although many of the most complex functions such as language and consciousness seem unimpaired, the loss of the ability to adapt and plan ahead makes all those other abilities less useful (Ornstein, Thompson 1984:36).

⁴⁵ Brain Hypoplasia

Primary and Secondary Disabilities

The life-long disabilities associated with prenatal exposure to alcohol are classified as being either a primary or secondary disability. These disabilities are described as follows by Streissguth et al. (1996) for the purpose of their initial study as

Primary disabilities are defined as functional deficits that reflect the CNS [central nervous system] dysfunctions inherent in the FAS or FAE diagnosis. Secondary disabilities are those that arise after birth and presumably could be ameliorated through better understanding and appropriate interventions. (cited Streissguth & Kanter 1999:27)

There are many pieces of global literature that deal with primary disabilities caused by prenatal exposure to alcohol but internationally acknowledged research in secondary disabilities has been carried out by an American research team operating out of the University of Washington School of Medicine's Fetal Alcohol & Drug Unit. This research team placed their participants into two groups, either FAS or FAE and used general levels of adaptive functioning, general intelligence and mastery of arithmetic, spelling and reading as a measure of 'primary disabilities'. The reason for using this measure is due to the fact that they can all express the central nervous system manifestations of FASD as a birth defect.

The Intelligence Quotient (IQ) information obtained indicated that only 9% of FAE individuals had an IQ below seventy⁴⁶ and that the IQ ranged between forty to one hundred and forty two with the mean IQ score being ninety.

Twenty seven percent of FAS participants' IQ's were under seventy with an range of twenty-nine to one hundred and twenty, with a mean IQ score of seventy-nine. When it came to spelling and reading, those diagnosed with FAE were found to have a much lower ability than would be expected of the IQ level and were almost one standard deviation⁴⁷ below the expected IQ performance in arithmetic. Those with FAS were found to have scores in spelling and reading close to IQ functioning, while in arithmetic they were found to be operating only with two thirds of a standard deviation lower than expected of their IQ level. Both groups were found to be operating at a much lower adaptive functioning level than is associated with their IQ levels. It appears that those with FAE fared the worst and were associated with greater discrepancies than those with FAS in relation to expected ability from IQ levels on all tests (Stressguth et al 1996). These results support the argument that IQ tests alone are not a good indicator of the abilities of the individual affected by Fetal Alcohol Spectrum Disorder.

Secondary disabilities are disabilities that those with fetal alcohol spectrum disorder are not born with, rather they are disabilities that occur as a direct result of neurological damage. What appears to compound these disabilities is the situation whereby these primary disabilities, particularly neurological, are not recognized. It is suggested by researchers in this field that these secondary disabilities could possibly be eliminated partly or completely with correct interventions and understanding. The eight major secondary disabilities that have been identified by researchers are problems and issues

⁴⁶ Within New Zealand individuals with an Intelligence quotient of under 70 are considered intellectually challenged.

⁴⁷ Statistical measure that measures variations from the average.

with employment, dependent living, alcohol and drug use, mental health, inappropriate sexual behaviour, trouble with the law, mental health issues, disrupted school experience and confinement⁴⁸ (Streissguth 1997, Streissguth et al 1996,1988, Copeland, Rutman 1996).

International research shows that those suffering fetal alcohol spectrum have an unacceptable level of secondary disabilities which are both costly to society and impair the quality of life. Abnormal behaviour and learning disabilities appear to persist across the life span of these individuals and international research suggests that there is no 'quick fix' approach to this problem. However we can reduce the level of secondary disabilities if more public and professional awareness surrounding the long term effects of primary disabilities become known. Diagnosis and intervention (the earlier the better) have been identified by Streissguth et al (1996) as 'strong universal safety factors' in the fight to reduce secondary disabilities. They state:

An early diagnosis may help the family better understand the root of their child's developmental delays and behavioural problems and empower the family to advocate for appropriate services particularly in the crucial first years at school. A diagnosis is an effective communication tool that enables caregivers to educate others about special needs of alcohol affected individuals (Streissguth et al 1996:64).

Primary disabilities must be fully understood in order for caregivers to appropriately manage and reduce the occurrence or severity of secondary disabilities. For many an early medical diagnosis (as shown in the next chapter) has been a key to success in their children reaching adulthood with minimal secondary disabilities.

⁴⁸ This is defined as having been incarcerated for crimes or as an inpatient for mental health and/or alcohol and drug treatment (Streissguth et al 1996)

CHAPTER THREE

The following text was written and given to me by one of my older participants who has in the past and will continue to be very much part of her FASD grandson's life while she is able. During one of my interviews with her, she expressed a love for writing and a wish to place her experiences in her own words on paper for my thesis. As an anthropologist I was delighted to include my expert participant's written account. Now that the previous chapters have explained just what FASD is, and the medical criteria for diagnosis, this chapter describes the lived experiences and living implications of FASD as told by a grandmother of an adult FASD individual.

A Grandmother's Story

To understand Neil's story it is important to know his parents, whom we will name John and Jane. Jane, his mother, was a child very sunny and bright, with a great sense of humour and fun. She had a love of music and plays by ear. She also has a love of horses and is a dedicated horsewoman. It was these qualities which have helped her through the last 20 years.

Neil's father, John, had a horrific accident as a young man and broke his neck, which left him paralysed from the neck down and on his back in hospital for 12 months. However he surmounted the insurmountable and walked again. The hospital called him the "Miracle Man". Even though he was left physically disabled he has overcome all obstacles over the years and married his wife, my daughter, 25 years ago. He is steady, reliable and down to earth. It has always been his influence that has kept Jane on an even keel. His disability left him unable to have children so they looked into adopting. One of the questions they were asked was whether they would consider a child with a disability? But Jane, very wisely, thought that seeing she has a disabled husband she didn't need any further complications.

Eventually along came Neil, aged 5 weeks. As my first-born grandchild I adored him. He was beautiful with curly hair and lovely creamy skin and grey eyes. But he was not a happy baby, and as time went on he became hyperactive, unable to settle to any one thing. He had screaming nightmares, which left him and the family shattered. Jane became troubled and took him to her doctor who analysed her as an 'over-anxious' mother. At a later stage, when they had moved to another area, she took him to another doctor and he diagnosed Neil as having a 'behavioural problem'. This is not necessarily a criticism of the doctors, very little was known about Fetal Alcohol Syndrome.

Time went on, going from one crisis to another and in 1983 when Neil was four, Jane and John took him to Wilson Home. He was there for about 10 days, during which time the institution procured his records from the hospital where he was born. To everyone's shock and horror it was found that the hospital was aware that the baby they allowed to be adopted had a problem. At age four he could not speak properly and seemed to have a language of his own, and had poor co-ordination. The final diagnosis was that this little boy suffered from Fetal Alcohol Syndrome, now commonly known as FAS. In 1983 little was published about FAS, and Neil was probably one of the first children in New Zealand to be diagnosed. As Jane puts it 'it was like having a death in the family, but the grieving is never ending'.

No stone was left unturned to try and put some order into Neil's upbringing. He was put into speech therapy and they bought him hand held computer games to help with his hand- eye co-ordination. He became extraordinarily efficient and could top the score of those who took him on. When he was of school age, he went to a normal school. His mother took him and virtually taught him on a one to one basis, with the help of the teaching staff, who were really wonderful.

He had a very complex personality. Loving, sweet and happy on the one hand and screaming and violent on the other. He grew very tall for his age and extraordinarily strong. Because of his size he was taught that he must never hit anyone.

During these hard years Jane immersed herself in her music and horse riding, her outlets that as she puts it 'keep her sane and Neil alive'. Her sense of humour has seen her through some very trying times. Under stress one can develop a very 'black' sense of humour, and she and I have some very funny incidents to relate to each other. Turning situations not funny at all into anecdotes of humour to relieve the tension and it still works today, all at poor Neil's expense, might I add.

Through Psychology Services Jane meet Mike Edwards, a very talented psychologist. He was her life-line, advising her, guiding her and eventually telling her she was a 'Gold Star' parent. He told her that Neil would always survive and that in order for the family unit to survive (as they now had a little girl) Neil would have to be considered as 'outside' the family circle. Unfortunately Mike passed away and Jane felt as if she had lost part of herself.

At the age of twelve, by a miracle and with Mike Edwards' help, Jane got Hoben School in Christchurch to consider Neil as a boarder. Hoben is a school specially designed for the likes of Neil – with a mental problem but the ability to learn. He came back home for the school holidays, but it was very hard putting him back on the plane to Christchurch. While he was there I wrote to him every few days and he wrote back sometimes - I still have his letters. Neil became very literate, writes beautifully, can do mental arithmetic, reads exceptionally well and is computer wise.

Before he went to Hoben, I bought him a computer, which I kept here so he could use it to keep him occupied. He spent hours on it and is a very proficient typist. I have watched him type and am fascinated with the way the minute he puts himself in front of a computer he is immediately in control. All of his complexes and syndrome melt away and he types and thinks at the same time. He has learnt his way around the internet, mostly self-taught, has a phenomenal memory for numbers like his Social Security number, bank account number and knows all the facilities a telephone can offer. He dragged me into the 21st century by telling me how to pay my accounts through the

phone services, has spent hours doing budgets on his computer and they look very professional and well set out. But with all this ability, he is unemployable.

He applies for jobs of various sorts, but always in the field of administration and fails to understand why no one wants to employ him. (He would be wanting to run everyone and everything). He has an aversion to physical labour, although he is 6ft tall, very strong with a fine physique, not to mention size 12 shoes.

He has almost an obsession to be a security officer and it is quite strange that his natural grandfather with whom he has never had contact, was a security officer. He is very streetwise with an inborn sense of survival. He is very healthy, I can't ever remember him having a cold. In spite of the junk food and sweet drinks he has consumed over the years, he does not have one filling in his teeth.

But to counteract that he has eczema – a very rare type according to skin specialists who find it quite fascinating and medication for his skin is the only medication he is on. He has in the past, been put on the usual medications dished out by mental health but now he refuses to take any. He vehemently states that he cannot function 'normally' (his words) while on them. But he is very responsible about his eczema medication and spends a lot of money on skin creams to stop the irritation. The eczema seems to come and go in cycles – one week he can be covered and the next week there is not a sign of it. It covers most of his body except his face, which is a blessing because he is a fine looking boy.

After he came back from Hoben at the age of 17, he spent a short time at Kingseat [mental health hospital], an experience that has left a mark on him even today. He was diagnosed at Kingseat Hospital as mildly intellectually handicapped. - on top of his other problems, so was put into Spectrum Care. He learned very quickly how the department functioned. He knew everyone from the CEO down and how their various positions in the department operated. Spectrum tried to give him a job in the department to try and develop his computer skills. He was such a disruption it was almost a case of

“him or me” in the various offices. He went from one housing situation to another within Spectrum Care, but was again a disruptive influence; he would not accept regulations and kept demanding to be moved on.

Finally at the beginning of 1999, he took himself into the Social Welfare Department, had himself taken out of Spectrum Care and put on a sickness benefit, deciding he could find his own way in the world. It has been an unmitigated disaster because once out of the circle he cannot get back in. It has been a procession of boarding houses, flats, flatmates - something in the vicinity of 20 in the first year, always with the same drastic result. No one can survive his hyperactivity and restlessness, wanting to run budgets for the household, not to mention his temper, insults and bad language when things didn't go his way. My husband and I have spent endless trips to move him from one place to another, fixing up cupboards and drawers, setting up his computer and a hundred other things.

Over the last 18 months his belongings have dwindled to a few clothes and all his records which he has written. Records from WINZ, untold telephone accounts and hire purchase accounts all carefully filed in east-light files. He does not handle money at all well, two days after benefit day he is broke. He maintains and I agree with him that people like him should be paid weekly instead of fortnightly. There seems to be a demon inside him, which drives him to keep moving on. He will leave a place in the middle of the week with no money for rent or food, but he can always find someone to take him on face value until benefit day.

Neil is very manipulative, he tells me one thing and his mother something else and plays one off against the other, so it invariably ends up with Neil verbally abusing his mother. One thing I have to say in his defence – he has never physically abused any of us. On one hand he is very friendly and social. On the occasion of his 21st birthday we wondered whether he would go through the luncheon to the end without walking out. He was lovely to everyone and at the end thanked everyone for his party and presents.

As his nanny I have become his security blanket and we have a special bond. He knows I love him unconditionally. He knows that I know that he is a compulsive liar and he will argue convincingly, to try and make me believe what I know is not true to be true. But in trying to convince me, I really believe he convinces himself that he is telling the truth. This makes lots of arguments. I always say that arguing with Neil is like arguing with a drunk except the only problem is that in the morning the drunk is sober but Neil will always have FAS.

I hate what this syndrome has done to Neil, he would be extremely intelligent but for that missing link [participant was referring to the disabilities Neil exhibits] . If I were to use one word to describe Neil I would say 'Resourceful'. He knows how much money he is entitled to as a beneficiary, and will argue loudly and forcefully to get it and more. Just ask the staff at the various WINZ [government work and income agency] offices he has been in!

He can be homeless for days at a time but can always find yet another place to set up home. He ends up in some grotty dump for \$80.00 or \$90.00 odd a week, but he is fanatically tidy and can make them look quite presentable. If he is lucky enough to have shelves or drawers, everything is laid out side by side – if there is a vacuum cleaner he will use it on the whole place. One day he looks like the traditional "bum", unshaven and grubby and the next day he is showered, clean shaven and tidy. Luckily he doesn't smoke or take drugs. He hates squalor and because he can only afford that type of place that represents to him 'very down market' I suspect this is the driving force that makes him move on, but who knows? He will probably never get the opportunity to find out. At 6.00 in the morning he can ring me after having slept in a mission, backpacker or walked the streets all night, and by 7 o'clock has found somewhere to live. He can be in the city and find a place on the Island. Time and time again I have fronted up with a week's rent to keep him off the streets, and to be honest what is more important. Two days later he is back in the city, homeless and not having eaten for a couple of days. He can always find a telephone to ring me. Yesterday he arrived at my place of work where I am a volunteer, complete with his meagre belongings, unshaven, rough and once again

homeless. In the end I gave him \$20.00 to get a bus back into the city where he could find a mission and at least have a meal. It was a very hard decision but I knew there is no way I can have him at home. He used his last \$4.00 to use the internet and found a place to live, and what's more he even got the owner to take him there.

Once again it was a pretty awful place. His room had a double window of which one was broken and boarded up. There was a dirty old carpet on the floor which hid a large hole in the floor, which went down to the ground. For that the owner wanted \$90.00 per week. That is where he is today, but who knows where he will be next week? I don't doubt that he will be on the move if the owner doesn't come up to his promise to fix the window – like yesterday! This morning I took his T.V and bits and pieces over and he was vacuuming the lounge. Yesterday he was dirty and unshaven, today he was showered and clean-shaven. I know that for tonight he has a roof over his head, so I will sleep easier.

He tells me he has been banned from the Casino because he abused the Security Officer, who told him he was spending too much money there. I sometimes wonder what goes on in his head – chaos I think, but in some weird way organised chaos. If he thinks he has a grievance he knows exactly where to go and can be very explicit.

Neil is afraid of no one. He has an air of authority which because of his stature, could be quite threatening to anyone not knowing him. He approaches bank managers and others in positions of authority with such confidence, he nearly always gets a hearing. He has a telephone manner - which should get him into good positions, but once an interview happens, the rest is history. Over the telephone he can be very convincing and has taken in many people. For example he wanted to start a security company and has had faxes sent to our machine setting out terms and conditions for the lease of equipment, phones, radio-phone and everything else he deemed necessary to set up a company.

Neil, although only 21 years old he knows this large city like the back of his hand. He walks literally hundreds of miles, from north-west into the city, from the mid-south to the east and back to the city centre - he is the original 7 league boots! At one stage, because he was a long way from buses, we procured a cycle for him and set him up with all the necessities. He cycled all over the city, which frightened me silly, but I just "put a ring of love" around him and hoped for the best. Eventually he loaned the bike and never saw it again.

I believe in God and have prayed for 20 years for things to be easier for Neil and his family. I know my prayers are answered. How else can a 21 year old wander around the city all hours of the night and walk to the places he does without coming to harm? When I haven't heard from him for two or three days I start to worry. Then out of the blue comes the phone call. He lists all the complaints of his last tenancy. It is always everyone else's fault and try as I might, I can never get him to accept any of the responsibility. We often end up having a blazing row and to end it I have to hang up. He rings me back, says he's sorry and 'Please Nanny darling, would you lend me \$5.00' knowing full well that his account is probably at least \$10.00 overdrawn, so I put \$20.00 into his account to feed him for another day or two. He always ends up saying 'I love you Nanny'. That is the only payment I will get but it is enough.

Neil has a very caring side to his nature. He had a relationship and lived with a girl for about 3 months. In some ways she was good for him but she and her friends were into drugs which Neil found hard to deal with. They had violent arguments and were eventually evicted because whilst Neil was paying his half of the rent, she wasn't. He didn't feel he could leave her because he thought she needed his support. Even now he talks about her and worries how she is coping. Underneath and in spite of everything, he still loves her but realises she is no good for him. Her friends have threatened him on occasions.

A favourite expression of mine is "Nothing is ever wasted including time because every minute brings a new experience". For the last 18 months Neil has been in training

for a job without knowing it. Several weeks ago his obsession to be a security officer led him to apply for a licence. With his perambulations around the city, it was a while before he found out it had been granted.

Immediately he applied for a job with a big security company and I am ashamed to say I thought that would be the end of it. But in the afternoon of his appointment he rang to say he had got the job, was complete with his uniform and radio telephone and he had to be at a certain place by 9 o'clock next morning and could he come and stay the night.

He arrived having hitched a ride from a distant part of the city, because once again he had no money. My heart nearly burst with pride to see this big uniformed young man arrive. We saw him to his job with \$80.00 to pay his way home for the next couple of days. He did a 4 and a half hour shift and went straight on to another job out south from 6pm till 2.30am. For the last week he has been all over the city doing extraordinary long shifts, but he has realised a lifelong ambition. Because of his itinerant lifestyle Social Welfare had no current address for him so they cut off his benefit.

When I say Neil has been in training for this job nothing could be closer to the truth. His knowledge of the greater city and his preference to go for long periods with little sleep plus the long distances he can walk have been a huge benefit to him. How long will it continue? Who knows. Whether he will be able to be reasonable under all circumstances will be the greatest hurdle. While getting from point A to point B under usual circumstances is a piece of cake – you and I just get in our car and go there! But with no car and no licence, it is quite a feat. I have picked him up and taken him on several occasions.

He has to be given every chance to make a success of this new career. Last night he worked in a hotel in town from 9pm till 3.30am and then was to be in a different part of town to start again at 7.30am this morning. I haven't heard today whether he made it on time, but knowing Neil and his fetish for punctuality he would have stayed in the city and used the time between at an internet place and gone straight to work.

It is hoped that this terrible problem will be taken a lot more seriously and that in the next few years people like my Neil will be given a fair go. Fetal Alcohol Syndrome is a malignant syndrome that can catch the unwary and the innocent as well as the seasoned drinker. It is devastating to the parents and impacts on everyone who comes into contact with the victims born with it. It cannot be cured like a broken leg, or a chest infection. It is there for keeps and it is a matter of who survives the longest [Neil or us]. Jane and I believe for several years that there are more FAS people wandering around the streets and jails than could ever be imagined. Jane can walk down the street and can recognise these children. Their behaviour and facial features in a large number of cases are indications of FAS.

Jane and I met for lunch and Neil rang to say he would like to meet us, which he did. Sitting across the table from him, the mother and the grandmother had the same thoughts. This was not Neil the FAS victim, this was Neil the Security Guard. Thank you God.

CHAPTER FOUR

The Essence of Medical Anthropology

During my research journey within New Zealand, I found many people wanted to know what medical anthropology was and what exactly we did as medical anthropologists.

Historically anthropology as a discipline has used the methodology of participant observation to gather information on often newly discovered populations. However it is noted by John Gledhill (1994) that in the 1890's the first British Association funded ethnographic survey was carried out on Irish and English communities. The purpose was to investigate the possible ramifications and implications politically and socially that could be created by mass urbanisation and industrialisation. This type of anthropological enquiry looking within one's own ethnic group and focusing on issues that affected the individuals as a group, was to be discouraged by the Edwardian government.

Anthropological methodology more often than not was put into motion for the purpose of understanding and documenting 'exotic' cultures in little known geographical areas. However as time and globalisation on a world-wide scale have come to pass, so have the discoveries of unknown 'exotic' cultural groups within our urbanised Western world. To anthropologists culture is seen as a fluid entity, one that changes in time adapting to suit the changing environment. So too is the discipline of anthropology. In the twenty-first century many anthropologists are again focusing enquiry on groups of individuals within our own cultures and societies.

This transition has encouraged the growth and expansion of anthropology into new sub-disciplines, diverse and yet individually specialised. Medical anthropology is one such sub-discipline focusing on specific health issues, such as my research into Fetal Alcohol Spectrum Disorder (FASD). As a social scientist it is important to be able to understand the wider implications, not just the medical diagnosis itself, but the daily difficulties this disability produces.

Since the 1950's with the emergence of the anthropology of health, medical anthropology as a sub-discipline of anthropology has had many different theoretical perspectives presented and debated. This in turn has allowed this field of anthropology to extend its boundaries in both focus and theory. Medical anthropology has from the beginning created its theoretical approaches from anthropological, social and biological scientific theories (Baer, Singer and Susser 1997). Different perspectives within medical anthropology have resulted in various critiques of medical anthropological theories. Such critiques, are according to Thomas Maretzki (1994:1585), a 'necessary foundation of all scientific and academic efforts'.

When examining the debate between Critical and Applied anthropologists, the critique by those practising critical medical anthropology involves applied medical anthropology within the biomedical context. Work carried out by applied medical anthropologists can often be seen by critical anthropologists as supporting the physician's power over the individual by working within the system. Guillermo Bonfil-Batalla (1996) suggests that applied medical anthropology merely addresses problems in a way that maintains the

status quo ensuring everything remains the same. Whilst on the subject of medical status quo, Hunt and Barker (2001) identify Wagner (1997) as suggesting that there is not the expectation that every social scientist including anthropologists will necessarily focus on challenging the status quo, but it is expected that they step outside their present cultural ideologies and boundaries.

Equally, applied medical anthropologists argue that critical medical anthropology has a huge problem with biomedicine⁴⁹. This problem with biomedicine is considered by applied anthropologists unfounded, suggesting that it does nothing to enhance the relationship between practitioners and patients. Johnson and Sargent (1990) believe that critical anthropologists see the doctor-patient relationship as one of unequal power with the patient holding inferior power, where the health care systems are viewed as part of an oppressive capitalist system. Csordas (1988) suggests that critical anthropologists utilise the concept of 'biomedical hegemony' identifying biomedicine as a type of ruling class ideology. Baer (1997) argues that this is simply an incorrect assumption, stating that critical anthropology does not regard physicians as a ruling class nor that critical anthropology only acknowledges the influences of a political-economic nature. He identifies work carried out by Navarro (1976) as one of the many examples of critical anthropology that suggest that biomedical professional power is not absolute instead it is of a delegated nature. Baer (1997) suggest that critical perspective views human health as a bi-product of 'dialectical interactions of natural and socio-cultural forces' that creates an environment that affects human health.

Scholars such as Joralemon (1999) identify the positive role both theoretical approaches have. He suggests that work carried out by applied medical anthropologists has been responsible for creating a greater cultural understanding for medical and technical experts. Critical anthropologists on the other hand are viewed as social activists often operating in an advocacy capacity, attempting to bring about change on a more general level. Baer et al (1997:33) view critical anthropologists as taking economic and political circumstances of disease and health into account, reaching people whose voices are not generally heard, identifying needs and requirements whilst at the same time striving to,

... contribute to the larger effort to create a new health system that will 'serve the people.' This system will not promote the narrow interests of a small privileged sector of society. Its creation requires a radical transformation of existing economic relationships.

However, Maretzki (1994) criticises some of the scholarly critiques that have been produced as placing too much energy in 'debunking' different approaches within medical anthropology. Others such as Donald Joralemon (1999) whilst discussing the problems of critiques between applied and critical medical anthropology agree.

I see little to be gained by the internecine conflicts sparked by medical anthropologists accusing each other of being either too radical or not radical enough. There are many ways to engage biomedicine and its practitioners in a dialogue informed by anthropologists' insights. (Joralemon 1999:98)

Johnson and Sargent (1990) identify Nancy Scheper-Hughes and Margaret Lock as offering a paradigm within medical anthropology called critical-interpretative. This perspective is what could be described as a middle road approach, which draws on both

⁴⁹ Term used to describe the dominant biological western medical system- Lowe (1999) terms as 'contemporary high-tech allopathy'

existing perspectives. The approach involves investigation into the actual lived experience of illness as well as broader socio-economical implications.

Thus, medical anthropology is no longer only the study of alternative medical systems; biomedicine is itself subject to anthropological analysis as a product of particular historical and cultural processes... Much as these authors insist that health and healing cannot be understood without attention to individual experience, cultural meanings, and the structure of society, Howard F. Stein urges attention to unconscious processes as they affect health beliefs and practices – and the anthropologist who study them. (Johnson, Sargent 1990:2-3)

Lowe (1999) supports the trend of a ‘third way’ and describes it as

An anthropology which truly moves between micro and macro levels of analysis, which combines political-economic analyses with “thick” description and relates the experience and expression of suffering to the structural conditions which cause it. (Lowe 1999:991)

There may be shortcomings surrounding differing theoretical approaches within medical anthropology as with any other human science discipline. But it is important to note that no one approach appears to claim superiority or exclusivity. Each perspective adds to our knowledge base, a multitude of voices rather than one. Thomas Johnson (1995:110) identifies ‘enhancing democratisation and eliminating mystification’, as a common ideal all genres of medical anthropology share.

Critical as well as applied medical anthropologists strive in their work towards humanitarian ends, so that the system can work better for those involved within it. In essence the medical anthropologist attempts to perform a dual role – often one of change agent, the other as an advocate for those whose voices are seldom heard. Action anthropology was presented to the anthropological arena by Sol Tax, in the form of the Fox Project, which was carried out from 1948 to 1959. Tax is said to have attempted to bring together academic and applied anthropology to create a practice termed as action

anthropology in his Fox Project and is considered by Foley (1999) to have resulted in suggestions that make anthropology (particularly academic anthropology) more relevant politically and socially. Action anthropology by today's standards appears to be an integral part of much anthropological enquiry as well as other social science perspectives and is often referred to as action research. This practice brokers an ideology that knowledge is acquired directly through action and that action will only come about through knowledge. Action research or action anthropology is a practice that requires large amounts of community or organisational participation in problem solving or, as my research has, involving large numbers of both community members as well as professionals, where information I have obtained surrounding FASD from both professional and community members has been disseminated by way of seminars. This type of action anthropology evaluated by audience feedback has I believe created behaviour modification in regard to attitudes surrounding alcohol consumption during pregnancy, and towards the FASD individuals and their caregivers among both professionals and community members. This type of anthropology allows for the sharing of information, which facilitates informed choices, a mode of enquiry that acknowledges the expertise gained by experiential knowing. Knowledge is the key to empowerment.

It is my hope that my thesis and work in this area will enhance and assist this process. Caregivers of those directly affected by prenatal exposure to alcohol are a collective whose individual voices as experts on the broader implications associated with FASD are rarely listened to or acknowledged as having merit by many professionals. These

individuals offer insight and experience that is rich in information. When looked at as a collective, these voices identify common themes and issues experienced by many with children suffering Fetal Alcohol Spectrum Disorder.

Nichter suggests that two important factors need to be addressed when embarking on medical anthropological research as the

... need to demonstrate the uniqueness and vitality of their [medical anthropologist] own multidimensional perspective based upon contextual problem solving. They [medical anthropologists] will need to play an active role in setting agendas, not just responding to the job market. (Nichter cited Hill 1991:9)

The emergence and development of medical anthropology in no way belittles or removes the importance of medical approaches. Instead the information gathered through medical anthropology is collaborative by nature - presenting another viewpoint, extending our knowledge base concerning a particular health issue, adding another piece of the jigsaw to obtain the whole picture. Applied critical medical anthropology, because of its interdisciplinary nature, obtains information from clinical medicine as well as the social sciences. Research carried out by medical anthropologists is described by Johnson and Sargent (1990) as the type that has the ability to lead directly to intervention.

When dealing with health care and associated services, Anderson (1996) views medical anthropology as a major contributor in the process of humanizing health services.

The medical approach is not wrong. Neither is that of medical anthropology. However, each in its way is incomplete. Physicians tend to look for causes and connections at lower levels, ranging across physics, biochemistry, anatomy and

physiology. Anthropologists are inclined to explore higher levels extending from psychology, sociology and political economy to the humanities. (Anderson 1996:41)

The importance and practical use of information gathered by medical anthropologists regardless of theoretical approach is not in dispute - at least not within anthropological circles. This, I am sure, is due in part to the universal anthropological method of data gathering. Regardless of theoretical approaches all anthropological data gathering is basically carried out in the same way. Pertti and Gretel Pelto suggest that for the most part anthropological methods are 'essentially theory-less' as data collection methods, consisting of direct observation in the form of a mixture of structured and unstructured interviews. They suggest that the investigators' theoretical approach will shape the

specific questions asked, and specific targets for observation.... it is in the language of theoretical discourse that anthropologists differ markedly, even when discussing basically similar data. (cited Johnson, Sergent 1990:270)

Medical anthropologists within America have been noted by Joralemon (1999) as providing their expertise and research skills not only in international health projects but in localised projects, unlike New Zealand, where the practise of medical anthropology is a relatively new endeavour. Joralemon (1999:92) states that medical anthropologists are

... most often called on to apply ethnographic knowledge to the assessment of health needs, the planning of culturally acceptable interventions, and the resolution of communication difficulties between health workers and patients.

On the subject of health care delivery and services Perry (1996) argues that generally consumers of health care tend not to have any direct input into the development of needed health care provisions. Rather than the consumers themselves identifying individual needs and requirements, care managers and health service providers are seen

as representative of the consumer's needs. It would seem that in order to create and develop effective health care or any other services that are focused on any illness or disability (particularly those who are not confined to a hospital or clinic) one must obtain an understanding of the insider's perspective - the perspective of the person living each day affected either directly or indirectly by that illness or disability. This information is exactly the type that is gathered through observations, case studies, individual and group interviews carried out under the medical anthropological methodology.

The insider's perspective is described by Perry (1994) as being concerned with the actual lived experience and what that means to an individual and how they interact with their environment, allowing the social constructions and common themes of their reality to be identified.

When discussing the "insiders" perspective, in contrast, is concerned with the meanings of the illness as described by people with the illness, rather than the social roles they may occupy at certain periods in their life, as indicated by terms like 'patients', 'sufferers' or 'consumers'... Thus two strands of research have evolved; one concentrating on specific chronic disorders...and the different impact they have on individuals' lives, the other focusing on chronic disorders in general and the problems they typically cause (e.g. disability and handicap). In both cases, the identification of common themes or problems among people with chronic illness is based on making comparisons between individual life-stories. (Perry 1994:49)

The types of narratives collected by medical anthropologists are seen by Somers (1994) as an ontological⁵⁰ condition of social life and are all part of the reconstruction of the notion of self. These narratives are a way of communicating in a meaningful way the realities of what happens to and around the individual. The information obtained through

these narratives has practical applications; as Mark Nichter (cited Hill 1991) suggests, one of the noticeable end results of previous medical anthropology has been in the area of stigma and alienation. The anthropologists and their findings have had an impact particularly in the role of reducing the stigma and alienation individuals may receive from others within and outside their communities due to an illness or disability.

In the case of this research, alcohol is the common denominator - without it we would **not** have any incidence of Fetal Alcohol Spectrum Disorder within our society. New Zealanders' attitudes, knowledge and protocols surrounding alcohol and its consumption during pregnancy are often minimal and in some circumstances non-existent. To look at the subject of prenatal exposure to alcohol as an applied critical medical anthropologist, one must investigate as Baer et al (1997) suggest the micro-macro connections that surround the focus of the study.

From the historical introduction of alcohol and its proliferation within New Zealand by early settlers to the current problem of alcohol usage during pregnancy, there does seem to be a strong macro-micro relationship, a relationship that is associated with very strong political/economic links past and present. On one hand, alcohol has historically and currently provided much needed revenue for Government's coffers, a situation wherein consumption equals much needed monetary gain. But on the other side, there is the risk of more cases of fetal alcohol spectrum disorder occurring within New Zealand society if alcohol consumption happens during pregnancy.

⁵⁰ Ontology – The study or theory of being or existence (Seymour-Smith:211)

This problem is costly to every society affected, one that requires substantial financial support which should, one would think, come from the pool of Government revenue obtained from the sale and production of liquor. However, this does not seem to occur. Instead the very people in power who traditionally have reaped the largest financial rewards from the consumption of liquor in New Zealand appear to downplay the seriousness of this problem. To date too little has been done to educate the public and reduce the possible incidence rate. Gone is the day when we as a nation can plead ignorance of this disability, or pretend that it cannot and does not occur in this population in light of the volumes of international research available. It is time for medical anthropologists to investigate this phenomenon, by listening to the experiences of those who know first hand what their journey for diagnosis and access to appropriate support has been like.

CHAPTER FIVE

The Anthropological Journey

In anthropology the term culture is a crucial component of our discipline. Roger Keesing (1981:68) suggests that the word culture describes a 'learned, accumulated experience' and /or 'socially transmitted patterns of behaviour characteristic of a particular social group'.

In practical terms the field methodology used in my research involved qualitative, action research in the form of nation wide educational seminars and advocacy. Qualitative research is both descriptive and interpretive by nature and involves the use of actual participant voice text and language. Eisner (1991) encourages the use of qualitative research particularly in educational projects and believes that interpretive research holds two meanings. One is what the experience held for those being studied, the other, the ability to explain why something is or has taken place. He rightly suggests that qualitative research is the ability to 'persuade by reason' rather than 'significant differences' and adds

In qualitative research there is no statistical test of significance to determine if results 'count', in the end what counts is a matter of judgement. (Eisner 1991:39)

Initially I intended to interview several adult FAS sufferers, but when dealing with three of my participants 'adult children', I found how difficult it was to carry out in depth conversations using a tape recorder to record our conversation, and how difficult it was to get anything more than an 'I don't know' answer to my questions. I observed that all

three of my informants found the interview process too difficult to deal with and I felt that pursuing this type of enquiry could have been detrimental to these informants. Consequently, I chose not to include the actual FASD individuals as my informants, and instead include persons that were caregivers. Foster, birth or adoptive parents, from different backgrounds - geographical, socio-economical and ethnicities - became my participants and informants. Experiences involving and pertaining to their children became the subject of my research. These individuals had a strong collective commonality of shared experiences relating to the disability of fetal alcohol spectrum disorder (FASD). All participants were or had been caring for an individual suffering FASD on a daily basis, experiencing daily routines and situations involving their affected children.

When I first decided to embark on my research, one of the most difficult problems was how to access participants: those who currently or in the past been a primary caregiver of a person diagnosed as suffering FASD. The New Zealand official information act and ethical principles surrounding patient/doctor confidentiality made it impossible for me to contact medical practitioners to find participants. However, this task in some ways proved easier than I had imagined. Networking with New Zealand agencies, friends and families that had or were dealing with children diagnosed as having FAS proved to be a little like a phone tree or what is referred to as snowball sampling. I learned that many knew someone who was or had been a caregiver for an individual suffering the effects of prenatal exposure to alcohol throughout New Zealand.

This was a slow procedure which was sped up with the support from the three New Zealand organisations, The Fetal Alcohol New Zealand Trust, a national trust, originally financially supported and set up by the New Zealand Alcohol Liquor Advisory Council four years ago, which now, at the time of writing this thesis, has closed its doors due to lack of funding. The other two trusts were the Fetal Alcohol Advocacy Southland, a voluntarily run trust originally set up as a support group by families with members affected by prenatal exposure to alcohol in the South Island of New Zealand and the Fetal Alcohol Support Trust Hamilton. All of these organizations ran advertisements in their newsletters calling for participants for my study from their members and subscribers. Those who answered my advertisement became what is known as a self-selecting sample. Prior to the commencement of my data collection I had forty-three Zealand participants who collectively had 38 medically diagnosed FAS children and adults. These participants all expressed a wish to be part of my study. Each felt that they had a contribution to make and experiences to share, both positive and negative. It was our hope that by sharing their experiences, others could begin to understand the wider implications of Fetal Alcohol.

My participants' children were born in New Zealand and covered a range of ages. For this study, I categorised statistical data that came from the interviews pertaining to each child's profile into four separate age groups. Eight children were under five years of age, sixteen were six to eleven years, six were between twelve and seventeen years and eight were eighteen years and over.

Through my established network, and in many cases through acting as a professional advocate for family members in different parts of New Zealand, a special rapport blossomed into the many friendships I made on my thesis journey. This allowed me a personal privilege of being very much a participant observer over the last 5 years in the life of a young New Zealand girl diagnosed as suffering fetal alcohol syndrome and her family. I met this particular family when I was presenting a workshop/seminar on behalf of ALAC.

Several days prior to the seminar, I was contacted via phone and asked if a meeting could take place between us while I was in the area. My future participant had heard about my research and interest in FASD through mutual friends and wanted to meet me personally. Arrangements which included the offer of accommodation for my overnight stay were made and ironically the only landmark I knew of in this area for a meeting place was a local tavern. Here we met and talked the afternoon away. I left feeling as though I had known this person for years. As time progressed, I became both a close friend and an advocate for the family.

On reflection I realise that this special relationship gave me a window from which I came to observe agency interaction (private and state) with this family. I experienced firsthand the often daily trials, humour and hard work involved with active care-giving for a child suffering FASD. Equally in this case study I was able to observe the difficulties and unintentional barriers faced by caregivers when dealing with a spectrum of social and health agencies. I also observed the marginalization of the caregivers'

expertise by professionals working with their child, that in some cases involved a total denial that FASD as a disability existed.

During my research I became involved with the New Zealand Fetal Alcohol Trust. During my time with the trust and after I left the board, I have involved myself in advocating on behalf of caregivers of diagnosed children and those suspecting their child has FASD. Many of those caregivers were experiencing serious difficulties navigating agency protocols in relation to juvenile justice, social and health services and particularly in the area of diagnosis. I attended parent and caregiver monthly support meetings, delivered educational seminars for both community and professional groups throughout New Zealand (Appendices I, II, III), worked with parents (Appendix IV) and ended up spending almost a year as a trustee for this organization. During my time there I worked on posters which were never produced due to a large reduction of funding experienced by the Trust (Appendix V). However it is hoped that these or others will be printed and made visible in places such as women's bathrooms in licensed premises (A5 size) on the back of the doors inside the cubicles. These posters were adapted from successful campaigns carried out in Canada with the language, among other things altered to suit the New Zealand multicultural society.

I was extremely fortunate with my studies as I was awarded a three year postgraduate merit scholarship by Massey University and a four thousand dollar grant from the New Zealand Federation of University Women. These were a huge help during my first four years of study. But the financial cost of my research and the length of study was far in

excess of this grant and my ever increasing student loan weekly payments made it extremely difficult to make ends meet. Without my mother's financial help and the goodwill and support I received from my friends, participants and community-minded people I met on my journey, I would have been unable to complete this thesis.

The first leg of my research journey was to get to Vancouver B.C in Canada to talk to agency people involved in the care and management of individuals affected by prenatal exposure to alcohol. This was enabled by a one-off grant from the New Zealand Alcohol Liquor Advisory Council for a return airfare to attend the 1999 Canadian Fetal Alcohol Conference in Calgary, Canada.

After the conference, which held a wealth of shared new information, I broke my return flight to New Zealand by having a stop over in Vancouver. On arrival I booked myself into the cheapest centrally located backpackers I could find on a major bus route. Over the next few months I arranged and carried out unstructured interviews with Canadian mainstream agencies - social, justice, health, and educational - to discuss provisions made within their agencies for this specific client group. This was an important part of my research, to understand how Canadian mainstream agencies have adapted existing programmes to suit these affected individuals. My knowledge base and accompanying literature collection surrounding Fetal Alcohol Spectrum grew considerably thanks to the resources and information supplied by these Vancouver agency workers, particularly the Vancouver Office of Special Needs Adoptive Parents.

What astounded me was the acknowledgment of just how expensive and extensive this problem was for their society. Canada has carried out some amazing FAS initiatives over the last few years, including,

- ◆ Extensive public education - on both a national and local scale
- ◆ Agreements with bartenders – bartenders will not be liable for court action for refusing to serve or sell alcohol to a pregnant woman. It is up to the individual bartender.
- ◆ Summer youth camps for youths affected by FAS.
- ◆ Safe houses – safe environments for victims suffering FAS.
- ◆ Twenty-two pregnancy outreach programmes developed – aimed at prevention and intervention
- ◆ Government warning signs - mandatory at alcohol points of sale.
- ◆ Provincial strategic plans on how to deal with the logistics of co-ordinating numerous public and private initiatives throughout British Columbia. Appointing official Provincial FAS co-ordinators.
- ◆ Additions to the judges’ handbook – involves special written instructions and guidelines for consideration by judges when dealing with FASD defendants.
- ◆ Telediagnostic services – Enabling diagnosis to be carried out in remote areas or areas that are not in close geographical proximity to existing diagnostic clinics.
- ◆ Changes to procedures and policies within governmental contractors and agencies – simple guidelines and protocols adapted to suit the FASD clients. In some cases as simple as mandatory education around FASD for potential caregivers including respite persons.
- ◆ School education programmes for affected children - resourced via provincially funded special education disability resources.
- ◆ Special sheltered workshops for those FAS persons suffering serious cognitive impairment.
- ◆ 24 hr supervision/respite organisations specialising in caring for FAS individuals.
- ◆ Government research funding specifically earmarked for FAS research.

What was interesting was that existing guideline changes within agencies had been carried out, had evolved from dialogue and consultation with FASD caregivers and other experts within individual agencies working with FASD clients. Within these agency changes, caregivers' voices were being heard and acknowledged as experts on the broader implications of FAS. The most valuable piece of information I obtained from my Canadian participants was to 'listen to those caregivers, they know the system and its inadequacy for dealing with FAS clients, most have had to experience and fight regulations and guidelines that do not take in to account the issues connected with FAS.' These professionals all supported my anthropological methods, many citing anthropological enquiry as an appropriate way to obtain 'reality' research information.

On my arrival back to New Zealand the major difficulty was the financial burden that accompanied my proposed research within New Zealand. I applied one last time at the beginning of 2000 for funding in an application outlining my anthropological research. Once again my application to ALAC (one of the few organizations that offered a postgraduate scholarship for the field of alcohol research) was unsuccessful.

My application was made after I had been funded the airfare to attend the Canadian conference, and after I attended by invitation from this same organization a meeting held in Wellington. This meeting had consisted of other professionals, mostly medical, from around New Zealand, who were currently researching in the area of prenatal exposure to alcohol in New Zealand. This so called 'Steering Committee' met once, discussed research past and present, and those present were informed that this committee would

meet sometime in the near future to discuss and share further information. Interestingly the convenor who arranged this 'Steering Committee' was extremely proactive and supportive of my research, but a senior member of the council itself who sat in on this meeting expressed his views on the subject. During this meeting he spent a fair amount of time reading his newspaper whilst sitting at the end of the board room table. This person stated at the end of the day-long meeting, that until we had New Zealand prevalence statistics there would be no funding money available. To my knowledge there has never been another meeting held nor has there been any push from the ALAC council itself to set up or recommend to the Ministry of Health a database of known diagnosed New Zealand cases to even attempt to obtain prevalence rates.

My rejection letter (written by the same senior council member) cited numerous reasons why my research would not be funded, some of which I believe were simply invalid due mostly to the writer's lack of knowledge and perhaps to some degree his personal attitudes.

We have only recently become aware of its existence; the ability to diagnose the condition in New Zealand is probably no more than six to eight years old... However, most diagnoses of these conditions are retrospective, and indeed are often made when a person is in their adulthood. Many of your prospective informants will have received a diagnosis only recently, although the problems have been life-long. This poses fundamental problems in the way you have set out the study, the information you will provide participants, the selection of participants, and so on.

At the time of data collection all my participant's children, with the exception of three diagnosed adults, were children ranging widely in age. My oldest participant had been diagnosed as a four year old in 1983 in Auckland by paediatricians at the Wilson Home.

Continued case management and support was carried out by a psychologist, the late Dr Mike Edwards. To the parents of this child at that time, he became what they referred to as a 'lifeline' and a 'sanity saver', one that was available any time of day to help the family cope and understand the behaviour and needs of their small adopted Fetal Alcohol Syndrome child. The evidence of this 1983 formal diagnosis, clearly illustrates that diagnosing for this disability has been happening within New Zealand far in excess of six to eight years.

One of the other paragraphs that dismissed my caregivers surrounded their unsuitability as participants.

Further more, by inviting only those who have received a diagnosis of FAS/FAE or alcohol related neurological damage (ARND), or those who have cared for such a person and who are only presumably associated with the two active groups [the Fetal Alcohol New Zealand Trust [FANZ] and the Southland Group] you have potentially biased your sample in an unhelpful way. The issue is perhaps more about the experiences of people who have lived through or cared for behavioural problems. Contact with an advocacy group or support group is not a compelling basis for inducting participants into the type of research you outline in the application.

The suggestion that the only way I had or could obtain participants was from the one source, established trusts rather than the possibility of a private network, is and was an erroneous assumption. What was a more major concern was the implication that these people are not considered experts and would have little or no contribution to make to our knowledge base on the subject, and were not suitable as participants because of their involvement with established support trusts. One might surmise that the author of this letter equates fetal alcohol spectrum disorder with alcoholic women. This attitude

appears rather conflicting considering ALAC itself set up the FANZ Trust as a national advocacy and resource base. My participants came from all walks of New Zealand life with varying educational qualifications and social economic status and none were alcoholics. The commonalities were a passion to raise awareness to lessen the incidence of FASD and a commitment to help their children and others achieve their full potential. All my participants hoped that their voices and stories will raise awareness and understanding of this disability.

In regard to the trusts themselves as organisations, the folk involved in the actual running and working of these voluntary trusts came from of a mixture of professional backgrounds. Not all are parents or caregivers of affected children, but similar to my participants, all have become experts in the area of fetal alcohol. Some trustees were experienced in FASD through personal situations such as having FASD family members, others through their capacity as professionals working with FASD clients. All have a passion to reduce the incidence of FAS in New Zealand through education and awareness, and to help families navigate the social minefield at both community and governmental levels. My personal knowledge of the people operating behind the scenes of these organizations is that they are an extremely knowledgeable, dedicated, caring group of people.

The actual diagnosis of FASD appears to be in contention with the letter writer as 'the issue is perhaps more about the experiences of people who have lived through or cared for behavioural problems'. The author of the letter appeared unable to grasp the broader

issues or to understand that behavioural problems are only one part of this disability, but in no way the only issue. If I was to interview as suggested, any caregivers with any child exhibiting behavioural problems rather than those with a medical diagnosis of FASD, this would have ensured the present status quo, defeating the purpose of my thesis and doing nothing to raise the awareness and understanding of FASD within New Zealand. Prenatal exposure to alcohol is considered by international experts to be one of the leading causes of mental retardation within American populations and possibly the rest of the western world (Burgess & Streissguth 1992 Abel & Sokol 1986). I find it difficult to understand why some players in Government advisory positions presume that the New Zealand population is unlike the rest of the western world and as a society immune to this disability.

Finally, it had been decided that it would be impossible for me to carry out my research on my 'robust budget' [wording I took as being sarcastic due to the small amount asked for]. My projected budget was considered too small to carry out this research. My projected budget was considered too small to carry out this research (a budget that changed from being an extremely modest shoestring version applied for, to an almost non-existent one). My eventual budget at times had me eating three meals of instant noodles per day, one week being stranded regardless of where I was until my weekly \$140.00 student loan payment appeared in my bank account. This loan payment enabled me to put petrol in my vehicle, travel to my next geographical location and interview while paying for my week's camping/noodle fees. Perhaps in retrospect it was meant to be a difficult road, and the fact that I was living in a van perhaps made me more

approachable, easier to establish a rapport with when personally meeting my participants. In many cases it was decided by my participants that I definitely was in need of a good wholesome home-cooked meal; a situation that I am eternally grateful for, in respect to my health and as a way of getting to know my participants on a personal level in their homes, allowing me to observe and engage in family interaction.

The ALAC Council member's letter also challenged the expertise and experiences of my participants and the methodology of Social Anthropology -

It is also unclear how the experiences of individuals will translate into 'best practice' guidelines for agencies; or if in fact, a medical/social anthropological approach is the most appropriate framework.

This revealed an inability to see any significant input that these caregivers could possibly have in the development of guidelines from which 'best practice' protocols and procedures can be identified in regard to fetal alcohol clients. This does not surprise me; after all, to many professionals, these parents are not trained professionals, therefore hold no acknowledged expertise. This is a particularly sad situation considering that within agencies little is known about how agencies' existing policies and practice either do or do not work for this client base. If you are having to navigate the system for your child, you very quickly identify barriers and difficulties with some existing agency protocols. Once again the expertise and experiences of caregivers of those affected by Fetal Alcohol Disorder is being dismissed as non-informative or of no particular value. To my mind these people are the real experts, they live with this disability and its consequences on a day to day basis. Their experiences, both positive and negative, are very real. There is life after diagnosis!

The failure to reconvene the 'steering committee' at a later date, left me in doubt as to the attitude of the actual council rather than the organization itself regarding the importance and possible significance and impact fetal alcohol has on New Zealand society. Amazingly, there have been some very pro-active initiatives over the last five years on the subject of Fetal Alcohol, including Trust support both professional and financial, posters, educational seminars, conferences and most importantly the funding of a successful documentary titled 'Drinking For Two' (for which I was a consultant and appeared briefly in this documentary). Advertisements highlighting FASD have screened on national television under the guidance of Tony McEwan and Philip Parkinson, members of the ALAC organization.

This advertisement unlike the New Zealand 'drinking for two' documentary content and message, was of a softy, softy nature. The acronyms FAS, FAE or FASD were never mentioned. The advertisement is simplistic and short, showing a foetus floating in amniotic fluid, accompanied by heartbeat and muffled heavy music (indicating a party). A little voice (that is meant to be the foetus talking) identifies the lifetime disabilities associated with prenatal exposure to alcohol while not actually naming them as 'suffering a hangover for the rest of your life'. When this advertisement first aired on New Zealand screens, I had a group of young mothers from the Hokianga area sit down and watch it. Their comments backed up the Canadian evaluations. One expectant mother went as far as to laugh and suggest that at least her baby was in training and would be able to deal with a hangover when he was older. For the target New Zealand

audience, an audience that has been identified as following high risk binge drinking patterns, a hangover for many is part of life - hardly a sensible analogy to use. This advertisement appeared in content and imagery to be the same as one used in the first Canadian public awareness campaigns. It is annoying that whoever chose this advertisement as being appropriate for New Zealand audiences took no account of the Canadian evaluations and critiques of that particular public campaign, which have been available for many years prior to New Zealand airing it on national television. These evaluations identified the format of the advertisement as a failure, consequently cutting short its allotted programme time and replacing with a more direct format.

The whole funding experience and the encouragement from many of my participants made me even more determined to carry out my research. I refused to have my proposed research shut down due to lack of funding before I had completed the most important section of the thesis - the New Zealand fieldwork. The next two major problems on my agenda had to do with interviewing. How was I going to interview participants? Obtaining voluntary participants was not the issue; in fact, I had more offers to take part in my study than I could have realistically interviewed given my situation and time frame. How on earth was I going to be able to physically attend these interviews that involved travelling the length and breadth of New Zealand ? How was I going to be able to afford accommodation of any description with a budget of \$140.00 per week?

The alternative was to carry out telephone interviews, but this appeared to me to be a modern form of 'armchair anthropology'. Telephones are generally an impersonal form

of communication, especially if you have never had the pleasure of meeting your participants. I felt that it was imperative that I meet and interview my participants on their home ground, as they needed to be in a space that they were comfortable and familiar with, that would be conducive to free-flowing conversation. Personal introductions were the only way I could assess my prospective participants' validity as participants. For example, I used this opportunity to make sure the informant did know the FASD individual well or that to the best of my knowledge my informant was not in a confused state or suffering serious mental health problems.

The answer appeared one day on the side of a road in the form of a red 1986, L300 Mitsubishi van with a 'for sale, as is, where is' (meaning no warrant of fitness and no registration) sign in the window. This vehicle had been converted rather roughly into a campervan with a white pop up roof (which gave the vehicle a comical mushroom look about the vehicle when it was up), a gas stove, storage space and a badly made wooden seat that pulled out to make a bed. I quickly learned, after the novelty had worn off that the bed was both uncomfortable with numerous design and workmanship faults (one being that once the bed was out it took up all available room in the van making access to cupboards and drawers impossible). The bed had been built for a much shorter person than myself - something that I thought wouldn't be an issue at the time of purchase, but in hindsight was a discomfort I had not counted on experiencing.

After a little negotiation and an agreed price of \$2,000.00, accompanied with a quote for some seriously major rust repairs for seriously little money from a local welder (who

was very supportive of my thesis), I purchased the vehicle. By the time my vehicle was warranted and registered I had planned and organised my travel arrangements to the best of my ability and had pre-booked a passage on the inter-island ferry (due solely to my mother's generosity). Prior to setting off on my field research, all my voluntary participants had received a consent form and an information sheet outlining the research itself, the length of time the interviews (approximately two hours each) would take and their legal rights as a participant in my study.

I had telephoned or communicated via e-mail with each participant numerous times over the many months it had taken to gather and organise my participants geographically for the purpose of organising venues and dates for the two interviews. This initial contact gave me the opportunity to 'break the ice' and get to know my participants at least in part in an effort to understand more fully their individual situations. The actual dates had to contain some flexibility as I was reliant on both finances as well as the reliability of my new home on wheels. The arrangements made with my participants were that I would telephone each participant the week before I was due in their geographical region to confirm our tentative appointment times and venues.

So my journey started and I slowly drove out of Auckland hoping the engine could and would make the journey, accompanied by my protector and mini burglar alarm in the form of a small 8 year old British Staffy, called Buggs, who might I add was absolutely useless as a watchdog but a great bug catcher and good company.

My interviews were carried out in most cases over a two day period. The interviews were unstructured and took about two hours each, depending on the size of the group (generally family members) participating. I used the first interview to obtain a general overview and basic demographic and personal information of both the caregivers and in particular the FAS individual. After the interview I would identify common issues and experiences contained in that first interview and use the second interview to investigate and explore these further. On my return to Auckland I was faced with having to transcribe my very numerous tapes. This was a daunting task, extremely time consuming and frustrating due to my slow typing abilities. As the transcribing progressed this process gave me the opportunity to obtain and collate statistical data in regard to a basic profile of each of FASD individual, as common behaviour experiences became very apparent. Personal information surrounding the FASD individuals is presented in graph form in the chapters that follow.

It must be noted that in regard to the statistics used in this thesis, from a scientific view, these results are not to be used to make generalisations pertaining to this population due to my lack of scientific sampling processes as a means to obtain interviews. Similarly the number of persons diagnosed with FASD in this study held in each age category are too few to be representative of all FASD persons. However I do feel that they need consideration in future research, whether social or bio-medical. For example, statistical information I obtained pertaining to the realisation or threats of suicide could have an impact on any national youth suicide projects being undertaken. This is a population of

individuals that my New Zealand research, as well as international research by Streissguth et al (1996), suggests could be a high risk group.

I believe that the medical anthropological methodology employed in this thesis was appropriate, in fact more appropriate than other enquiry methods, to begin to grasp the broader issues faced by families effected by FASD. Anthropological methods are tools that are not exclusively used by anthropologists, and in my case, as a social scientist, they allowed me to examine the social realities of those people directly and indirectly affected by prenatal exposure to alcohol. This methodology allows the participant to have a voice. These participant experiences translate into a wealth of first hand information, that needs to be acknowledged as expert information in relation to their experience. My participants collectively through personal experience have shared commonalities through living with FASD: by virtue of their shared experiences they constitute a social group whose experiences differ from the rest of society.

Researchers such as Heather Olsen et al (1993) report that the American occurrence of FASD yearly is five times higher than Spina Bifida and double the number of Down Syndrome births. These researchers have identified FASD as a preventable disability that is reaching serious population proportions within America. International observers are also surprised at the lack of interest and intervention happening in New Zealand. In 1998, I had the opportunity to discuss the FASD situation in New Zealand with a representative from Heineken International, a brewery that has vast financial brewery interests in New Zealand and is based in Holland. He considered maternal alcohol

consumption as a form of 'alcohol abuse' and could not believe the lack of public education and the low level of awareness he had observed whilst on business in this country. His knowledge of New Zealand drinking patterns added weight to his concerns, particularly in light of volumes of internationally recognised research available on the subject. My informant (as did several of my Canadian informants) regarded New Zealand as being 'well behind the eight ball' compared to all other western countries he had visited in his official capacity in the fight to prevent FASD.

CHAPTER SIX

The Macro-Micro Relationship & Political Modes of Operation

I have identified myself as working within an applied critical medical anthropologist's paradigm, with a commitment to action research. At a theoretical level Baer et al (1997:19) suggest that:

Medical anthropologists are interested in topics such as the evolution and ecology of disease, paleopathology, and social epidemiology; the political economy of health and disease; ethnomedicine and ethnopharmacology; medical pluralism; cultural psychiatry; the social organisation of health professionals, clinics, hospitals, national health systems and international health bureaucracies; human reproduction; and nutrition. At an applied level, medical anthropologists work in areas such as community medicine, public health, international health, medical and nursing education, transcultural nursing, health care delivery, mental health services, health program evaluation, health policy, health care reform, health activism and advocacy, biomedical ethics, research methods in applied medical anthropology, and efforts to control and eradicate a wide array of health related problems... In the past, medical anthropologists tended to focus on health problems at the local level and, less often at the national level... For critical medical anthropologists, the future has already arrived, in that they have for some time been urging making micro-macro connections – ones that link patient suffering to the global economy.

When attempting to understand macro-micro relationships, Immanuel Wallerstein's (1974) World Systems Theory is relevant, particularly in how it relates to New Zealand. Wallerstein sought to describe a universal, modern capitalist world system involving the political economy.

A world-system is a social system, one that has boundaries, structures, member groups, rules of legitimation, and coherence. Its life is made up of the conflicting forces which hold it together by tension, and tear it apart as each group seeks eternally to remould it to its advantage. It has the characteristics of an organism, in that it has a life span over which its characteristics change in some respects and remain stable in others. One can define its structures as, being at different times strong or weak in terms of the internal logic of its function. (Wallerstein 1974:347)

Wallerstein's paradigm is suggested by Seymour-Smith to be a social system created on an international division of labour, divided into zones.

This system creates 'core', 'periphery', and 'semi periphery', zones with differing participation in the overall economy, and with differing internal class economic organisation. (Seymour-Smith 1986:291)

Wallerstein's theory, as with all theory, has not escaped critique, and has been criticized as being flawed in that no provisions have been made to include internal influences and the individual. Marcus and Fisher (1986) suggest that the world-systems theory relies on detailed research of regions and historical periods, identifying this paradigm as a possible macro view of society and history. However they view this theory as a much-needed new paradigm, one that sought to explain the modern global economy – a way of explaining the effect of the macro system on the micro system. In New Zealand's case (the micro), the macro has historically been Great Britain, by virtue of the colonisation process that involved the establishment of permanent European settlements and sovereignty.

While this macro-micro connection process was happening in early European New Zealand history, along with it came a political mode of operation: accumulation and legitimisation. James O'Connor, using a Marxist paradigm, explains his theory of state modes of operation as follows:

...the state must try to maintain or create the conditions in which profitable capital accumulation is possible. However, the state also must try to maintain or create the conditions for social harmony... The state must involve itself in the accumulation process, but it must either mystify its policies by calling them something that they are not, or it must try to conceal them. (O'Connor 1973:6)

To legitimise its existence it is imperative that the state meet various demands from those who have suffered from this accumulation process, in order to ensure a collective loyalty by the masses. For the state to maintain its legitimacy it must juggle two basic functions of a capitalist state – social capital and social expense.

It could be suggested that this particular political mode of operation has been part of the British political scene for centuries and is not just an American political process. The raising of taxes on gin in the early 1700's could be seen as an example. Legitimation by the Government in the form of legislation is presented publicly as being for the good of the masses, while ensuring the continuation of the accumulation of favourable financial returns. Though it may reduce the amount consumed by the impoverished masses (as those with money would pay the extra and retain their drinking patterns and those who could not stop would continue), this tax increase insured that a possible decrease in consumption had little impact on revenue profits.

This legislation appears to have been brought about by those few with traditional political and economical power over the masses under the guise of being for the 'well-being' of the underclass rather than for productivity. One can imagine just how the behaviour associated with drunkenness, exacerbated by poverty and political powerlessness was affecting the fabric of British society. Those most affected were a minority whose birthright traditionally entitled them to hold all positions of power, kept in their traditional lavish lifestyles by the productivity of the masses.

The historical glimpse of early New Zealand I offer in this chapter plays an important role in this thesis. I believe that this historical information surrounding alcohol legislation contains clear examples of the political processes discussed by O'Connor and Wallerstein. In today's society I believe these same political processes exist but they are covertly disguised and more difficult to observe.

It is under this paradigm that I wish to present the regional history relating to alcohol of one small geographical area of New Zealand, the Southern Hokianga. My reasons for choosing this area were firstly, because this is the geographical area where alcohol was first introduced to the Maori people, who as a cultural group had no prior contact with fermented beverages until the first early arrivals of Europeans. Secondly, I have been and will always remain an insider/outsider in this small rural predominantly Maori community, a community that has been fully supportive and helpful in my current and previous academic research which previously focused on identifying significant others within this community and attitudes surrounding alcohol. Thirdly, due to the process by which alcohol was introduced and proliferated in early New Zealand, it seems a reasonable assumption to suggest that FASD may well affect large numbers of New Zealand's indigenous people both historically and currently. Maori have been identified through repeated New Zealand health and educational statistics as being a population in need. When I was obtaining participants for this research the ethnicity of the participant or their FASD affected child was not an issue, however out of thirty-eight participant's FASD children, twenty were identified as being of Maori descent.⁵¹

⁵¹ Total New Zealand population March 2001 = 3,586,731 Total Maori population = 526,281
Percentage of Maori in total population = approximately 14.67%

This chapter examines a clear example of the effect of the macro system (Britain) on the micro (Southern Hokianga peoples) politically, economically and socially via the introduction and control of alcohol. This information highlights the modes of operation manipulated by those in political power and which I believe are relevant historically and currently to alcohol use in New Zealand.

The inclusion of this historical case study is in an effort to explain more fully the place of alcohol in the lives of New Zealanders; a point of reference in understanding how our attitudes and social norms regarding the use of alcohol have to a degree been shaped by historical attitudes and legislative direction. The material used in this chapter originated from both written documentation (published and unpublished) from local oral accounts and from those living in this geographical area. As Evans-Prichard (1969:60) states:

To know a society's past gives one a deeper understanding of the nature of social life at the present time, for history is not merely a succession of changes but as others have said a growth. The past is contained in the present as the present is in the future.

The History of Alcohol in the Hokianga, 1795-1946

The Hokianga is a natural harbour nestled along the upper northern west coast of New Zealand that historically was controlled by two Maori sub-tribes of the Popoto people, Nga-Te-Tora and Ngahe-Ngahe. One of the oldest cemeteries in this area is named 'Hirane' and is situated in Motukiore alongside a salt water inlet flowing from the Hokianga inlet. The earliest headstones and local informants indicate that the first persons to be buried there were those people whose tribal affiliations were with the

Utakura area, as their bodies were brought down the inlet on canoes to their final resting place. The origins of those who are buried suggests that this cemetery was a boundary maker of significance. Strict protocol allows only those who have a right through marriage or land tenure to be laid to rest within their own geographical area.

Initially the majority of this area appears to have been under sub-tribal ownership rather than being used for residential purposes, particularly the area known as Motukiore (Rat Island). The Maori place name associated with this area was Te Horeke, which in later years was shortened to Horeke. The exact meaning of this name appears to be in dispute as Reed (1952) suggests that this name means 'to throw a spear'. Other sources compiled by the New Zealand Post Office (1967) states its meaning to be 'to skip a paddle'. However my informants whose ancestors held original land tenure in this area, insist that it had something to do with a spade. I feel that these local inhabitants are possibly more correct as early European visitors to this area have recorded observations on the complex, well organized, intensive agriculture carried out in pockets of land throughout the Hokianga area as they sailed up the harbour.

Early traders and whalers visited and bartered for provisions, usually in the form of muskets. It was recorded that in 1837 the purchase price of one ton of flax was one musket (Wright 1959). Flax gathering for the European market created ill health for those who were directed by their chiefs to be involved within the industry. These workers had to settle and live in damp marshy areas where flax thrived in order to supply raw flax for a growing European industrial demand. These were areas where

dwellings were not normally located due to the dampness and other associated problems, but the flax grew in abundance (Lee 1987).

One of the most important features of the globalisation process is the control of commerce and finance. This is evident when one looks at the introduction and adoption of the British monetary system. Evelyn Stokes (1953) identifies three different stages in the Maori-Pakeha economy. Between 1790 and 1840 money was of no use and a bartering system was established for trade. Local chiefs were in complete control of the natural resources and had the right to distribute them as they saw fit. The years 1830-1840 appear to be the beginning of a cash economy through trade demands and thirdly, a semi-commercial economy was set up to accommodate direct trade between Maori and the established European settlements in 1840-1850. This economic pathway slowly but steadily brought about huge changes. The traditional agricultural, hunting and gathering society was changing into a society made up of farmers, labourers, direct traders and ship owners in response to European demand for local goods and resources.

According to Harrison Wright (1956), initially liquor had little effect on the Maori population of New Zealand. He suggests that they were taught to acquire a taste for it over a period of years. Maori people had no traditionally fermented beverages prior to European introduction. When alcohol was first introduced to Maori society it was initially referred to as Waipiro (foul stinking water). Prior to 1820, early settlers arriving in the Bay of Islands observed that the local indigenous inhabitants simply did not like

the taste. In fact in 1820 correspondence from a European observer named Cruise is quoted as saying:

I never met a New Zealander that liked spirits, even those aboard the whalers...they may be induced to taste wine or grog but it is with reluctance. (cited Wright 1957:69)

It appears that in order for Maori to develop a taste for alcohol, there had to be a permanent European drinking population settled for several years. The Hokianga area over time became such a place, with the influence and encouragement from whalers, traders and sawyers who settled in this area. Settlement of Europeans was encouraged by many of the Maori chiefs, especially in the Hokianga area (Reed 1956).

During the early years of European settlement one powerful man within the Hokianga area, both influential and partial to alcohol was Thomas McDonnell. McDonnell operated under the protection of the Hokianga chiefs on the northern shores of the Hokianga, trading in flax and spars and by 1830 owned the Horeke ship yard (Laws 1945). During these times McDonnell and other Europeans such as trader Baron Te Thierry and White, the local Wesleyan missionary, who was to arrive in 1820 to operate and settle in this area. Motivation in part, appears to have been for self-interest and financial gain. Both wielded great influence over the local population and coincidentally at the same time amassed extensive private land ownership within the Hokianga.

The impact of the British on local Maori via trade once again was obvious, as the sale of muskets and powder created a serious imbalance of power amongst the different tribal groups. With the aid of European weaponry, Ngapuhi dominated all those they engaged

with in territorial warfare. A Maori proverb pertaining to the wars between the Ngapuhi and Waikato tribes and the influence European weapons had on the outcome is presented by Jane McRae (1987:73) stating : There is Hongi Hika [Ngapuhi Chief] who has the new scourge [bullets], making a thorough destruction of Waikato.

The Wesleyan missionaries settled permanently in 1826, in the Hokianga area. They arrived via personal invitation from the paramount chief Patuone, once it was established that they would not interfere with the purchasing of muskets and powder (Ross Papers n.d.). They chose to locate themselves in Mungungu (which means ‘broken in pieces’) in the Southern Hokianga area. This was against the wishes of Patuone as he wished them to locate in the Waihou area where he and his men could provide better protection against other Maori tribes who traditionally were at war with each other. On their arrival Reverend White and his wife recorded information surrounding the European settlements in the area. Two such settlements were identified, one in Te Horeke consisting of twenty shipbuilders and another further towards Waihou, made up of five sawyers who cut timber and made oars for the Australian market (Laws 1945).

Around this time the sheer volume of liquor landed in the Bay Of Islands by traders was brought to the attention of the Governor of New South Wales. At this stage in New Zealand’s colonisation history there were no formal representatives of the British Crown residing in New Zealand. Thomas Kendall, a resident of the Bay of Islands, was appointed by the Governor of New South Wales as a Crown representative in an attempt to deal with this growing problem. Drunkenness leading to crime was an escalating

problem in both Maori and European populations, and more importantly no revenue was being collected from the sales and consumption of alcohol. The Hokianga, as with several northland areas, were in essence a free for all in the distribution of alcohol.

In response to this problem Kendall appointed three chiefs from the area – Hongi, Ruatara and Korokoro - to assist him in regulating the amount of spirits landed in this area. Due to the fact that it was not illegal to land and distribute alcohol, those that made their living by these means resisted strongly any attempts. Consequently this initiative to regulate alcohol was totally unsuccessful (Gittos 1982). During the 1830's the consumption of spirits by Maori was becoming more widespread and was observed and recorded by some of the Europeans residing in the Northland area. Markham who was an Officer of the Crown while in the Hokianga observed a huge shift in attitudes surrounding the use of alcohol by the local Maori. He recorded his observations of this change in attitude, identifying a major Maori name change for alcohol when offered rum by a local Maori, who called it "Whi-pi or good water, as rum is no longer called Why-Pecker or stinking water." (Wright 1959:70)

The Chiefs of the Hokianga area were getting increasingly concerned at the widespread drunkenness of both Maori and Europeans in their area. This concern lead to a joint Maori and European local initiative to prohibit the importation of spirits to the Hokianga. This was attempted with the aid of both White, the Wesleyan missionary, and McDonnell, who in 1835 became a self-appointed representative of the Crown (Wright 1959). Through this action McDonnell is said to have lost favour and influence with the

European settlers in this area but gained favour with local Maori chiefs. Interestingly it is noted by Murray Gittos (1983) that it was extremely unlikely that McDonnell himself had any intention of suffering a prolonged personal deprivation from alcohol. Instead this ban for all others except himself would be a financial advantage -sober workers increased both productivity and profit margins.

Both Jack Lee (1987) and early records from manuscripts by Edward Markham (cited McCormick 1963) suggest that death due to drowning whilst intoxicated was commonplace for many Europeans during this time in the Hokianga area. Today anecdotal evidence of this lies within the mission graveyard. Most of the earliest European gravestones have the inscription within the epitaphs citing drowning as the cause of death. Locals suggest that the deaths had been a combination of not being able to swim and being very drunk while rowing out to their moored ships.

Similarly, White's intentions could be challenged. He and his European wife, Elizabeth, as well as McDonnell were all self reported and observed as being not only consumers of alcohol but brewers and distributors of spirits (Law 1945, Lee 1987). White is also noted as treating his converts and mission workers as nothing more than slave labour in the industry of sawing timber for spars to obtain the needed funds for the mission and personal profit (Gittos 1983, McCormick 1963). It would seem that once the mission was established and the process of Maori conversion to Christianity had begun, alcohol was identified as causing problems for the conversion process. It could be surmised from

the records that perhaps sober people would have been easier to convert and kept on the path of salvation and hard labour than drunken, hung-over persons.

To instigate an alcohol ban on September the 14th 1835, a meeting was called and was attended by twenty Europeans and a larger number of Maori. When Europeans engaged in the alcohol trade were asked to desist, it was met with what has been recorded as a very hostile response (Grittos 1983). Thomas Styles, a prominent member of the developing liquor industry, refused point blank. To add to the hostility surrounding this ban, some of the mission Maori discovered spirits in the boat Styles had arrived in beached on the shore. While this meeting was underway they secretly tipped all the liquor contained in the boat into the tide. Styles, as one can imagine, was incensed by this deliberate destruction of his alcohol, and threatened to instigate his Maori protectors to take revenge on the mission people. This threat never came to being but at the time it was said that all mission personnel armed themselves until the situation had blown over.

Regardless of the lack of European support for this initiative, action was still carried out by a small collective of both European and Maori. The Maori chief Moetata, his men and two European captains by the name of Young and Oats were directed to intercept all ships as they sailed into the Hokianga Harbour. Once they had boarded the ship and had located liquor they systematically tipped it into the tide while the captains of these vessels were powerless to intervene. As one might expect, this ban and subsequent action was met with substantial resistance by those on the land, particularly the Europeans. The mission house was to become the scene of a drunken protest by local

Europeans, who were observed dancing around the mission chapel with bottles of rum clasped firmly in their hands. However this protest was to end tragically with the death of Captain Styles, who had become involved in a drunken brawl with Jacky Marmon the first European to settle in the Hokianga (Lee 1987, Laws 1945).

The choice of men directed to carry out this policing of the alcohol ban was rather ironic to say the least, and one must question the window of opportunity that appears to have been created for financial gain for those chosen to enforce the ban. In essence this action ceased any competition for the local distributors of liquor within the Hokianga. Major Oaks himself was historically and currently at the time of the ban very active in the liquor trade with his chief Maori ban enforcer Moetata, one of his main customers.

Interestingly it is noted that in December 1836, just over a year after the ban was introduced, Style's ship, aptly named the 'Industry' under the command of Oaks was attacked and sunk off the coast by Moetata's people. It was suggested that this came about due to the fact that Oaks was still, even with the ban in place, actively involved in the sly grog trade (Grittos 1983). However with Moetata as one of his best customers, one has to presume that there was perhaps more to this dispute than just Major Oaks's disregard for the ban. At the end of 1835 it was noted by White that many communities were slipping back into alcohol use openly and the ban was eventually not enforced.

In the years that followed, it is suggested by Wright (1956) that signs of alcohol addiction by Maori were becoming apparent, creating a situation whereby it was actively

lowering the ability of Maori to cope with the changes occurring around them and combat unintentional European diseases that were introduced. It seems that a major contributor to this situation was the fact that ready access to cheap rum and low-grade spirits not used by Europeans accelerated this process and contributed to many Maori deaths throughout New Zealand.

On the 12th of February 1840 at Mungungu on the Hokianga harbour, fifty-six Hokianga chiefs were the first to sign a Treaty with the British. This document is referred to as part of the fully signed 'Treaty of Waitangi' (Lee 1987, Olssen, Stenson 1992). So began a new phase of European economic and political dominance within both the Hokianga and the rest of New Zealand, resulting in Europeans immigrating to New Zealand to settle permanently. The Southern Hokianga prospered, due to the natural resources it contained and was to acquire both a sawmill, owned and operated by John Webster, and a post office in 1846. This first New Zealand post office had a dual role: it operated both a post office and as a point of sale for alcohol (New Zealand Post Office 1967). This tavern, although no longer a post office, still operates as a point of sale for alcohol under the original name of the Horeke tavern, and is still a focal point for community gatherings and socialization.

In 1847 the Sale of Spirits Ordinance, the first of the liquor legislation created by the Queen's representative Governor Grey, was introduced. This legislation was for European protection due to the threat of a Maori uprising and banned the sale of guns and alcohol to Maori. The Hokianga itself appeared unaffected by this ordinance as sly grogging flourished and a legal point of sale/post office for alcohol sales was established

in Horeke (which in 1870 was to become the first licensed premises in New Zealand). It very soon became obvious that the European settlers were blatantly ignoring this law and continuing to supply Maori with alcohol for profit (Eldred-Grigg 1984, Sutch 1969).

By 1850 the plight of Maori men and 'half-caste' girls drinking alcohol and the problems of lawlessness associated with the European population when consuming alcohol had escalated and had reached an unacceptable level. This problem was so serious that Waikato chiefs residing in a different geographical area to the Hokianga, petitioned Parliament to make them aware of the problems being experienced. In answer to this problem, much to the petitioners' displeasure, legislation was tightened for Maori alone. No attempt was made to deal with the wide-spread problems caused by the European population, nowhere in this legislation was there any reference to the European drinking population. There was an increase in the fines for Maori caught purchasing liquor rather than the fines for Europeans selling alcohol to Maori (Eldred-Grigg 1984). This legislation once again accommodated European profiteering from alcohol and was no hindrance to revenue profits at the expense of the indigenous Maori population.

It is around this time that economic activity within the Hokianga area was declining along with the natural resources. Many Europeans with no ties to the Hokianga area moved to Auckland where employment could be found and land could be obtained through an exchange of Government land scripts. Ruth Ross suggests that by 1864 the only Europeans in this area were those who had put down the deepest roots, often

married to Maori women. She quotes F.E. Maning from The New Zealander newspaper, August 1864 giving a glimpse of the declining Hokianga settler society:

... there is not one European female in the whole district who is a settler's wife, all the settlers being married to native women of Maori descent. (Ruth Ross Papers)

With regard to alcohol consumption in 1869, James Buller notes that an environment existed in the Hokianga that accommodated the consumption of ten thousand British pounds worth of imported spirits, with two thirds of this total being consumed by local Maori (Laws 1945).

In 1870 the then Minister of Native Affairs, Mr McLean, introduced his Outlying Districts Sale of Spirits Act. This act has been referred to as the Licensing Regulation for Maori Licenses. This regulation was in all appearance a positive response by the Government to a serious social problem. This Act created a situation whereby licenses were given as long as the appointed Maori Officer (a European) of the area consented to that particular person (usually a European) holding such a license. But equally if it was the wish of the chiefs in an area, that area could be proclaimed as a 'dry area' where no alcohol sale licenses would be granted. However, when one looks at this particular piece of legislation, the motivation for its introduction has been interpreted by many researchers as being far from humanitarian. Rather, the monetary losses from tax revenue due to sly grogging and illegal sales in this area was the major concern and had to be controlled (Fleras 1982, Awatere, Casswell, Cullen, Gilmore, Kupenga 1984).

Three years later in 1873, changes were made to existing laws that saw the inclusion of Maori as part of liquor licensing boards that had been set up around the country three years prior. These persons, or assessors as they were referred to, had the power to veto or renew liquor licenses in areas that contained large populations of Maori. At the same time Legislation was changed to allow Maori of 'good character' to hold such liquor licenses. Rutene-Rewiti (1994) and Awatere et al (1984) suggest that it was not uncommon for these assessors themselves alone to hold the liquor licenses (termed as a Bush License) for their areas. This in essence would have ensured a continuation and increase in excise revenue obtained from Maori areas, by removing non-tax-paying competitors by Maori policing efforts accompanied with heavy fines imposed on those found breaking the law. The Taheke Hotel is an example of this legislation, being one of the areas in the Hokianga where Maori owned and operated a licensed premises (Lee 1987). However the Horeke Tavern itself remained under European/Pakeha ownership and licensee.

Economic competition surrounding resources in the late 1870's escalated the economic slump experienced by those residing and working in the Southern Hokianga. During the 1880's the Southern Hokianga was to experience two major events. Firstly, proposals for roading into the area, which even up until recently have always been unsealed, adding to the isolation and difficult access to the Southern Hokianga area. Secondly, the beginning of western communication technology in the form of laying telephone cables across the harbour (Lee 1987).

In 1900 there appeared to be a public growing concern in regard to the ill effects alcohol was having on the Maori people. In response The Maori Councils Act was passed by the New Zealand Government. This legislation involved the recruitment of Maori Chiefs to police the consumption of liquor amongst Maori in their area. But from all accounts it appears that over the next eight years this piece of legislation was not particularly successful. In theory the concept of Maori policing their own peoples' alcohol consumption sounded good. But unfortunately as suggested by my local informants, alcohol consumption at that stage in the Hokianga, had eroded the power and health of many of the chiefs as well as other Maori people in that area. This initial legislation was changed in 1908 under the Licensing Amendment Act to allow Maori men to apply for a prohibition order against any male relative. This in effect was intended to encourage family members to inform on each other, denying the access to alcohol through fear of being reported to authorities (Rutene-Reweti 1994). There appears to be no record or information on a local level that indicates that this legislation created any reported incidents in the Southern Hokianga area until much later around 1935. These two pieces of legislation appear to have been viewed publicly as a way of dealing with the very negative problems created directly from the proliferation of alcohol for accumulation by the state via the Maori population. This whole agenda may have been placed in a larger public arena due in part to the lobbying from community (mostly European) and church groups opposed to alcohol.

The year 1910 brought about new legislation that was to see Maori men in non-proclaimed areas entitled to buy and consume liquor in licensed premises. As far as

drinking rights for Maori women went, they were forbidden to purchase or consume alcohol at any time. The only Maori women that were legally entitled to the same drinking rights as Maori men (to be able to purchase and consume liquor on licensed premises, no off sales) were those who were either married to Europeans or living with Europeans who owned or ran licensed premises (Rutene-Reweti 1994). It appears from local informants' accounts that this particular legislation caused many a child as I was told, 'to be born on the wrong side of the blanket' within the Southern Hokianga area. To add to the imbalance created by alcohol legislation against the Maori people, Awatere et al (1984) point out that early Polynesian immigrants from the Cook Islands and Niue always enjoyed equal drinking rights to those of the European population throughout New Zealand. Meanwhile, in contrast, Maori were bound by what appeared as restrictive legislation surrounding purchase and consumption of alcohol.

During this time, although Maori were restricted by legislation surrounding alcohol, it appears to have been extremely ineffectual in the Southern Hokianga area. According to local Maori informants who were in their mid eighties when interviewed, many began making home brew that was consumed privately in homes, as well as the fact that even though Maori men were not legally entitled to buy off sales, the local publican always let them. It appears that different families held different views surrounding alcohol and many community peers were identified by members of these communities as being 'great drinkers in their time'.

Because of the isolation and remoteness of Motukiore and the distance to the Horeke Tavern, most of the men who drank in this area would use a boat to get across the Hokianga inlet to the Kohukohu Tavern on the Northern shores of the Hokianga. It was and still is a quick trip, one that was reliant on the tides. If individuals got drunk or missed the tide, they had to simply wait for the next high tide, more often than not in the tavern. My elderly informants from Motukiore informed me that in their young days young people generally didn't drink alcohol. Any functions involving alcohol consumption was policed by the 'old people', who did not tolerate bad drinking behaviour. If people got too drunk they were reprimanded and sent to bed or dealt with by the Marae committee. Punishment dished out for inappropriate behaviour usually consisted of having to weed the Marae community gardens. My participant who spent several sessions weeding said that it was a shameful experience as the whole community would know what you had done as they went past.

Women consuming alcohol within this community became more noticeable during the war years when most of their sons and partners were on foreign soil involved in the war effort, many of whom died on foreign soil, never returning to their place of birth. During this time women had to take on roles within the community that had been traditionally carried out by their men and actively took part in fund-raising events to raise money for the war effort (often in private homes) that almost always involved alcohol consumption by women. Consequently, between World War I and World War II, alcohol was becoming more and more openly an integral part of community events.

During these times alcohol was illegally purchased from the Horeke tavern in the form of small wooden kegs and transported by boat to Motukiore. Transportation by water was in an effort to escape observation by certain members of the community locally known to oppose the use of alcohol, those who could and would invoke the right to inform the authorities under the Maori Councils Act 1900. If locals were caught transporting or consuming off sales from licensed premises a heavy fine was imposed on the offending person/s by the courts. In some ways, once Maori were legislated to police their own, nothing much was done to stem the consumption rates. Some would argue that this legislation was an attempt by the state to moderate and control the problems using tax and fines as a deterrent.

On close inspection all the legislation appears to serve the interests of the Government's accumulation process. A reduction in consumption would equal a reduction of profit and directly impact on the accumulation process. The government of that time could be seen by the masses to be addressing the social ill effects caused by alcohol through their punitive legislation. This scenario provided a situation where once again consumers rather than the suppliers were subjected to fines if caught. It obviously wasn't in the best interests of the state to impose fines on the very persons who paid tax on illegal sales of alcohol, neither was it in its best interests to stem the consumption levels.

During the period 1945 to 1946 liquor legislation was repealed due to the return of the men from war. The Hokianga area provided men that helped make up the largest and least heard about Maori battalion called 'company A' which was made up of Maori men

born in and affiliated to Northland who identified as Ngapuhi. New Zealand found itself in a situation where Maori men could consume and purchase off sale liquor while serving in the New Zealand army on foreign shores, yet were unable to do the same in their own country once they had returned. At this time Maori men were given equal drinking rights to that of Europeans, allowing both the consumption of alcohol on licensed premises and the right to purchase off sales. Included in this new law change was the inclusion allowing Maori women entry and entitlement to consume alcohol on licensed premises.

In 1945 the Social and Economic Act was passed in New Zealand. This act was supposedly intended to provide Maori people with a system that established an internal form of social control. It is noted by Fleras (1981) that this particular piece of legislation paved the way for the establishment of Maori Wardens - a community based form of police force with a very restricted power of authority. These wardens were expected to deal with any problems created through alcohol consumption within Maori communities at social gatherings as long as they did not interfere with tavern and hotel profits. Due to the restricted - almost non-existent- legal authority, the wardens had been granted, this legislation meant their ability to deal with problems that presented themselves was minimal. Finally in 1948 legislation known as the Licensing Amendment Bill was passed which accorded all New Zealanders male and female, Maori or non-Maori, equal drinking rights.

Alcohol has historically been used by those at the macro level, who in this circumstance were the British, to destabilize the very fabric of Maori society, by the introduction and

proliferation of alcohol. This historical glimpse I believe shows just how strong the impact of the British was. We see that in the early stages of European colonisation when Britain (the macro) did not have full authority over the Maori people (the micro), Maori initially did not participate in alcohol consumption and found it a foul substance that only Europeans drank, a situation that changed with the establishment of permanent European settlements. Maori leaders such as the chief Patutone (while the resources lasted) held large stakes in the economic development of the Hokianga area. This created a situation where he and his people were partners and equal participants in the 'core', periphery and the semi-periphery zones as described by Wallerstein's (1974) world systems theory. This appears to have been due to the fact that Maori still had full control over their natural resources prior to the introduction and adoption of the British monetary system.

As time went on it becomes apparent that coupled with the influx of settlers, so came the depletion of natural resources in this area. Maori became relegated to positions within the overall economy as the periphery (in cases where control, though dwindling, was still held over shrinking resources), and semi-periphery zones. Maori held a lesser role in the economic development of New Zealand, often as the labour force used to acquire major economic gains for the Europeans. Maori society changed dramatically to the ways, beliefs and laws of the British through pressure, remodelling Maori society to mirror the British. However the place of Maori within this new society also mirrored the British class system with the majority of Maori winding up socio-economically taking

the place of what could be seen as equivalent to that of the bottom rung of the early British class system.

Throughout the early New Zealand history of alcohol the legitimisation of the process of accumulation was through the introduction of legislation, much of which was aimed at the Maori people and their alcohol use. Taxes generated from the European population were easily obtainable and alcohol appears to have been a significant cultural factor for many of the European settlers' lives. This legislation appears to have been motivated and put in place to ensure the process of accumulation increased and proceeded unhindered.

Under the guise of being the only way to save the Maori from the ravages of alcohol, initial legislation (possibly attributed to the church lobbyist) was created and enforced by those who were active in the introduction and proliferation of alcohol for financial gain. Similar to the early parliamentary gin reforms in Britain in the 1700's, alcohol legislation seems to have been a pawn in the hands of industrialists, politicians and clergy within New Zealand. Most early alcohol legislation was aimed at removing illegal traders dealing in alcohol. Far too much was being consumed by the Maori people with few proceeds of the sales ending up in the Government's coffers. In an attempt to take advantage of the situation where Maori demand for and consumption for alcohol was growing (an important market as the European market in New Zealand was already well established), it was important for the state to introduce legislation to protect and widen their vested interest in a new and growing market.

This legitimisation process had to appear to be for the benefit and well-being of the Maori people, in a bid to be a way to reduce the carnage alcohol was visibly reaping within Maori society. This legislation had the ability to manipulate public belief in so far as it was seen as the act of a responsible, caring and compassionate government addressing a serious, very public problem. Many people, particularly Maori, had their standard of living and health adversely affected by unscrupulous European traders selling large amounts of often low grade dangerous alcohol for their consumption. All this introduced legislation looked on the surface to be addressing these problems, but in reality it enabled the state to gain almost total control over the revenue generated by the sale and consumption of alcohol, ensuring none of the legislation for Maori people, particularly when it came to restricted access, impacted on the accumulation process or the demand. It created a situation making the revenue collection process smoother, cutting out any competition while authorities were yet seen to be addressing the problem.

One may be asking what this historical overview has to do with the focus of my research on Fetal Alcohol Spectrum Disorder. Central to the whole issue is the need for Government funding and legislation to help reduce the impact Fetal Alcohol Spectrum Disorder has on New Zealand society in today's environment. I believe this problem has affected generations of New Zealand people, both Maori and European, ever since its introduction to New Zealand, and that it will require substantial funding to reduce the occurrence. Large amounts of revenue have been historically obtained by the proliferation of alcohol. Alcohol is still a vehicle for state accumulation, yet it is still

extremely problematic. We have known that there is a direct link between women consuming alcohol during pregnancy and Fetal Alcohol Spectrum Disorder since 1974, but this has received little or no attention or acknowledgement. It is in my view totally unacceptable and immoral for a government that has traditionally obtained vast amounts of revenue, most of which would have funded early New Zealand infrastructure, to remain silent on what could be a serious intergenerational problem within our society. This mode of operation has prevailed in New Zealand governments in the past and is, I believe, still operating today.

In this century we have a different situation to the historical proliferation of alcohol; we have arrived at a time when the known dangers of alcohol consumption during pregnancy are being downplayed by government agencies with a lack of legislation or directives. This will become clearer in the chapters ahead. What has been done in the past cannot be undone, however societal norms and attitudes surrounding alcohol and its widespread usage in today's New Zealand society have been created in part by our history.

CHAPTER SEVEN

How Much is too Much: Do We Have a Problem Here?

The question that is so often asked by people about alcohol and pregnancy is: what time in the pregnancy can the baby be affected by the mother consuming alcohol and when is it safe to drink during pregnancy? The answer is there is **no guaranteed safe time** during a pregnancy. There has been an ongoing debate internationally as well as locally in regard to what is safe and what is not safe. It seems unlikely that we will ever get a unanimous agreement from researchers about what is a 'safe threshold for alcohol consumption during pregnancy' and findings from research carried out in 1982 by Nitowsky still appear to be accurate, he suggests that:

There is inadequate information about the possible adverse effects of lower alcohol intake, including social drinking. Thus the lower limits of teratogenic effects of alcohol are unknown. (Nitowsky 1982:1216)

It has been suggested that low levels - 1-2 standard drinks of alcohol and one occasion of binge drinking - at a critical time can affect the foetus (Day, Richardson 1991, Mills, Graubard, Hariey, Rhodes & Brends 1984). The reality is that researchers just don't know enough about low dose effects -except the impact on the foetus from low doses will vary from pregnancy to pregnancy. Just because one consumes alcohol during pregnancy does not automatically mean that the developing foetus exposed to alcohol will be affected. It is a case of Russian Roulette - every time you consume alcohol during pregnancy you place your baby at risk. We do know that the foetus is more susceptible at different times during the pregnancy corresponding with physical development. Researchers have identified foetus susceptibility, variations in alcohol

dose, maternal metabolism and gestational timing as all contributing to the outcome for the infant (Sokol, Clarren 1989, Olsen, Burgess 1997, Niccols 1994). In 1981 the American Surgeon General recommended total abstinence and went one step further directing medical practitioners to ensure:

Each patient should be told about the risks of alcohol consumption during pregnancy and advised to not drink alcoholic beverages and to be aware of alcoholic content of food and drugs. (cited Plant 1985:18)

When reviewing incident rates it appears rates differ among populations as do drinking patterns of consumption. American incident rates provided by Sampson, Streissguth, Bookstien, Little, Clarren, Dehaene, Hanson, and Graham (1997) estimate that in 1975 the incidence of FAS in the Seattle population was 2.8 per 1000 live births and in Cleveland for the period 1979 to 1980, the rate was placed at 4.6 per 1000 live births. The combined estimated rate is considered by Sampson et al (1997) to be conservative; the whole spectrum (at this time referred to as FAE and FAS) of this disorder in Seattle between 1975 and 1981 was said to be at least 9.1 per thousand live births. This statistic equates to almost one per 100 live births. French statistics from Roubaix over the period 1977 to 1990 place the incident rate of FAS as being between 1.3 and 4.6 per 1000 live births among the population samples tested.

Research carried out in the United Kingdom by Bridget McConville (1991) on British communities provided findings that indicated a rate of between 1 per 1000 live births and 300 per 1000 live births. Some of the reasons that may explain the huge differences in incident rates in this study could be due to socio-economic or cultural differences among different communities that make up the British population; communities that

practise different cultural drinking patterns and attitudes towards alcohol and pregnancy. Both international and local literature suggests that differing attitudes and practices surrounding the consumption of alcohol are dependent on an individual's culture (Park, McMath, Smith, Herda, Banwell 1991, Sandmaier 1992).

Different prevalence rates among different communities within one population have been identified in other international studies. Depending on the community studied, May, Hymbaugh, Aase and Samet (1983) reported a prevalence of FAS within different American First Nation communities as being between 1.3 and 10.3 per 1000 live births. Dr Micheal Moffatt and Dr Albert Chudley, when discussing research carried out on a community of First Nations people from Manitoba Canada, are quoted in the 1997 Canadian Medical Association Journal as saying

We're talking roughly 100 cases of FAS/FAE [per 1000 live births] on the reserve and that qualifies as an epidemic in my book ... The medical records indicate that about 40% of the children, who ranged in age from 5 to 15 years old, had been exposed to alcohol in utero. (Square 1997:59)

As for New Zealand, the only specific research on this issue was an estimate on the number of New Zealand children under the age of 10 affected by prenatal exposure to alcohol. This work was carried out by Drs Leversha and Marks and published in 1995. This was a postal survey sent to New Zealand paediatricians in 1993, requesting the number of children with alcohol related birth defects that were currently under their care. The authors indicated the likelihood of underestimation of actual numbers in this research could be significant, as a lack of medical awareness would equate to lack of diagnosed cases.

Current surveillance for alcohol related birth defects depends on an individual paediatrician considering the diagnosis only when faced with a perceived at risk infant or child, and there is likely under recognition. An increased awareness of the risks of alcohol consumption in pregnancy and the full spectrum of alcohol-related birth defects is required.(Leversha & Marks 1995:502)

Leversha and Marks suggest that the New Zealand prevalence rate is between .33 per 1000 live births and 5.9 per 1000 live births. Interestingly this estimate after being published was challenged and refuted in the next issue of the New Zealand Medical Journal by Dr Gavin Glasgow (1996), another medical practitioner. Glasgow placed the prevalence rate as .33 being the maximum, citing American incidence figures obtained from research carried out by Abel and Sokol in 1991, despite statistical information from the American Centre for Disease Control (1995) which identified .67 per 1000 live births. Stratton et al (1996) as with many researchers acknowledge that the FASD diagnosis is a complex one, suggesting that there is a strong possibility that reported incidence rates can be expected to be grossly underestimated.

Ernest Abel has been active in the research area of Fetal Alcohol for many years and was conducting research on FASD in the 1970's. However, his latest research published in 1998 titled : 'Fetal Alcohol Abuse' has been critiqued by other American researchers as having many flaws. His ability to create an estimated 0.5 cases per 1000 live births as the overall incident rate for FAS within the industrial world from 29 'prospective' studies is unacceptable, as well as his suggestion that FAS is a 'peculiarly American problem'. Fred Bookstien (1999) goes as far as to state that Abel's use of literature was biased as he ignores important statistical research that was available at the time of this

research and that it did not reflect a 'balanced review of information available'. This negative critique of Abel's latest work does not by any means negate the importance, nor the contributions he has made in previous research, however it does place serious doubt as to the quality or accuracy of his latest figures.

Glasgow's belief in Abel's estimates as being indicative for New Zealand unfortunately shows his lack of knowledge of cultural differences in relation to drinking patterns. As previously mentioned, research surrounding drinking patterns nationally as well as internationally suggests that the differing attitudes and practices surrounding alcohol consumption are dependent on an individual's culture (Sandmainer 1992, Park et al 1991). Therefore it is not relevant that an estimated New Zealand prevalence rate mirror that of America or Britain; we are a different culture. Our history differs as do our differing cultural drinking patterns within our multi-cultural population. We cannot simply accept international incident rates carried out on different ethnic populations as being an accurate mirror image of the New Zealand situation. Different incident rates have been identified within geographically different communities of single populations, so how can any one global estimate be anything but guess work?

To what extent do pregnant women in New Zealand consume alcohol? To start with, it is important to bear in mind that the highest risk drinking pattern associated with fetal alcohol agreed on internationally is 'binge drinking' (Schenker, Becker, Randall, Henderson 1990, Jacobson, Jacobson, Sokol, Martier, Ager 1993). This information should be setting alarm bells ringing loudly as numerous researchers have in the past

identified this drinking pattern as common practice for many New Zealand women during their peak child bearing years (Awatere et al 1984, Rutene-Reweti 1994 , Wyllie, Zhang, Casswell 1993). As for alcohol consumption by New Zealand women during pregnancy, Counsell, Smale and Geddis (1994) found that 41.6% of women in their sample population consumed alcohol during pregnancy. Interestingly, it appears that the higher socio-economic status groups were those who consumed alcohol regularly.

A report to the Ministry of Health on nutrition during pregnancy in June 1999 shows that 81 % of their participants consumed alcohol prior to knowing they were pregnant and 29% of women surveyed continued to drink after notification of pregnancy (Watson & McDonald 1999), many drinking to excess. What must be taken into account is the fact that serious damage can be done to the foetus during the 19th and 20th day of pregnancy, a time period during pregnancy when most women don't even know that they are pregnant.

These international prevalence statistics have indicated that prenatal exposure to alcohol is acknowledged as a serious problem in other countries. Yet, even in light of volumes of information having been available for the last 31 years regarding alcohol consumption during pregnancy and the reams of information we have on New Zealand women's drinking patterns, there has been a considerable amount of resistance in acknowledging that we could have a very serious problem within our society. This ostrich type behaviour of putting one's head in the sand and ignoring the possible reality of the New Zealand situation is unacceptable. Information about the dangers of drinking while

pregnant that is offered to New Zealand women is quite simply a 'watered down' form. What is interesting is that New Zealand health officials still today 31 years after the discovery of Fetal Alcohol Syndrome, have chosen not to follow the American and Canadian initiative requiring mandatory education of women by their doctors on the dangers associated with alcohol and pregnancy. Indeed there appears to have been in the past and even today a resistance on the part of authorities particularly medical and political within New Zealand to acknowledge the existence or seriousness of fetal alcohol spectrum disorder.

The 2001 Ministry of Health directive directs medical professionals to adopt a harm reduction ideology, to encourage a decrease in both frequency and dose of alcohol during pregnancy, rather than abstinence and compulsory education via health professionals of New Zealand women. In essence the New Zealand Ministry of Health and its associated agencies have in all probability unintentionally upheld the status quo by marginalizing the seriousness of this issue and the need for medical professionals to update their knowledge surrounding alcohol and pregnancy. Every New Zealand woman has the right to information that is both accurate and standardized surrounding the danger of alcohol consumption during pregnancy. This would give a greater awareness allowing many women to make an informed choice surrounding continuing or discontinuing alcohol consumption during pregnancy. At the very least for some, pregnancy can be the motivational force behind seeking treatment.

New Zealand appears to lead the Western world with our harm and risk reduction ideology particularly when dealing with portions of our population who suffer addiction problems. From this portion of the population reduction is more realistic as an achievable outcome for those addicted rather than total abstinence. However what is of issue concerns the other much larger population of New Zealand women who are not addicted. New Zealand women are being deprived of the right to be fully informed due in part to a lack of knowledge on the part of various professional health services. During my research I found the midwife population with whom I have had discussions were the most knowledgeable on the subject. All knew about the dangers of prenatal exposure to alcohol and talked about abstinence rather than moderation with their clients when appropriate. Other professionals held differing views.

An example of this situation was when a pregnant friend informed me that her doctor didn't really believe in Fetal Alcohol and that alcohol in moderation was fine for both the mother and baby. She said that she only drinks alcohol on one occasion during the week and had reduced her consumption by at least 2 drinks per occasion – reducing her intake from approximately 7 standard drinks to 5 standard drinks per episode, thinking that's ok for the baby as she had done what her doctor directed, and after all he should 'know these things'.

The lack of factual directives and the guidelines surrounding supposed 'safe levels' of alcohol during pregnancy to doctors from the New Zealand Health Ministry is due to the recommendations formulated for government by the Royal New Zealand College of

Obstetricians and Gynaecologists (RNZCOG). These guidelines are an exact replication of recommendations produced by their British counterparts which interestingly take no account of the volumes of internationally recognised Canadian or American research. At the end of the day to be educated around this issue equates to New Zealand women being able to make an informed choice, one that has been based on accurate standardized information - to drink or not to drink during pregnancy.

Medical practitioners themselves are being sent a mixed message by government agencies. The chief executive of ALAC (Alcohol Liquor Advisory Council) is quoted on page 31 of the March 1999 issue of New Zealand Doctor magazine, suggesting that abstinence guidelines during pregnancy would be an 'alarmist approach', stating:

..there is no evidence to show a moderate amount of alcohol will harm your baby....RNZCOG guidelines on alcohol and pregnancy state: "There is no conclusive evidence of adverse effects in either growth or IQ at levels of consumption below 15 units per week"...Many newly pregnant mothers will unwittingly imbibe before pregnancy is diagnosed. If one has in place a policy stating that no amount of alcohol is safe then there is a great potential for unnecessary anxiety, guilt and requests for therapeutic abortion...

This statement in itself contains several issues that need to be addressed. Firstly, just what exactly is a moderate amount? This statement identifies fifteen drinks per week as moderate consumption, but as binge drinking is commonplace among New Zealanders, does this mean that fourteen units of alcohol during a single binge drinking session once a week should be deemed safe? Different interpretations of just what constitutes a moderate amount of alcohol will be based on individual cultural and personal attitudes surrounding alcohol usage. My definition of moderate drinking differs greatly from most other people that I have asked. Many I asked stated that 4 or 5 drinks on one occasion

was moderate drinking. Secondly, the RNZCOG's (Royal New Zealand College of Obstetricians and Gynaecologists) guidelines of 'below 15 units per week were highlighted in large bold type and headlined on the front page of the national paper, The New Zealand Herald. This reporting led to the comment by one of my pregnant acquaintances that there was no problem with her drinking. She explained that she only went to one party a week and only has about eight drinks at any one time, which 'wasn't a worry' as it was at least six drinks under the safe amount. Surely it would have been in the best interests of the public that the wording be a little more responsible and directive - under two drinks per day or on any one occasion? Two drinks per day sounds very different to under 15 per week. The way we present written information will have a huge bearing on how people will perceive and interpret information provided. I can say exactly the same thing as the RNZCOG do in their guidelines but change the message's impact and importance by including one word 'There is no conclusive evidence of **no** adverse effects in either growth or IQ at levels of consumption below 15 units per week'.

Lastly, the information presented is not accurate, especially if it appears that we are setting a benchmark that is promoting a 'safe' level of alcohol consumption in New Zealand during pregnancy. Published American and Canadian research has been available for years. Research by Nitowsky (1992), Jacobson and Jacobson (1994), Streissguth et al (1994), Phillipson (1988) to name a few, investigated the implications of low and moderate alcohol intake during pregnancy. This research appears to have stemmed from an increase in alcohol-related neurological and behavioural effects being

observed in offspring born to women who were considered 'social drinkers'. We simply don't know enough in regard to possible teratogenic damage due to low doses of alcohol during pregnancy.

Day, Jaspere, Richardson, Robles, Sumbamoorthi, Scher, Staffer and Cornelius (1989) report findings surrounding physical abnormalities in infants were associated with reports of heavy drinking - heavy drinking was defined for the purpose of this study to be at least 0.5 ounces of alcohol or at least one standard drink of alcohol per day, during the first 2 months of pregnancy. Jacobson, Jacobson and Sokol (1996) suggest that there was an increased substantial risk of intellectual impairment for children borne by women over 30 years of age who drank during pregnancy. This and other research was and has been available years prior to this guideline. Why is it so important for government agencies to downplay and ignore internationally accepted research findings that have been accumulated over some thirty years of seriously funded research?

Instead, we adopt the 1996 guidelines set in the United Kingdom by the Royal College of Obstetricians and Gynaecologists. This group of British medical professionals set a British national guideline which set a specific level of alcohol consumption considered safe during any pregnancy, as being unquestionably correct. Creditable professional medical critiques opposing that same guideline have been available and accessible for policy debate prior to the New Zealand official stand. One example is written by Spanish researchers connected to a centre for behavioural teratology, who state:

However, contrary to the conclusions in the RCOG [British], we believe that there are reasonable data indicating functional and physical consequences

following exposure levels of less than 120g of ethanol /week. Although we may never know the amount of alcohol any particular woman needs to consume to affect the child, we do know that these effects are 100% preventable. While one might advise the pregnant woman who has been drinking less than 2 U/day that the risk to the fetus is relatively small, given the current data it would be clinically prudent to advise abstention during pregnancy. (Guerri, Riley, Stromland 1998)

The key phrase in this quote is 'clinically prudent' and I would argue it is clinically and morally prudent to advise abstention. How can a group of medical professionals whose expertise is in obstetrics and gynaecology, collectively decide what a safe level of teratogenic exposure is when even the experts in teratology themselves state that under two units a day still creates a relatively small risk?

Another interesting anomaly is that out of all the western countries surveyed by the International Centre for Alcohol Policies (ICAP) at the time of writing this thesis, only New Zealand and the United Kingdom do not recommend abstinence during pregnancy. Our own researchers Drs Leversha and Marks (1995) appear to support the Australian National Health and Medical Council's (1992) recommendation of abstinence rather than the British guidelines. The Australian council identifies low doses of alcohol as being unsafe during pregnancy and their recommendation is that responsible maternal drinking of alcohol is abstinence, up to 2 drinks a day hazardous and more than 2 drinks per day harmful.

The paper written by the British RCOG on this subject seems to emphasize the safety of consumption on a weekly basis of 120 g or 15 units per week throughout the paper. However this article ends with a recommendation that no more than one drink of alcohol be consumed per day during pregnancy. This important recommendation differs from

and contradicts the main discussion of this report and is noticeably absent from the ALAC discussion. In fairness it may have been omitted by the editor of the New Zealand Doctor. Thankfully, a retraction contradicting this official stand was published at a later date by ALAC, stating that ALAC's official stand was one of abstinence. Unfortunately this retraction and information did not receive the same multi-media treatment nor did it appear on the front page of the national newspaper.

This situation points to the reality that even among different agencies knowledge and personal attitudes surrounding the seriousness of this issue vary quite considerably. On the 9th of September 2002 on the 6 pm news on Television One, the ALAC representative was discussing concern over the large number of New Zealand women (42%) identified as drinking during pregnancy in New Zealand, while promoting and advocating for abstinence for the full nine months of pregnancy. This public speech aired on national television on international Fetal Alcohol Day seemed to me to highlight positive changes in attitudes within certain organisations.

Clinical Practice: the First Step in Prevention and Intervention

Many women I interviewed identified their doctors as not having discussed their maternal drinking patterns or informing them of the risks involved with alcohol consumption during pregnancy. However all participants interviewed who had had a pregnancy at sometime since 1998 stated that their doctors had routinely inquired about and discussed the dangers of smoking and the importance of stopping for the health of

the developing foetus. International medical research is available that identifies alcohol as being responsible for more damage on a developing foetus than cigarette smoking, but the health emphasis appears to be on maternal cigarette consumption and not alcohol.

None of my birth mother participants indicated that they had been informed by their General Practitioner about the dangers of alcohol consumption during pregnancy. One of my participants with a 5 year old child recently diagnosed with Fetal Alcohol Spectrum Disorder stated:

Well the pregnancy was a total accident and I had two more periods before I missed a period and found out I was pregnant, so I had no idea. I was still very much in the honeymoon stage with his father – who is an alcoholic, so we drank every single day, big long binges...

I also discussed with my doctor that I was really concerned about the amount I had drunk. I told her I was drinking a cask of wine a day and binging all weekend. Her attitude was – Oh no, no that's ok, everybody drinks a bit in the beginning and you know that's fine....

Another participant whose baby was born in 1999 had been trying for 7 years for a baby. When she was told by a delighted doctor that she was pregnant, he suggesting that she and her husband knock the top off a bottle of champagne and celebrate this wonderful occasion. This particular doctor in hindsight would have wished he had not suggested this as my newly pregnant friend launched into what her husband amusingly referred to as her 'maternal protection mode'. After she asked him to repeat what he had said she proceeded to educate her astonished doctor about the dangers of alcohol and pregnancy. My friend had no intentions of celebrating her good fortune in any way that

could even remotely place her long awaited baby at any risk and had no intention that her doctor ever suggest it to any other pregnant woman.

There still appears to be a lack of awareness surrounding the seriousness of maternal alcohol consumption by many medical professionals within New Zealand in regard to prevention and intervention, even in light of the large volume of research available. In 1995, Leversha and Marks (1995b) carried out research in an attempt to understand 'doctor's attitudes, knowledge and clinical practice' using as their participants a random sample of general practitioners, all paediatricians and obstetricians within New Zealand. Results indicated that their clinical practice did not reflect their attitude that maternal alcohol consumption was a health issue of importance. 84% of general practitioners and 89% of obstetricians felt they were knowledgeable enough to be able to inform others on the risks of alcohol and pregnancy. Yet only 40% of general practitioners and 59% of obstetricians routinely enquired about their client's alcohol consumption at the first appointment when dealing with pregnancy, 9% of general practitioners and 17% of obstetricians reported they never asked. Within this research only 46% of the sample group recommended abstinence and the three different professional groups all held differing opinions on the recommended 'safe level'.

This New Zealand specific research was similar in findings to research carried out by Carole Donovan in 1991 on a sample of American (New Jersey) physicians. The purpose was to attempt to understand the knowledge and attitudes towards screening clients for prenatal alcohol consumption risks. Results suggest that clients were not

routinely questioned about their maternal alcohol consumption. Many reasons were offered by the research sample to explain why they did not screen. The most common reasons appeared to be a denial of FASD occurring in private practices and the fear of offending private clients.

One certainly cannot make the generalization that all doctors working within New Zealand are lacking knowledge surrounding the consequences of prenatal exposure to alcohol. Leversha and Marks (1995b) identified that there were medical professionals currently practicing within New Zealand who did routinely question and educate their pregnant clients around risks of alcohol and pregnancy. However, none of my birth mother participants were informed via their general practitioner. Although the sole responsibility of education around this issue should not exclusively rest on medical practitioners, it is an important start. After all, medical practitioners already play a significant role in educating and directing their clients on other health matters such as smoking.

As a matter of sound clinical practice, all doctors should have a standardized knowledge base in order to provide better health service outcomes. Routine screening of pregnant clients and the knowledge base to competently educate pregnant women on the risks associated with alcohol consumption during pregnancy, could play an important role as a preventative intervention in a bid to reduce the occurrence of Fetal Alcohol Spectrum Disorder within New Zealand. Several of my participants stated that they were warned

every visit to the doctor about the dangers of cigarettes and pregnancy, but nothing was said about the dangers of alcohol and pregnancy.

In light of the extensive international literature surrounding the effects of alcohol as a teratogen, accompanied by credible information on pregnant New Zealand women's drinking patterns, I believe that New Zealand has a very just cause for concern in regard to prenatal exposure to alcohol within our society. We are a small nation of binge drinkers, a drinking pattern that in literature has been repeatedly identified as one of the high risk drinking patterns associated with fetal alcohol spectrum.

It is a reality that we will never stop some cases of Fetal Alcohol Syndrome Disorder. Many pregnant women consume alcohol prior to realizing that they are pregnant. We as a country are naïve, to say the least, if we believe that we have no New Zealand children being born each year affected. However the prevalence rate of both Fetal Alcohol Effects and Fetal Alcohol syndrome would reduce with New Zealand women being nationally educated about the risks of alcohol and pregnancy. Those who are planning pregnancy armed with knowledge may choose to abstain from alcohol during the whole process of trying to get pregnant.

Changing public attitudes towards something that is neither illegal nor considered dangerous must start somewhere and I believe that medical professionals are one such vehicle for the dissemination of information. For many pregnant women medical professionals are a 'significant other' in their lives, especially during their pregnancy.

Information given to pregnant women is suggested by Ihlen et al (1993) to be more effective if given via another significant source or person rather than a campaign. Bearing that hypothesis in mind, medical professionals along with many others have an important part to play in the education of women to the dangers of alcohol and pregnancy. But to be effective it is imperative that the information they are providing is up to date, accurate and standardized, not a reflection of the doctor's personal attitudes surrounding alcohol usage.

Awareness of the risks of alcohol consumption in pregnancy needs to improve and education needs to be within the medical profession as well as in the community at large. (Leversha & Marks 1995b:430)

One of my own personal experiences in regard to education and differing attitudes surrounding alcohol consumption during pregnancy among medical professionals surrounds a planned week long educational visit to the West Coast in August 2002. I was asked if I could possibly come to the Coast to deliver some seminars to several community and professional groups by a caregiver living in the West Coast. When my hosts were attempting to obtain funding for my airfares they approached the local West Coast Crown Public Health promotion representative for a financial contribution in exchange for professional development on this subject. During planning of this week-long seminar, I was contacted by phone by one of the medical officers of Crown Health from Christchurch. This medical officer of health explained that he had reservations about supporting my trip even though I was not charging professional fees. His disagreement involved the abstinence message I was going to give the public in regard to safe drinking patterns during pregnancy. His problem was that the public could be getting two different messages. The message of abstinence during pregnancy

from myself and the official crown public health message that of a reduction of alcohol intake. It was suggested that we would have to discuss my stand on this issue, indicating that I was the one who would have to change my message before approval would be given. To be fair it must be understood that the Ministry of Health guidelines do direct doctors towards a harm/ risk reduction ideology.

This is a subject that I feel passionate about and I believe my knowledge base has been well researched. I informed the medical officer that I was not prepared to negotiate this message and that my stand was supported by credible international research. The end result was a request for me to send (at my expense) supporting documentation surrounding this subject for the team of medical officers of Crown Health to debate their stand on this issue. One would have thought that an issue important enough to warrant a meeting would have initiated a serious literature research by Crown Health employees themselves. I was informed from another source that within Crown Public Health different medical officers apparently held individual differing views on what constituted a 'safe' level of alcohol consumption during pregnancy. There obviously was not a standardized message given to pregnant clients serviced by this agency, in fact 'safe levels' of alcohol consumption during pregnancy appear to be left to the discretion of the individual practitioners.

The outcome of this whole debate resulted in the medical officer concerned being observably absent from the meeting set aside to discuss this issue. However what was refreshing was the number of midwives and other nursing professionals who turned up

to the meeting to argue and support my stand. Thanks to their support and the West Coast office of Crown Public Health my airfares and seminar timetabling were arranged.

The results of these seminars on the West Coast from evaluation forms provided by Crown Public Health showed that approximately 225 people attended six three hour seminars for public and professional groups. 138 persons filled out the evaluation forms and of them, 137 felt they had a better understanding of FASD. All 138 said they would recommend the seminars to other colleagues. In the Crown Public Health report it stated

This project achieved the desired objective and to a certain degree the numbers that attended the seminars exceeded initial expectations. The success of the seminars was very much the result of having such a knowledgeable presenter... The majority of general comments made in the evaluations were of a very positive and constructive nature and further endorsement of the project's success.

A full copy of the evaluation reports are contained in appendix II , however included in the evaluations were comments such as:

This was very important and now I know why my neighbour has steam coming out of her ears most days.

This has been absolutely awesome and Margot has made such a difference to my life as a parent of FAE children.

We need to get this information out to mothers before they get pregnant.

Informative, interesting and well presented. My attitude has changed as a result of increased knowledge. Thank you.

Explains the behaviour of a significant number of students – that's scary.

Fantastic. I want to give up teaching and become a medical anthropologist.

A fascinating topic and one that is of concern in the schools.

I liked the emphasis on 1) avoid judging the behaviour. 2) avoid judging the parents.

Having two girls with this problem a lot of things I never understood are clear now.

Understandable overview of a serious problem in our society that I had "heard" about but had no information on.

It seems that the New Zealand public and non medical professionals are ready and hungry for information surrounding this subject. So too are pregnant women. Many people in the general population appear to be ill informed on this subject, some having no awareness at all. The end result of these educational workshops has, I believe, been a positive change in both awareness of this disability and a greater understanding of the wider implications affecting sufferers' and caregivers' quality of life. Feedback from workshops held for 179 Parents As First Teachers (PAFT) an organization involved in educating parents, national training (Appendix III) arranged by the national office of Early Childhood Development supports this. Among the comments were:

Keep better records if women have had a drink of alcohol during pregnancy. It can make a difference.

Be more assertive regarding pregnancy/alcohol and attempt to let people know the disastrous effects.

Be more observant in looking for possible FAS/FAE mothers and babies.

Everyone should know about FAS/FAE.

The first time I have heard this talk. Absolutely amazing, scary as to the implications – short term/ long term.

Not to be judgmental about families.

This is a topic that needs to be brought to the attention of every person in this country.

This is the biggest issue facing the women of NZ.

I didn't know anything about this so I feel to me a book has just been opened and now I have to keep reading.

Every presentation that I have carried out over the last five years within the New Zealand public has been met with similar comments. To sum up the role and importance of education and awareness surrounding Fetal Alcohol Spectrum Disorder, I feel compelled to quote from an American psychologist residing in New Zealand by the name of Beverly Lundell, who on page one of the August 2002 Fetal Alcohol New Zealand national newsletter states,

One must take the seriousness of FAS, drinking during pregnancy, beyond themselves to the greater community to aid in prevention and support of those already affected. As one is called upon, we must take the responsibility to bring awareness and consciousness in this preventable disability.

CHAPTER EIGHT

Access to Diagnosis and Health Implications

Doctors' and social agencies' knowledge base on this issue obviously impacts directly on both the families and individual clients in terms of access to diagnosis and management. With minimal knowledge comes minimal access to specialised paediatricians or psychologists by way of referrals for the purpose of diagnosis. Most of my participants found the road to obtaining a diagnosis through a specialist paediatrician an extremely difficult route to travel. When asked about how they obtained a referral to a specialist most had the experience of having to really take their general practitioners to task.

The only reason she [doctor] finally agreed to write a referral letter was because of my insistence and the fact that she had seen that program on T.V.⁵² ... she [doctor] was surprised to find out that 1-3 drinks could do damage and I said 'Yes I know and I drank a whole cask of wine a day, look at his behaviour, I want him looked at'.

* * *

The only way I got an appointment with a specialist to test for Fetal Alcohol was to demand and insist on a referral from my doctor, I have never demanded anything from my doctor ever, but my friend who knew about FAS – cause she has a child with it told me to go in there and demand.

* * *

Well... we knew she was fetal alcohol, it was written all over her face and things. I said to CYPS she needs to be diagnosed. We argued the point that it had to be done so she could get the help she needed. Plus we had to find out ourselves cause she was a real handful when we first got her. It was a nightmare. Oh Yeah, Yeah, we'll get around to it, we'll get round to it. Then one day I was fed up and tired of fighting for seven months over this. So I did it myself, went to my doctor, to my GP and he referred me to the hospital. I went to the hospital and she did all the tests.

* * *

⁵² 'Drinking for Two' a New Zealand documentary produced by Communicardo and ALAC.

A lack of awareness unfortunately can result in a lack of monitoring and follow up procedures for possible problems, physical as well as mental health problems associated with FASD. Many sufferers of prenatal exposure to alcohol, as discussed earlier in this thesis, appear to be susceptible to serious birth defects and continual illnesses.

Just over 58% of my participants' charges were reported as having obvious birth defects as babies, with 19% identified as having heart murmurs and other heart problems. Other common medical problems presented were urinary tract problems, kidney blockages, glue ear and continual ear infections, lack of fine motor skills, problems with weight gain, feeding,⁵³ colic type conditions.

Prior to diagnosis the frustration experienced by my informants was generally at an unacceptable level, everything they did just did not work. Sleep programmes appeared to be the most common initial help offered and were often given to the new parent with an order to adhere to the programme and all would be well. After several weeks of implementing the sleep programme and no changes in sleeping behaviour most parents returned to their doctors or post-birth care agency. When informing the professional that the programme simply did not work, they found themselves being held responsible for its failure, accused of not following the programme properly. Reading between the lines many of my informants felt that their parenting abilities and honesty were being questioned. Others felt their local medical practitioner simply refused to believe their descriptions of what they were experiencing at home, attempting in many circumstances

⁵³ This is often due to poor muscle control of the mouth making sucking movement difficult to achieve.

to explain the behaviour as being caused by over-anxious parenting. One of my informants described her situation with her baby as follows:

He cried and was colicky, you couldn't put him down. He was the epitome of the nightmare baby... there was one crunch point in time when he would have been about ... oh... thirteen or fourteen months old when I took him to my doctor and I said, 'There's something wrong with him! Please do something.' He just looked at me and said 'Mrs, he's very highly strung and you will just have to learn to cope' and sent me home.

Many of the caregivers described being wakened nightly by their child screaming; several participants referred to these incidents as 'night tremors'. This is when their child has a startle-type response during their sleep causing them to wake screaming uncontrollably. I have witnessed this sleep disturbance on numerous occasions, and during the episode the child is quite inconsolable. It appears to be neurological in origin, with the ability to disturb sleep patterns. Four of my informants described the experience in the following ways:

We called them night tremors until he was about 10 although from then on he still had them periodically... we got him onto medication when he was 4 or 5 and it got 80% control over them...

* * *

You just couldn't comfort her once she was awake, she would just sob herself back to sleep. I felt so.. helpless there was nothing I could do to make whatever it was go away, every night for the first 7 years, then they suddenly stopped.

* * *

Absolutely scream and scream, for the first ten months we didn't get a full night's sleep, she would wake up absolutely screaming.. You couldn't console her - it was very difficult. Sometimes we would take turns... Ben would say, "I know I'm not going to be able to settle her, you'll need to do it." Sometimes he could but she used to sob and sob and sob. Just crying her little heart out on my shoulder, might only be for five minutes then she would go to sleep and I would put her down again. She may wake again in two hours, she may sleep through... I'd think oh my God, here it goes again!

* * *

Screaming fits at night... Yeah, what did we used to call them? We called them night terrors, that's what we called them. I couldn't even go near him, George was the only one that could console him, I couldn't console him at all.

When my participants spoke of their children as babies and young children, the odd facial cranial features exhibited by some of these children were described by their caregivers as 'ugly', 'odd looking wee thing', 'funny looking kid', 'a pathetic looking waif, you know little, tiny, quite ugly really', 'looked like a little pixie'. One participant recalled the first night they had their first new adopted baby Jan, sitting in her pushchair. After staring at his new baby for a long time and a long period of silence, he said, 'She's funny looking isn't she, can we take her back and get another one? She's really ugly!' Horrified at her husband's suggestion, the new mother informed her husband that there was no way this child they had waited on a list for years for, was going back. Their new daughter in her mind was perfect, she had all her fingers and toes and besides neither of them were stunning beauties. This ended up being a decision about which my participant in hindsight said,

If I knew then how much heartache, worry, sadness and frustration I have gone through with Jan growing up knowing something was wrong, but no one would believe me except my husband - all focused on or around that funny looking wee baby. Yeah, I should have given her back.

Most of my women informants instinctively felt something was wrong with their young baby not just because of developmental delays but visually, as the following three of my participants stated:

Then I read about Fetal Alcohol and the wide apart eyes, and thought yes, that's it, and a couple of other face things is just about there but it is minor. Just little things like that made me want to know more.

* * *

I don't know what was wrong but she was different, that's the only way I can describe it. To me, Mary looked like Down's Syndrome people would go up to her pram, cause we had a new baby. Yeah, you could see them struggling for words for this funny little thing.

* * *

Yes, club feet, and she has had earaches since she was a toddler, and she has had glasses there for a while. Her face always looked deformed ... always. You always knew that there was something wrong with her.

New Zealand appears to be most resistant in accepting the diagnosis, particularly by a high percentage of medical as well as current social services. On a national scale, there appears to be a tragic lack of standardized protocols and guidelines for professionals to follow when dealing with affected individuals and their families. Access to specialist professionals in certain geographical areas of New Zealand is also a serious issue. There appears to be a reluctance to refer these suspected children to medical professionals scattered around the country that specialise in FASD diagnosis. The situation is exacerbated by current area health funding if the specialist practises out of another public hospital in another geographical area.

A case study that highlights this problem surrounds a child who is currently 12 years of age under the care of the Child, Youth and Family Service (CYFS). In June 2003 at the age of nine years and three months a public health developmental paediatrician reviewed Amanda. During this particular appointment the Ritalin dose Amanda had been prescribed for ADHD behaviour since the age of five was being checked. The paternal grandmother accompanying the child, when asked, denied any maternal drinking had occurred during pregnancy. On examination the doctor noted in his report,

Amanda, aged nine years three months. Amanda continues to attend school in [geographical area]. Unfortunately she does not receive any teacher aide assistance, ORS funding, nor ongoing OT or PT. Amanda can be a little verbally impulsive, and often attention seeking. Her behaviour is variable from day to day, not due to taking Ritalin. Amanda remains emotionally dependent and anxious... Amanda was happy, talkative and remains emotionally immature... and head circumference is 48cm below the 3rd percentile. Mild dysmorphic features... Firstly I do not think Amanda needs an increase in her Ritalin, but she clearly needs education. Ideally Amanda should receive teacher aide assistance, in addition to the small amount of reading assistance at present...

At a later date when contacted by the Fetal Alcohol Trust, which at this time were acting as advocates for the family, this same doctor stated that the only reason he didn't diagnose Amanda as Fetal Alcohol Syndrome was due to the misinformation surrounding maternal alcohol consumption. However, now that he knew the maternal drinking history he felt that Amanda's facial features, cognitive ability and behavioural deficits fitted the FAS profile. He felt confident giving a diagnosis of PFAS.

Due to the lack of acceptance by CYFS that health issues and behaviour exhibited by Amanda could be due at least in part to FASD and the minimal educational assistance received, the Fetal Alcohol Trust once again advocated on behalf of the family for access to a paediatrician specialised in FAS diagnosis. The argument presented by the trust for the referral was sound and sadly correct. 'Without a correct diagnosis the needs and requirements would, and could, not be met'.

Amanda's behaviour began deteriorating seriously at her new school. She was described by those witnessing her behaviour as having 'lost the plot' and becoming unmanageable. A serious episode involving other children occurred which interestingly

coincided with the child experiencing a major routine and environmental change. FASD children, we know, do not cope well with change in any form and tend to express their inability to cope with unacceptable and often aggressive behaviour.

Because of this latest episode at school Amanda was sent to be assessed by the psychologist for Child & Adolescent Mental Health Services by her CYFS caseworker. This was a caseworker who was reported by the FASD advocate as a person who quite simply did not believe in the existence of FASD. The family advocate argued that unless the person doing the assessment was familiar with FASD diagnosing, it was a waste of time and tax payers' money.

The result of this psychiatric assessment was that Amanda was diagnosed as not suffering Fetal Alcohol Syndrome but rather Post Traumatic Stress disorder. This diagnosis comes as no surprise to me. Fetal Alcohol Spectrum Disorder or any other terminology associated with the results of prenatal exposure to alcohol are not included in the Psychiatric Classification DSM-IV, meaning it simply doesn't exist for those professionals who are solely dependent on the current DSM-IV manual as a diagnostic tool. Dr Kieran O'Malley, the Acting Assistant Professor in the Department of Psychiatry and Behavioural Sciences of the American Washington State University, describes FASD as a 'neuropsychiatric condition' one that involves on-going mental health problems. Dr O'Malley, as well as his appointment at the University, has a Community Psychiatry Consultation practice in Calgary Canada solely with patients suffering FASD and autism. Other international research identifies a high rate of

psychiatric problems exhibited by those affected by FASD (Famy, Streissguth, Unis 1998, Streissguth 1996, Streissguth, O'Malley 2000).

The Trust again advocated for the involvement of a paediatrician whose expertise included diagnosis of FASD and on behalf of the family lobbied CYFS for an appropriate referral for Amanda. The result was an appointment made for July 2003 with the children's clinic for paediatric assessment generated by CYFS. While waiting for that public system appointment, a private appointment in February 2003 was offered and accepted by the family from an Auckland paediatrician, considered by many as an expert in FASD diagnosis. This appointment was to reassess some of Amanda's health problems, in particular, problematic behaviour and learning deficits in school. Financial aid to make this happen was loaned to the parent by the much under-funded and under-resourced Fetal Alcohol Support Trust.

After Amanda, then aged eleven and three quarters years of age, had her assessment, the Auckland specialist's report states,

Amanda was born at 36 weeks gestation. Her mother [name] was drinking heavily for the first four months with her husband regularly daily and bingeing at the weekends. At birth Amanda was thought possibly to have a chromosomal anomaly and was transferred down from [place name] to [place name] for investigations. She has subsequently had slow development, walking at nearly two years of age, late talking and is still two years behind at school and struggling. She has been held back one year. I note she has no special aide at school. She is reading just appropriately for her age and is attending [name] Middle School.

Last year, in November, Amanda had some suicide attempt apparently following... This issue has been investigated and is closed now... She is described as anxious, highly-strung and prone to outbursts and quite weepy at times. She

occasionally lashes out at other children. She is teased and bullied by other children and has difficulties in making peer friendships. She is having difficulties in understanding the consequences of her actions at times.

On examination Amanda is an attractive child with slightly unusual face, mild Mongolian slant and slight epicanthus. Her head is small on the 3rd centile... General examination was essentially normal. She is showing signs of puberty with... Amanda has a history that would be consistent with Fetal Alcohol Syndrome, and certainly Fetal Alcohol Effects. She is dsymorphic and has microcephaly, she has had developmental delays and attention deficit problems since birth. She also has a psychological profile that might suggest a fetal alcohol influence on her brain development.

My recommendation would be that she should certainly have consideration given to having a Teacher-aide in the classroom given her problems, to make sure that she does not fall further behind with her limited educational abilities.

A copy of this report was automatically forwarded to Amanda's General Medical Practitioner who in this circumstance was obviously the source of the referral. When CYFS were told about the diagnosis carried out in Auckland they appeared to be reluctant to accept the results, insisting that Amanda attend the July appointment at a public Hospital Children's Clinic in their current health area as they had arranged.

Amanda attended that review, but not before a meeting involving agency appointed medical and welfare professionals (not including the family doctor nor specialist paediatrician), all of whom were involved with Amanda, was called by CYFS. This meeting interestingly and perhaps conveniently was called and attended while the family FASD advocate was away attending a two week FASD conference in Canada. Amanda's birth mother states that no one attending this meeting including doctors and caseworker, would acknowledge the Auckland diagnosis and said,

I was finally told what they thought was wrong with Amanda as Dr [name] wouldn't give me a straight answer when I asked her before. Dr [name] (Child

mental health) had decided Amanda was not ADHD or FAS but had Post Traumatic Stress Disorder, from what she had been through. I then stated that Amanda had a confirmed diagnosis of both ADHD and FAS. Once again I got shot down for this... and the girls would stay at [name] house until another home can be found for them.

As earlier pointed out, Amanda attended her agency-arranged appointment in July and subsequently the interview and report was carried out by a Registrar who had not seen her before. The following list consists of presenting issues identified and listed under the heading 'Problems':

- a. Behavioural and learning difficulties with Attention Deficit
- b. ?Foetal Alcohol Syndrome
- c. Altered appetite
- d. Previously under legal guardianship of CYFA
- e. Mild Eczema

The subject of Fetal Alcohol Diagnosis was obviously in doubt as it had a question mark placed before it. As for presenting problem item d, I'm not sure just how the fact that this child had previously been under legal guardianship of CYFS was identified as a presenting problem. Under the heading of history the report stated,

I saw 12 years and 3 month old Amanda in Dr[name]'s Outpatient Clinic for review today with her mother and her caregiver grandmother. I felt caught in the middle of a debate with this particular consult. As you are aware Amanda has had a number of behavioural problems over many years and has been investigated in[place name]. Most recently Amanda was looked after by Dr [name](first specialist in this saga), Paediatrician in Auckland since 1977 and he diagnosed Attention Deficit and Foetal Alcohol Syndrome. She was seen in the Paediatric Outpatient Clinic here in August of last year by Dr [name], registrar then Dr [name]... Suffice to say that her behaviour has been difficult to control at various times and most recently she has been involved in the [name] Fellowship, which is a group who deal with particularly behaviourally challenged children in school, and also Dr [name] from the Child and Adolescent Service. In the time I spent with Amanda, I could not comment on the ultimate etiology of her behaviour, however she was very labile with her mood, while at the time seemingly cognitively aware of more than she was willing to admit to. During the consultation... The medication trails do not seem to have been very successful and currently Amanda is being weaned off Aropax started at Child and Adolescent Services... soon she will be on no medicine.

Recently the parents have been concerned that Amanda is not eating particularly well, however on her growth chart she has moved from the 25th centile to above the 50th centile in a matter of 6 months

On examination the doctor wrote,

On examination she looked well grown, alert and active... She had the unusual facial features as previously described and I have had photos of these done for documentation today. She has no other dysmorphic features; in particular she had normal hands and feet, which are not particularly small. Her eyes did not look particularly almond shaped.

The next part of this medical report was concerned with the opinion of the doctor carrying out the examination. He wrote,

When Dr [name] saw her earlier this year was not particularly impressed that she had Foetal Alcohol syndrome and possibly Foetal Alcohol effects would be more likely if anything. In the meantime the family have attended Dr [Auckland specialist] in private in Auckland at the [name] Medical Centre, where they say she had been diagnosed once again with Foetal Alcohol syndrome. The family once again failed to bring along those reports but said they would send them to me... We have decided to ask Dr [name], Paediatrician who has a particular interest in Foetal Alcohol Syndrome and Effects to look at her and give us his opinion and I will forward the photos to him for the Washington Facial Scoring system prior to meeting with Amanda...

What's wrong with this picture you ask? What is of major concern is that a child presenting with a history of behavioural and learning difficulties, who already has two independent FASD diagnoses, was sent for yet another assessment. Not to mention the chromosomal anomaly suspected and later proved unfounded after doctors identified this infant's facial cranial features as being far from normal at birth. Having her feet and hands used as a measure for the diagnosis of FASD is both unusual and incorrect. I have come across problems with the development of nails in babies but never having small hands and feet as part of the diagnosis. The Auckland medical report states 'She is dysmorphic and has microcephaly'.⁵⁴ That does not mean she has small hands and feet.

⁵⁴ As discussed earlier, the older the child gets the more difficult it is to identify facial cranial anomalies of pixie looking, or looking like Down's syndrome babies.

To be fair there are thousands of medical conditions affecting children that paediatricians have to face on a daily basis, no one can be an expert in all. But a small amount of brushing up on available current medical information concerning physical, learning and behavioural problems associated with this disorder would perhaps make a huge difference. Judging from the last medical report, the actual diagnosis had been previously discussed and in dispute.

When Dr [clinical director] saw her earlier this year ... was not particularly impressed that she had Foetal Alcohol syndrome and possibly Foetal Alcohol effects would be more likely if anything.

This argument seems to suggest that possible Fetal Alcohol Effects which in lay terms means 'brain damaged', is a lesser problem than Fetal Alcohol Syndrome therefore bears no consideration for any future treatment for mental health issues. How on earth are we going to deal with presenting mental health problems if we don't acknowledge the possibility and the wider treatment implications of brain damage? How can treatment be effective if it does not take into account the individual's often limited cognitive and adaptive functioning associated with FASD?

Amanda's history is not unlike others who have serious learning and behavioural deficits through FASD . Tragically in Amanda's case, several serious suicide attempts were made by the age of 12 years. This anecdotal evidence is to me a pretty good indicator that presenting issues need be taken seriously, particularly in light of a medical report that states 'various medication trials do not seem to have been successful'. Perhaps the suggestion that brain damage may be responsible for her behaviour should

have been investigated more fully. Amanda's caregivers observed that she had been in a 'zombie state' when picked up [from a home for particularly behavioural challenged children] as well as days off school due to being in a 'zombie' state, and being unable to stay awake after having what appears to be a possible serious reaction to a new medication.

I got a phone call from [mental health case worker] to say she was coming over, which she did. When she got there she gave me the script for another type of medicine and told me it was from Dr [child and adolescent mental health CAMS], this was on Thursday. I gave it to her on Tuesday morning and she had such a bad reaction from it I had to keep her home, she was like a walking zombie, she couldn't keep awake. Mum rang Dr[name] and told her about Amanda's symptoms. She got into a huge panic and told mum to take her to a doctor straight away. Mum got off the phone and told me this, she said in her opinion I didn't need to take her as she was a lot better by then. At about five [CYFS and CAMS case workers] turned up at my house. I had a friend here so they asked to speak to me outside.

I did this and it was then [CAMS] told me that they wanted Amanda to go to [name] house to have medication given where she could be observed. I was hesitant at letting Amanda go as she was still very unstable after the [allegations of school yard advances of a sexual nature occurring] affair. I then rang mum who came down and we all talked. [CYFS] then told us if we wouldn't let Amanda go she would be removed by the police. At this time I agreed but not without protest as I thought this way would be less upsetting for Amanda. Amanda left with them.

Just how much inter-agency dialogue has been actually going on concerning this child?

Obviously the registrar was not privy to viewing the diagnostic report carried out by the

Auckland Specialist. He appears to be aware as he verbally alluded to its existence.

CYFS and the Child, Adolescent Mental Health Service (CAMS) who were major

players in this child's care and protection and actively involved in the psychiatric

treatment were provided with a copy of this diagnosis, yet appear to completely negate

the diagnosis as a possibility during this meeting.

Why wasn't a copy of this legitimate Auckland diagnosis (obtained through a serious financial commitment on the part of the mother) attached to this child's medical record? I wouldn't have thought it was necessary for the caregivers to be held responsible for the registrar not sighting it, considering the extensive number of agencies involved in the care and protection that had been notified in writing and supplied with a copy of the diagnosis. Why was it so important to spend time disproving the specialist who works for a different health authority in the largest children's hospital in New Zealand? This precious appointment (in New Zealand, the public health system has notoriously long waiting lists) would have been better spent investigating her current cognitive and adaptive functioning skills. This could have a huge influence on the type of treatment or ongoing support and intervention necessary for the current or future management of this individual, especially if tests indicate brain damage. I don't understand what was achieved by this appointment, her eye sockets (a measurable anomaly for one end of the FASD continuum) were not even accurately measured. Instead it was reported that her 'eyes did not look particularly almond shaped'. The outcome of this long awaited appointment was another waiting list for an appointment assessment by another paediatrician within their hospital, whose professional opinion obviously counted, unlike the Auckland specialist.

How well prepared was the primary caregiver of Amanda (who has serious literacy problems) by medical and other professionals involved in her treatment to ensure she understood the medical implications surrounding side effects of Amanda's condition? Even the implications of withdrawal? Amanda has been on the drug Ritalin (a stimulant)

since she was five years old (a worry seeing as it is not recommended for a patient under 6 years of age). This was stopped abruptly and exchanged for a drug called Aropax over a year ago, and Amanda is now, as the registrar states, in the process of ‘weaning off Aropax started at Child and Adolescent Service’.

Aropax is a Paroxetine Hydrochloride, a drug similar to Prozac but manufactured by a different pharmaceutical company. This drug is listed as having the potential for increasing panic symptoms at the beginning of treatment when used to treat panic disorders. Aropax is generally used for anxiety, depression or obsessive-compulsive disorders, but has addictive qualities requiring a gradual withdrawal. This is another factor that seems to coincide with Amanda’s deteriorating behaviour both at home and in the classroom as did the change from Ritalin to Aropax medication. What social support was put in place to monitor and assist the caregivers with possible behaviour that could be due to medication or detoxing, particularly in light of her being ‘difficult to control at times’? After all, the child was in the birthmother’s care and the fact that CYFS had insisted this birth parent attend parenting classes not once, but three times over a three year period if she wanted custody back, indicates their view on this parent’s parenting skills (which may be well founded).

This parenting course in itself can be a particularly frustrating experience for the parent, in that the course is not designed for these special needs children – what is taught just doesn’t seem to work on FASD children. Yet where was the family support or the home monitoring to ensure this parent was helped to deal with what could be an extremely

volatile situation, other than several doctors' appointments? The family to this day have little or no understanding of what occurred at the CYFS group home and why she was agitated and in a 'zombie state' when she left. This parent, who is trying to the best of her abilities to be a good parent, is being completely left out of the loop as to her daughter's medical matters rather than being fully involved or consulted. It almost appears that complete ownership rather than guardianship of this child rests firmly with CYFS, the medical team, and the courts.

I mention the court because this situation is sadly complicated and not complete. While this part of my thesis is being written, a judge of the New Zealand court who has no idea of the implications, needs and requirements of a child with FASD, is in the process (with little objection from CYFS) of giving custody to the birth father who has had little to do with these children in previous years. This person may or may not live in an environment more suitable but lives in a totally different geographical area. Therefore, I do hope for the sake of CYFS and the new caregiver, that they put in place serious monitoring and support strategies to assess safety and educational requirements surrounding this child. It is imperative that they empower the birth father to succeed as a permanent caregiver through education around FASD. If there is to be any hope of success and a reduction in possible secondary disabilities, understanding of this disability in order to cope and deal with what will be difficult challenging behaviour will only come about through knowledge. An environmental change is not going to suddenly make all problems disappear over night. Granted the occurrence of secondary disabilities will diminish with appropriate environments but appropriate environments generally

involve serious intervention strategies and a full understanding of the cognitive and adaptive functioning limitations. Amanda's special needs, given her current and ongoing mental health issues compounded by serious learning and behavioural deficits, must be met. Equally a realistic level of support and resources (particularly respite and FASD education) must be provided for whomever ends up with full custody of this child in order for the placement to be successful.

This case study is not meant to negate or refute the fact that there are those working within our health and social agencies who are well aware of the implications and seriousness of the diagnosis FASD. These persons act accordingly in areas such as support and placement, ensuring intervention is an ongoing process. A good example of this is in the form of an advertisement placed in the *North Shore Times* on the 16th of November 1999.

Ana

Ana is 10 months old. She is Cook Island/Maori/European. Ana is an alert and responsive child who is reaching her development milestones appropriately. Because of concerns about the possible effects on Ana of alcohol and drugs in utero, Ana has had, until recently, paediatric oversight. While there are no present concerns, the possibility of future problems cannot be eliminated. Ana requires parents who have knowledge, ability and experience to meet her present needs and possible future special needs. Contact with biological family will need to be maintained. Applicants must live in the Auckland region. If interested please contact:

Child, Youth & Family
Telephone 914-1155
(Office Hours)

**PERMANENT
PLACEMENT
UNIT**

The advertisement features a silhouette of a young child standing next to a bag. The text is arranged in a column on the left, and the silhouette and bag are on the right. The title 'Ana' is in a dark box at the top left. The contact information is at the bottom left. The 'PERMANENT PLACEMENT UNIT' logo is at the bottom right.

Figure 11. Placement advertisement North Shore Times 16/11/99.

Several of my informants, all of whom were from the largest city area in New Zealand, had nothing but positive experiences from their medical and CYFS caseworkers. They have been open and honest and actively supportive with access to appropriate services to help deal with presenting behavioural problems and organising what should be mandatory appropriate respite care. Unfortunately these caseworkers knowledgeable on FASD, appear rather thin on the front line and are far outnumbered by those who have no understanding or minimal knowledge surrounding the implications of FASD.

This advertisement, which to my mind was both appropriate and responsible given the level of difficulties that can be associated with these children, ensured neither the future foster parents nor the child are set up to fail. This open policy gives the prospective caregivers the opportunity to learn about this disorder. This gives an opportunity for an informed decision on whether this child will suit an existing family environment or, as has happened on many occasions when caregivers have been unaware of this disorder, rocked its very foundations. This type of upfront case management will in turn lower the frustration levels of both parties. Anticipating and knowing how to deal effectively with certain problematic behaviour that often accompanies FASD ages and stages is imperative to success. Understanding the limitations and identifying certain behaviour as an expression of the brain damage will allow the foster parents and respite families to place far more realistic responsibilities, expectations and understanding in the home.

This informative advertisement was placed by the Auckland Child Youth and Family Service (CYFS), and is in total contrast to the very same agency in a different

geographical location - those currently involved with Amanda's care, who deny her condition. This situation, and many others I have come across, show an alarming lack of continuity across the country highlighting a general lack of national guidelines and protocols surrounding clients with this diagnosis. There exists a serious need for all those employed within our social and mental health services to have a sound understanding of the problems that may impact on their ability to provide appropriate and cost effective services to accommodate clients diagnosed as FASD and their families.

During the writing of this thesis I have had many experiences involving the negation of this diagnosis by a multitude of agencies including youth justice. This I believe is the result of not understanding the broader implications this disability can have on existing processes and, as with many medical professionals, personal attitudes. One particularly sad story started with a phone call from a psychiatrist employed by social services to work with a mother who was not coping with her two children, both of whom were diagnosed as suffering FASD.

CYPS had been involved with these children for many years as the mother had been dealing with some serious addiction problems for many years. It was through her addiction that I had come to know her and her oldest child years prior to my phone call, in my capacity as a caseworker for the National Methadone Services many years ago. The psychiatrist said that her client had seen me on the 'drinking for two' documentary and asked if I would work with her client in a professional capacity helping her

understand her children's disabilities and help with parenting strategies. She believed that her client's confidence and self esteem was being eroded by her inability to deal with her children's serious behaviour deficits.

Due to the fact that I had known her client previously I agreed to work with her. I had always got on well with this woman and knew her history well. When working as her caseworker I had always found her to be easy to deal with and generally a nice person who really did try to be a good mother to her then one child. Over the two years I worked with her she had always really tried to break her addiction habit. In my view her early relapses were in part caused through the unhealthy relationship with the father of her children, a relationship she did not seem able to leave, that was both physically and mentally violent. When I left my place of employment she was illegal drug free and now was reported as being totally drug and previous husband free.

I always remembered her as a kind, caring person whose child was the motivational force for attempting to be drug free. Her daughter always appeared an extremely bright, hyperactive young child that demolished an entire room in fifty seconds, one that rarely complied with her mother's requests. I found the child hard work when she was present at her mother's appointment. In fact, exhausting would be more appropriate and I only had to deal with her for up to an hour. I shudder to think how mentally exhausting care giving would be, twenty-four hours a day, seven days a week.

The psychologist and I agreed that the CYPS office in charge of the family would make an appointment with the proviso that they provide an office or room for these meetings to take place. Many months passed and I heard nothing and eventually forgot about my phone conversation, when out of the blue I received a phone call from the CYPS caseworker.

The caseworker introduced herself and asked if I would be prepared to work with a family who were about to foster a FAS child. I questioned her about the child's history and was told her mother had recently committed suicide with a deliberate drug overdose and a family member was to take custody. The case worker then went on to say what a shame it was as the mother had been one of their 'success stories', she had been drug free for two years and had successfully completed two parenting programmes with flying colours. At this point, sadly, I realised that this child's mother was the same person I had been contacted about many months prior; this whole episode could hardly be considered a success story. This was a case of too little, too late and once again parenting programmes designed to deal with children who are not brain damaged but rather need appropriate support. This is not to say that working with me would have prevented her taking her life, but as she had requested the help in the first place, having control over some of her children's behaviour may in turn have given her some feeling of having some control over her life. We will never know the answer.

Mental Health Issues

As for mental health issues, nearly 58% of my caregivers' charges suffering FASD in this study have a history of mental health problems including emotional instability. In the fifteen year plus age group, depression appears to be a serious problem with 63% of my cohort fifteen years and over suffering bouts of serious depression. Fifty-four percent had repeatedly threatened suicide, with 27% unsuccessfully attempting suicide.

Similarly 27% suffered serious panic attacks and 72% had issues surrounding Attention Deficit Disorder. Of this group 72% had been seen by psychiatrists and counsellors for problems including Attention Deficit Disorder, Conduct Disorder, depression, panic attacks, psychotic behaviour, Post Traumatic Stress Disorder and suicide attempts.

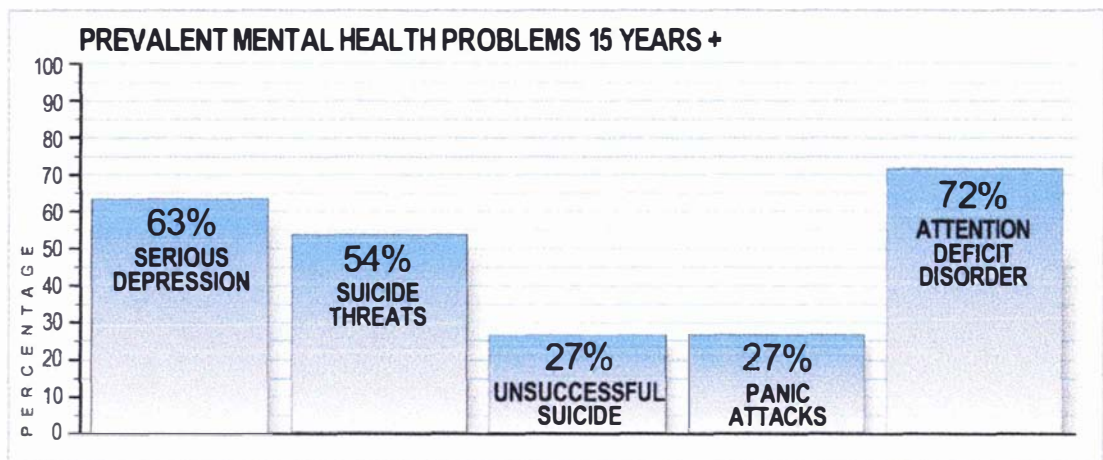


Figure 12. Prevalent mental health problems in FASD individuals. N=12

This client group are users of our current mental health services, possibly in large numbers, and to my mind bear serious consideration for monitoring. Family members need to be aware of signs indicating any common associated mental health problems. Referral must be made quickly to Mental Health Services for treatment and importantly

ongoing monitoring. It is imperative that those professionals involved in the mental health field have a high understanding of dual diagnosis issues. They must be able to understand the limitations of their clients diagnosed as suffering Fetal Alcohol Spectrum Disorder and have an understanding of the needs of the caregivers (the burnout rate is high). Those affected by FASD are not an easy client base to be working with. They can be frustrating and difficult to work with, they appear engagingly articulate, verbally give the impression of competence and comprehension of jointly created strategies designed to overcome problems being experienced. However on leaving the session, more often than not, they continually fail to use any of the planned strategies formulated. This is often because they have been unable to retain the information or quite simply cannot see how that strategy can be implemented. Brain damage created by prenatal exposure to alcohol often results in the individual having a strong ability to 'talk the talk' but more often than not, unable to 'walk the talk', accompanied by the inability to show remorse for past and present actions.

It is imperative that professionals understand the serious implications this diagnosis can have on care and protection, particularly placement and respite issues, regardless of their personal and unqualified views regarding alcohol as a teratogen. Acceptance and understanding should in turn develop into intervention strategies that acknowledge and accommodate this disability. Intervention can make the difference between another dismal statistic or a success story. New Zealand as a country has a sorry track record when it comes to the safety of many children within current social services, particularly in the area of placement. Unacceptable numbers of children are being involved in home

violence. We don't know how many of these dead or permanently damaged children could have been FASD whose behaviour has been the catalyst for violence.

Supervision Issues

Accidents play a huge part in health issues connected with FASD. These children appear accident prone with many being reported as spending a summer with plaster casts on legs and arms after accidents. However being accident prone is not the problem, rather the lack of being able to predict the consequences of actions and a serious hyperactivity problem tends to mean these children unintentionally hurt themselves, often seriously. Unfortunately many FAS/FAE children and adults require constant supervision including while at play. Dangerous play practice is a difficult concept to teach these children; in fact any notion of danger seems to elude them.

In my six to eleven year old cohort (N=16), 14% could always be left without supervision, 18% sometimes and 68% never. In the twelve to seventeen year old group (N=6), 16% could always be left without supervision, 50% sometimes and 34% never. However amongst the 18 years plus (N=8), 50% did not require supervision whereas 50% required it sometimes. What was disturbing was that 90% of the fifteen years plus group (N=12), were identified by participants as having a reckless disregard for the safety of themselves or others.

A good example of this situation concerns a ten year old girl who had a dangerous habit of hopping onto her push bike, riding as fast as possible straight out of her steep drive

without looking for traffic onto the opposite side of the road. She did this regardless of whether oncoming vehicles were approaching or not, then proceeded to weave up the road on the wrong side of the road (often encouraging a much younger playmate to

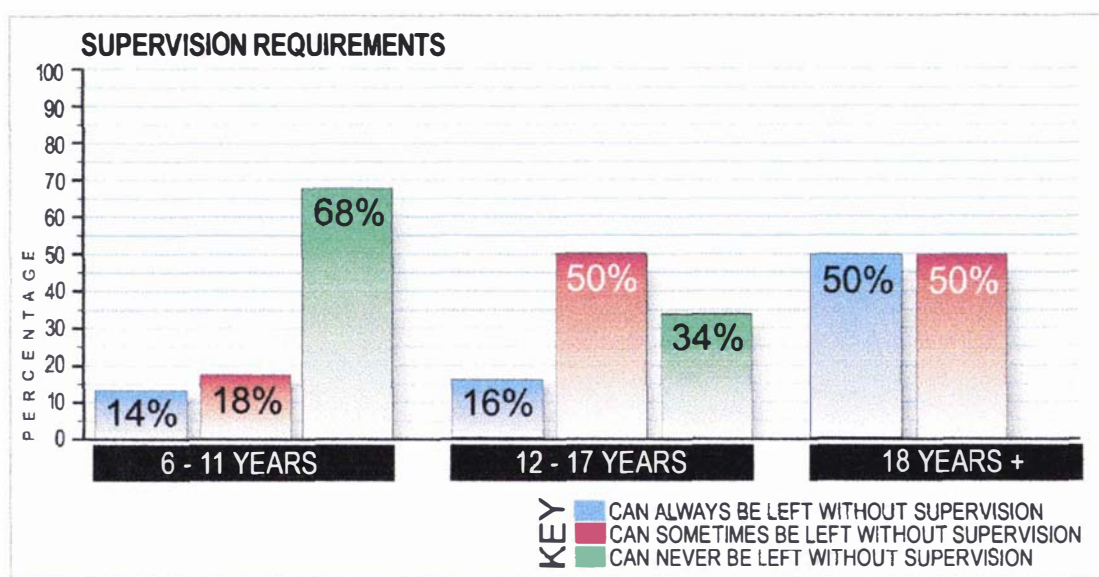


Figure 13. Supervision requirements. N=30.

do likewise). After being warned on several occasions about the possible consequences by her caregiver, her pushbike was taken away for a week as a way of punishment for driving carelessly and dangerously on the road. Strategies to prevent being driven mad by constant requests for the bike over that long week consisted of an enlarged print of that month's calendar week being placed on the fridge. Every morning that the child got up she would mark a large x in vivid red felt pen on the square representing the day and date. This turned an abstract concept such as time into a visual concrete concept that the child could be directed to when the dreaded 'can I ride my bike' question was asked. After two days the child ceased asking and would regularly go to the fridge to consult with the calendar.

When the long week was up she was allowed her pushbike back but was instructed that she was not to drive on the road as she had before but to use the footpath instead. All appeared fine – every time she was viewed by her caregiver she was cycling on the footpath. However on the third day the caregiver noticed she wasn't on the footpath – in fact, she was nowhere to be seen. At this stage my participant started to panic and ran up the road looking for her child and bike. To her horror both were located in an adjoining street where her child and bike with a pillion passenger were seen to weave in and out dangerously on the wrong side of the road between moving traffic.

When child and bike were walked home the caregiver started to scold the child for her actions which had been contrary to her instructions. Her child broke down into tears pronouncing her innocence, stating she had followed her instructions and was always using the footpath on the road outside her home as she was told to. She could not understand why her caregiver was so angry. This made the caregiver stop threatening more punitive action as at that stage she realized that her child had taken the instructions quite literally. She was heeding the directives and rules on the road outside the house, but couldn't associate the next street as being a similar situation whereby the same rules applied. This is not uncommon and examples of this behaviour were given by all my participants with FASD children over four years of age. It appears that it is extremely difficult for those affected by FASD to identify any given situation to be the same or similar to any other experienced situation where previously learned experience can be applied.

Many a burnt hand has been experienced by some of my participants' children, the most common being placing a hand on a stove element that is glowing red hot – not on a conscious level but rather on impulse with no idea of consequences. The child more often than not will learn from that painful experience and not attempt a repeat performance on that white stove at home. However they will think nothing of placing their hand on the next door neighbour's hot stainless stove element. Again no previously learned experience seems to fit the current situation. Accidents, as one can surmise, can occur frequently if these children are afforded no more than normal age appropriate supervision.

Access to diagnosis is a difficult path to undertake, experts in diagnosing are few within New Zealand. This situation is further complicated in many circumstances by non-expert professionals especially in the medical profession ignoring expert diagnosis in favour of a treatable diagnosis which in many cases is treating just one of the manifestations of FASD. Internationally, research indicates that most FASD clients suffer ongoing mental health issues through out their lives. It is imperative for all our mental health professionals to have a sound knowledge of all aspects of FASD and in some situations I believe a moral and ethical responsibility to acknowledge other medical professionals diagnosis or at least enter into dialog with the other diagnosing professional to ensure misdiagnosing is reduced to a minimum. FASD will not simply go away if we ignore its existence, which sadly appears to be a recurring theme within New Zealand medical communities, especially mental health arenas.

CHAPTER NINE

Developmental Delays

Out of my research group, 52% as babies were identified as having developmental delays in talking, 36% experienced developmental delays in walking and 41% were reported to show serious hyperactive behaviour.

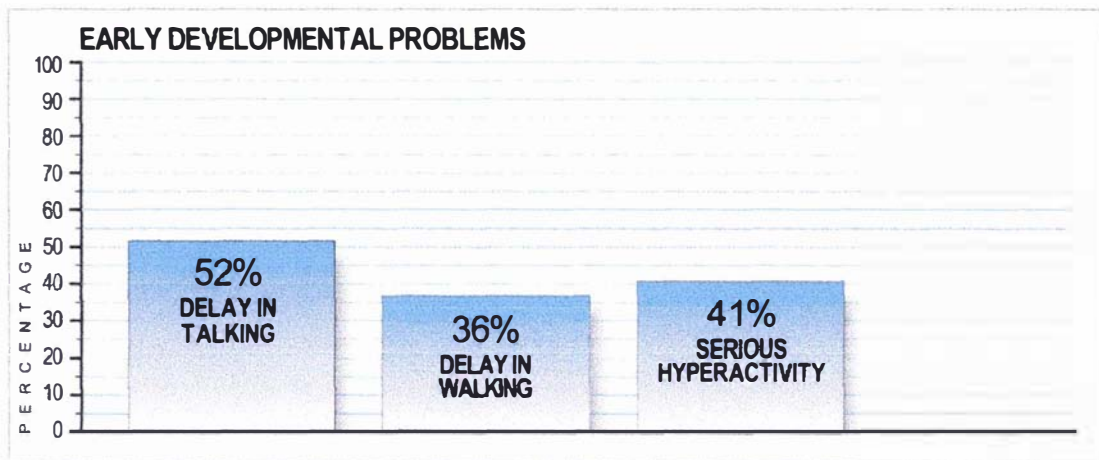


Figure. 14. Early developmental delays. N=38.

Four of my participants described the early development of their children in the following ways:

He was about eighteen months old, all his milestones had been right on target, but his talk was still very unintelligible and he was always a clumsy sort of child. I took him to the doctor because of his speech. They gave him audio tests and said if his speech 'wasn't firing' by the time he was two, then they would actively do something about it. So when it wasn't firing away, we took him back and he was referred to a children's clinic... he had his own language until he went to speech therapy, when he was three or three and a half. So that was the mode of

communication up to that point when he went to the therapist. Plunket⁵⁵ I think organized it.

* * *

He was...was dead wriggly, really, really wriggly, you couldn't even hold him...you know at three months, at five months he was rolling everywhere. It took two people to put a nappy on him...he was allergic to nearly everything. He was on soy milk, but he was allergic to sugar, salt any dairy products, everything until he was about twelve months old...He had asthma and eczema as a baby. He still has asthma now but not all the time.

* * *

It took them ages to get her to talk at Kindy. If she is determined to do something it's real hard to get her to change her mind.

* * *

She was always sickly with bad glue ear and well behind in her development. She started walking well after any of the other kids and her speech was slow and her vocabulary really poor compared to everyone else's kids as well as my own.

The list of common behavioural and developmental problems that follows is taken mainly from a booklet published by the Canadian Society of Special Needs Adoptive Parents (SNAP), the Adoption Council of Canada (Graefe1998). What I think is of immense importance is that this Canadian booklet was the result of both caregivers and professionals contributing to the content creating a user-friendly informative guide book for parenting FAS children. This list is by no means exhaustive as all persons affected are individuals, and no two persons affected by FAS are going to exhibit exactly the same developmental and behavioural manifestations. Few, if any, will show all these problems, but all will identify as having experienced a large number of these difficulties. This list is a guide only and is in no way a diagnostic tool as other medical problems can be expressed in similar ways.

⁵⁵ Plunket is an organization that provides support and help to mothers with newborn babies. It was created and established in New Zealand in 1907.

INFANTS

- ◆ Feeding problems often due to weak sucking reflex and poor muscle tone (feeding can take hours).
- ◆ Cries a lot, irritable and trembles a lot.
- ◆ Often disinterested in food
- ◆ Slow to reach expected age appropriate developmental milestones (walking, talking toilet training etc).
- ◆ Sensitive to sound and sight, particularly touch.
- ◆ Failure to thrive (weight gain a problem).
- ◆ Often ill due to a susceptibility to illness.
- ◆ Sleep disturbances creating erratic sleep patterns that have no predictable wake sleep cycle.
- ◆ Bonding difficulties often with primary caregiver and other family members.

PRESCHOOL

- ◆ Poor coordination due in part to poor fine and gross motor skills.
- ◆ Short attention span.
- ◆ Extremely social, indiscriminate with relationships and often overly friendly.
- ◆ Unresponsive to verbal warnings and is unable to comprehend the concept of danger.
- ◆ Exhibits non-compliance and temper tantrums.
- ◆ Hyperactive and easily distracted.
- ◆ Cannot deal with change, responds well to structured routine.
- ◆ May be excessively talkative and intrusive giving the impression that speech is not impaired or has less depth in language than peers and expressive speech is delayed.

- ◆ Exhibits more of an interest in people rather than objects.

EARLY SCHOOL

- ◆ Poor performance of learned tasks may seem deliberate, but child suffers ‘flow through phenomena’ a lack of retention ability with information.
- ◆ Doesn’t appear to learn from experience, an inability to utilize previously learned behaviour in a different setting.
- ◆ Clumsy from poor gross motor control and difficulties with tasks requiring fine motor control such as handwriting, shoelaces, buttons etc.
- ◆ Has difficulty with understanding or predicting consequences
- ◆ Difficulties with mathematics rather than reading or spelling.
- ◆ As age appropriate classroom attention requirements increase, the child exhibits noticeable attention and/or memory deficits often accompanied by a serious lack of impulse control.
- ◆ A tendency to socialize with adults or younger children than with their own peer group.
- ◆ The internal time clock seems to work sometimes or not at all, tending to exist in the “here and now”.
- ◆ Have difficulty separating reality from fiction.
- ◆ Temper tantrums, lying, petty stealing and can be inappropriately tactile.

MIDDLE SCHOOL

- Reading and spelling abilities have reached full potential.
- ◆ Often easily distracted and influenced.
- ◆ Difficulty understanding or predicting consequences.
- ◆ Good verbal skills but poor comprehension, often giving the appearance of being able but in fact lacks the actual ability.
- ◆ Increasing difficulty mastering academic skills that are new, maintaining attention, and or completing set academic tasks.

- ◆ Difficulties with abstract concepts and language, tend to be concrete thinkers.
- ◆ Development of cognitive and physical (particularly fine motor) development is delayed.
- ◆ Unable to grasp an understanding of expectations and social rules.

ADOLESCENCE

- ◆ Low self-esteem and motivation.
- ◆ Lying and stealing, anger and aggression.
- ◆ Depression or other mental health problems.
- ◆ Faulty logic, lacks the ability for basic critical thinking and poor judgment skills.
- ◆ School problems leading to expulsion, suspensions, detention.
- ◆ Problems expressing remorse, responding appropriately or comprehending others' needs and requirements.
- ◆ Management of time and money is poor.
- ◆ Places others and his/her self at risk with behaviour.
- ◆ Tend to be identified by others as being unwilling to learn, lazy or slow.
- ◆ Difficulties with labelling and identifying feelings.
- ◆ Extremely impulsive, easily influenced and often show a lack of inhibition.
- ◆ Good verbal skills can “talk the talk” but unable to “walk the talk”.
- ◆ Often victims of peer exploitation and manipulation.

ADULTS

- ◆ Appear rigid and compulsive.
- ◆ Unable to live independently, or possess good parenting skills.
- ◆ Unpredictable often inappropriate behaviour.
- ◆ Depression and or suicide threats or attempts.

- ◆ Socially isolated and withdrawn.
- Alcohol or drug problems.
- ◆ Difficulties in retaining job placements.
- ◆ Serious money management problems.
- ◆ Victims of social and sexual exploitation.

Importantly, we must not look at all these characteristics as being completely negative, in fact, some are strengths which need to be continually acknowledged and reinforced.

Some of these positive characteristics mentioned by Graefe (1998:12) are:

- ◆ Often high moral attitudes, have a rigid belief system and a strong sense of fairness.
- ◆ Trusting and friendly, loyal and loving.
- ◆ Sensitive and concerned.
- ◆ Extremely verbal.
- ◆ Musical and artistic with good creative intelligence.
- ◆ Strong sense of self.
- ◆ Spontaneous and energetic.
- ◆ Questioning and curious.
- ◆ Rich imagination (needed for writing, poetry and exceptional story telling).
- ◆ Great sense of humour.
- ◆ Long term visual memory can be exceptionally good.

Common Behavioural Problems

These are not easy children to deal with. This section of my thesis identifies some of the major behavioural problems reported to be experienced among my participants’

FASD children. Problems surrounding repeated lying in the face of hard evidence was one behaviour reported as involving 93% of my FASD group 5 years and over (N=34).

Seventy-five per cent of this group had past and current problems surrounding ownership of property, a problem termed theft in our society, but affectionately known to those familiar with this common FASD behavioural problem as ‘collective gathering’.

It seems as if the concept of private ownership does not exist, what’s mine is mine and what is yours, is mine. All these individuals were involved in collective gathering that was not for personal financial gain, many used these items for the purpose of giving to friends.

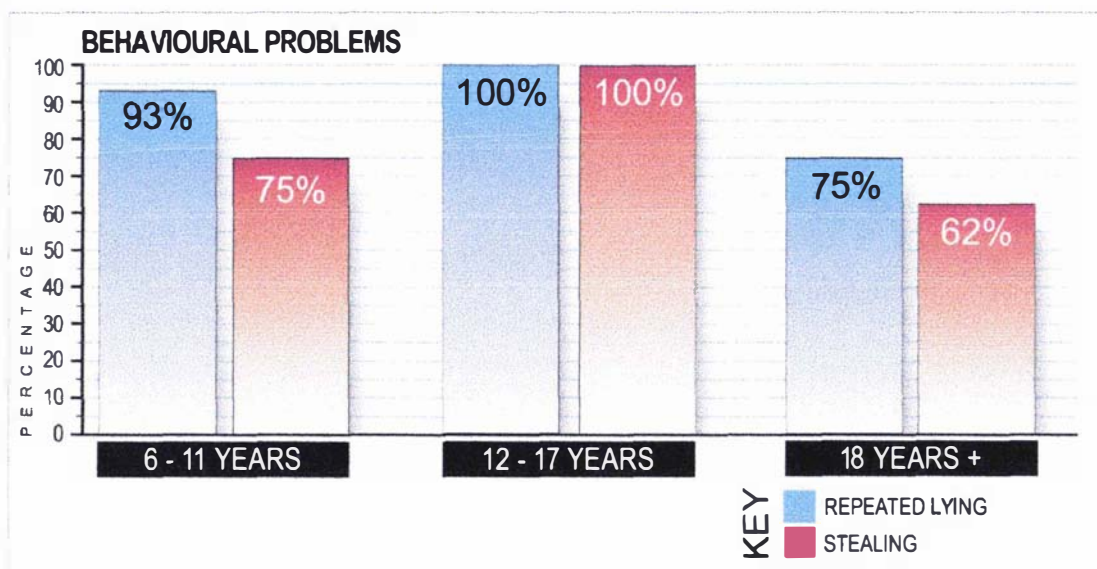


Figure 15. Behavioural problems: lying and stealing. N=30.

Many a story came from my participants surrounding their children's problems, which appear to be of serious proportions. The age group where this was most prevalent was in the twelve to seventeen year age group. Lying becomes a repeated behavioural problem, especially when one of the deficits involves problems with sequencing and memory. Most of my participants described their FASD children as having very active imaginations. Often when recalling a given situation or experience on the surface it appears very plausible and colourfully accurate. However, truth and story can often appear to merge and become a single entity for many of those affected by FASD. If a caregiver knows that the FAS child or adolescent is lying, a good strategy to use is to engage the child ensuring eye contact asking (without annoyed facial features) 'truth or story'. This should be repeated several times while the child is telling the tale stopping their conversation in order for the child to answer the question. It is imperative that if the child changes from 'truth' to 'story' during the story that you do not react negatively. It is important that they feel safe to reveal that it is a 'story'. Several informants have found this an effective tool for investigating the truth. Often fact and fiction are combined.

Generally a verbal challenge seems to evoke an automatic response of absolute denial for any wrong doing or blame for any situation, even when they are caught in the act, red handed. This problem of fact or fiction can be both frustrating and dangerous. I would not wish to have a FASD affected individual giving witness testimony in a court of law, particularly if the prosecution/defence rested its case on that person's recalled eye witness account of an event that they witnessed six months earlier.

Four participants describe their experiences as follows:

She would just go into anything she wanted. She was like a magpie! She would take things...she puts things that belong to people in weird places where you never find them ever again, unless she decides to bring them out. It might be that day, it might be five months later, it might be a year later. But sometimes they surface - like my bridle is a prime example of that. She stole my bridle (horse equipment), it was a really good one and we don't know to this day where it is. It's down the horse paddock, where her horse is probably. There is a lot of undergrowth there you'd never find it unless she wanted to bring it out. Knives and forks disappear like this, babies bottle lids disappear like this [clicks her fingers], there is just a constant stream of things disappear.

* * *

Things would go to the same hiding place, little stash places and once a week we would search and return everyone's items of property. Even though she knows that we will look in this place as we did each week she still stashed it there, forgetting that we found it last week. She has the sneakiness to steal but not the ability to conceal it.

* * *

Oh yeah, she'll argue black and blue that she didn't do it and she doesn't know how it got there ! She can look you in the eye with Milo⁵⁶ all over her face and say "I didn't touch the Milo, I didn't eat that tin of Milo. You get a shocked expression like 'What Me!', why would you think I did it" she feigns real shock. If a stranger who didn't know her would be really convinced that this child couldn't have possibly done this. She is so convincing, that's the funniest part.

* * *

It's like she believes it, you would really believe her and you have to sort out what she has told you and take little pieces out of it. It takes ages to sort out but now I say "Anne is this what you mean" and she will say yes. I have to sort it out or there will be bits missing. I have to get her to repeat it. It's not like she is deliberately doing it, it's not for personal gain. As for stealing, if it's left there it's hers to take.

One of my participants would search her daughter's bedroom, with her daughter's help every Sunday placing all the items that she knew were not her daughter's on the bed. Together they would try to identify the owners of these foreign items and together drive around the neighbourhood returning them to their rightful owners. Local people and

neighbours were aware of this 'collective gathering' problem and knowing that their possessions would be returned had no problems with this form of intervention. Over the next few years it became something of a ritual. My participant indicated that suddenly one Sunday, there were no possessions to be returned and from that day on her daughter to her knowledge, ceased to help herself to items she did not own.

Property Destruction

A high percentage of my participants reported property damage as another major problem experienced. This is a costly consideration when 76% of the FASD group (N= 30) were identified as being involved in repeated property damage, and 26% were reported as deliberately lighting fires (all without intent or understanding of the consequences). This is obviously a serious financial drain on families as several of my participants were uninsurable due to repeated claims resulting in excess amounts and fees so high they can no longer afford it.

Much of the damage appears to happen when, as my participant describes it, their child was 'losing it' in anger. One of the participants I visited had almost every window boarded, cracked or holed due to their FASD child, who would on at least one occasion every month have a mammoth temper tantrum. This temper fit usually resulted in windows being smashed. This had proved financially too much for the single foster parent who now had no means to repair or replace with reinforced safety glass. Sadly, this situation made the house cold and dark and

⁵⁶ Milo is a chocolate drink, packaged as small sweet chocolate crystals mixed with milk and/or hot water.

draughty, hardly conducive to good health for a young baby, herself and two other children.

When discussing property damage and fire lighting, four of my participants described their experiences in the following words:

Yip! Oh we've got a good starter... At a very, very early age. We learnt that there was no such thing as leaving lighters and matches around the place. In fact most of the time now these days, I don't possess them and I have to borrow one off someone or light my cigarettes off the stove. Basically if they are left around they get misappropriated. We have had toilet paper fires in the bedroom, we have had rubbish fires on the door step.

* * *

The other week I had the fire on to warm the house. You can turn it down so it goes all night. I have to get up and check her through the night to see if she's in bed. I got up to check her and I have a white mat in front of the fire. I found it all scorched and she was sitting with a couple of sparks on a towel on top of the mat, quite happily watching it smoulder. If I hadn't got up there would have been a big fire, she's just [pause] fascinated with fire.

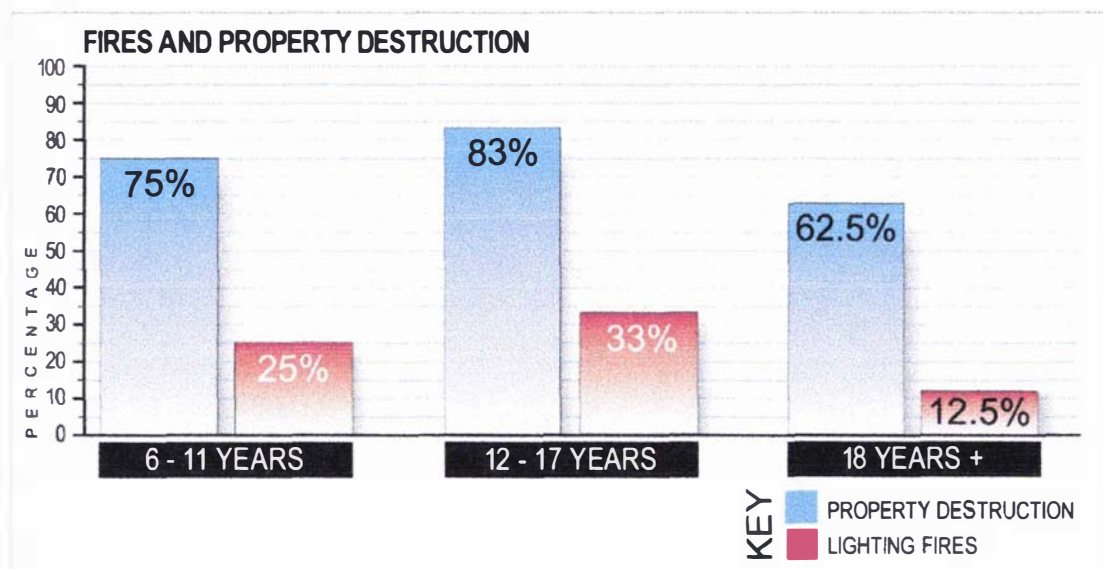
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He punched holes and kicked holes in all the walls.

* * *

Yes I said he had been involved in arson over in [town]..the fire lighting was before he was ten.

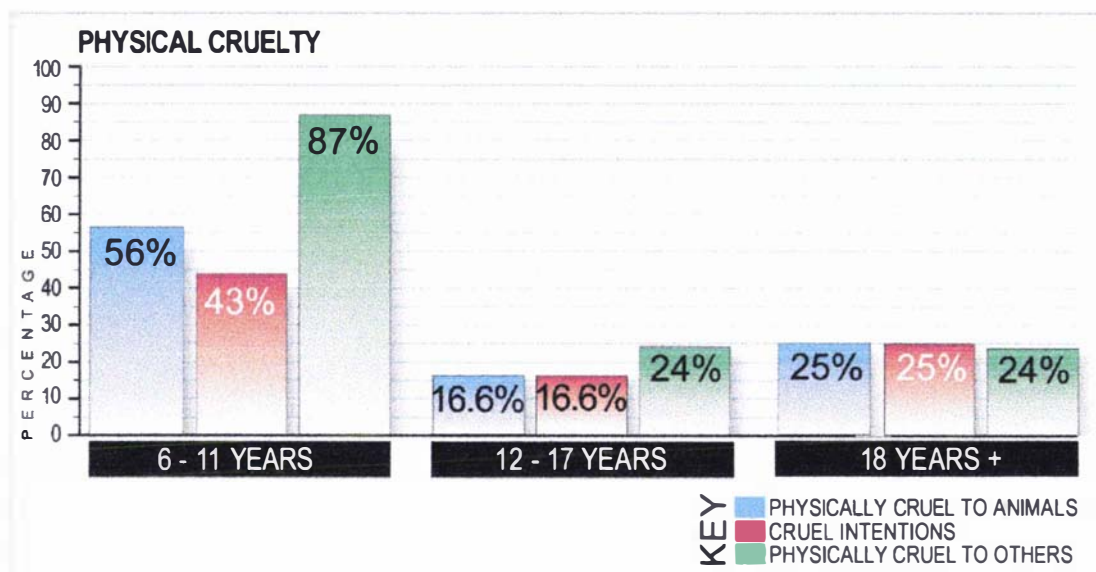
Figure 16. Property destruction. N=30.



Physical cruelty and violence issues

Supervision is a serious issue, particularly when cruelty appears to be a common issue with many FASD individuals. Overall 62% of the FASD cohort (N=30), were reported as being repeatedly cruel to animals with 33% being reported as deliberately cruel. Most of this behaviour was reported in the six to eleven year age group (N=16), where 56% were identified as being cruel to animals, with 53% deliberately being cruel. When questioned about physical cruelty to other persons, 70% of all my participants' FASD children (N=30), were reported as repeatedly showing this behaviour. Of this total 87% of the six to eleven year old age group (N=16) and, 66.6% of the twelve to seventeen year age group (N=6) were involved.

Figure 17. Physical Cruelty. N=30



These are serious issues as both the safety of other family members and family pets can be compromised. These children need to be supervised when around animals and other children and ideally not placed in situations where this can occur. Leaving a family pet and an FASD child unattended for five minutes in the car while popping into a store, or leaving a FASD older child in charge of play generally would not be a wise move unless these children have proven themselves dependable.

For FASD individuals age appropriate responsibility and behavioural expectations are often unachievable. Many of my participants reported incidents of their child deliberately being cruel to younger children, and incidences of biting, kicking and pinching were a recurrent theme. Three participants described their children's cruelty towards younger children as follows:

If she is not watched she's mean to little kids. Yeah, she will pinch them or punch them, she will punch them in the head. She's started a lot of fights. At school she's thrown stuff... I know what she can do and what she's quite capable of, she can be quite dangerous if you let it be.

* * *

Yeah, you have to watch her with the baby, or if you hear the baby scream or cry or something like that and there is no explanation for it except Joan's in the room and she's been caught hitting my girlfriend's baby and little kids. She's mean to them when you're not watching.

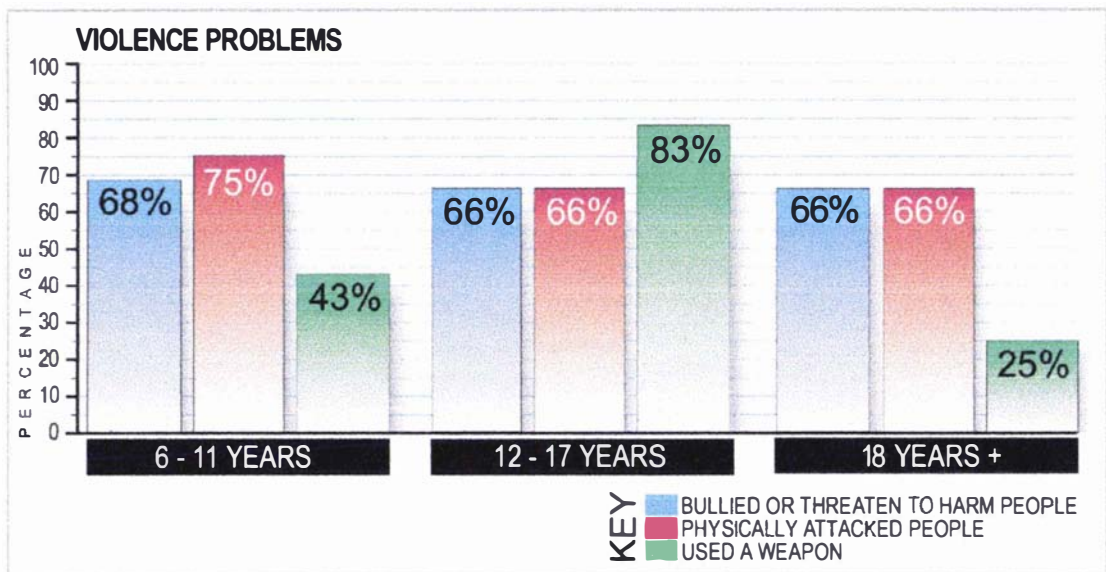
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I think [sibling] went through a lot because he was always using stand over tactics with her, although he never sexually molested her and most of the time he didn't hit her.

Bullying, physical and threatening behaviours towards others is a common behaviour that was reported as being exhibited by a large proportion of my study group. Seventy percent had repeatedly bullied or threatened to harm another person, 70% had been

responsible for physically attacking other people and 50% had used a weapon capable of inflicting serious injury such as a knife or a heavy piece of wood. In most circumstances where a weapon had been used it appears that the close coincidental proximity of the weapon to the disagreement was the main reason for its use - impulse rather than planned. Many of my participants spoke of repeated occasions when sibling arguments escalated to where the FASD child or youth would totally lose control, reacting violently usually throwing both items and punches. One participant described her daughter's anger as, 'She just goes off like a bomb, a bomb, it's hell, it's like hell'.

Figure 18. Violence Problems. N=30.



One of my informants told me that as his son grew with age so did the violence and severity of the force he used. During one serious sibling altercation his non-affected son was stabbed twice (seriously) with a large kitchen carving knife that had been grabbed off the kitchen bench, an episode that was ended only when two male adults physically

wrestled him to the floor disarming him. Most of my participants described their children as being caring and loving, however quick in losing their tempers often due in part to frustration levels or stimuli overload. All potentially dangerous situations tended to be incidents where the weapons involved had been used simply because of accidental close proximity at the time when an argument started. Another participant described the following:

He has only got wild here once then he picked up a knife off the bench and slashing and thrusting it around in anger. But I managed to calm him down and he put it down. He had done it once before at another place. Yes he threw some knives when he was in the respite home. We couldn't cope, he would threaten to knock your block off and getting difficult at this age. [Female sibling] was absolutely petrified of him at this stage so we had to think about her welfare. He was getting dangerous.

Only one of my participants reported that he believed that the use of a weapon involved in the altercation with his FASD youth was premeditated, the weapon had earlier been placed in a position that was hidden but easily accessible by the FASD youth.

The first signs of these common behavioural problems appeared for 50% of my FASD individuals between the ages of two years and six years. The first type of behavioural problems exhibited appears to have been lying, then stealing and acts of physical cruelty being the third noted problem. These are very real issues that must be taken into consideration when placement, both permanent and respite, is being discussed. Safety for other family members is paramount.

CHAPTER TEN

Social and Personal Problems

Social problems that are associated with FASD sufferers are problems that have an immense impact on daily functioning and are indicators that identify this group of people as needing intensive hands-on supervision and help with daily activities. These problems make it difficult, if not impossible, for adults suffering FASD to achieve a good quality of independent living without help. Amongst my participants FASD children (N=30), 96% had problems with losing their temper, 76% were reported as easily and often repeatedly getting too aggressive or violent and 56% had problems surrounding sexuality. The major sexuality problem most frequently reported was masturbation in public, promiscuous and predatory behaviour.

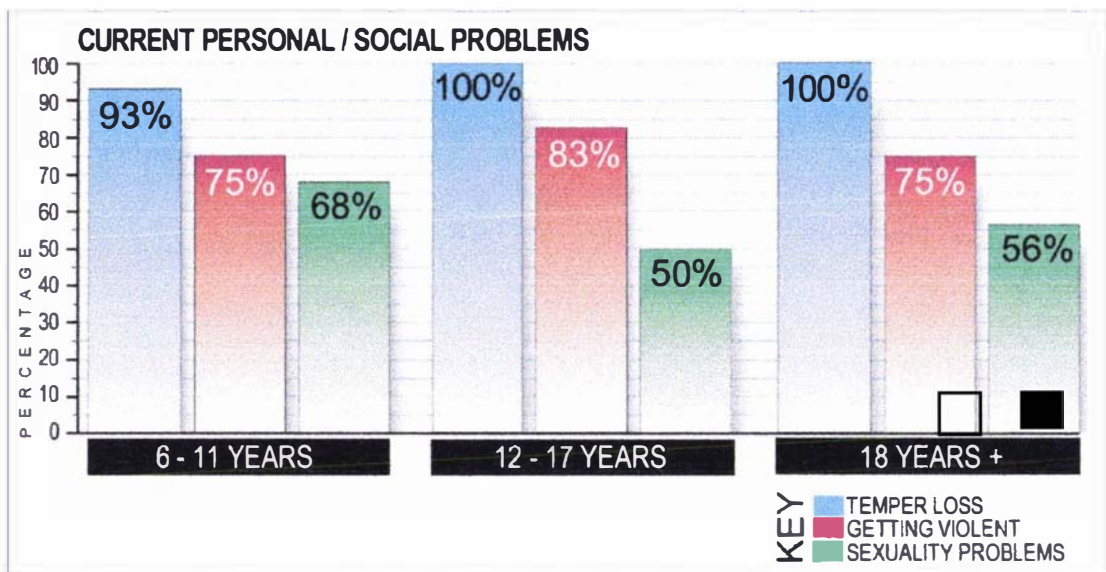


Figure 19. Current Personal/Social Problems. N=30.

Placing an adolescent FASD child with a history of cruelty to younger children both physically and sexually in an uninformed foster/respice family was the experience of one of my participants. This couple were fostering for CYFS and had two young girls and a young son of their own. Urgent placement was required for a child and with little notification, my participants were delivered a child to care for with no mention of the FASD diagnosis or other serious behavioural problems. Sadly the victim of this story was their young son. He was subjected to serious abuse from the new foster child who had been accorded age appropriate supervisory responsibilities and privacy. After an investigation by my participants, it was discovered that this child had been removed from two other foster homes for similar problems. This situation, I believe, bordered on criminal negligence on the part of CYFS. Had the foster parents been warned of his history and diagnosis, they stated, they would have deemed their family home as an inappropriate environment in light of the fact that they had three other small children.

A lot of FASD children are extremely tactile and impulsive, which accompanied with frontal lobe damage (the part of the brain responsible for controlling inhibitions) can create many problematic situations for FASD caregivers and their families. This can be a problem that is exaggerated by the FASD individual's lack of understanding of the abstract concept of personal space. One of my informants described this situation as follows:

When he walks into a room you know he is right there. Right on top of you. He has no idea of personal space and hovers right behind you, right in front of you. If you walk he's right beside you pushing. He has no sense of personal space.

Often independent observations of these children's tactile, inappropriate behaviour in a setting outside the home have, for several of my foster participants, resulted in unfounded accusations of sexual abuse. Interviews with siblings and other family members of FASD girls exhibiting promiscuous behaviour revealed that none of the older male siblings would hug or pick up their foster sister. They were uncomfortable with her tendency for inappropriate touching or rubbing, and most did not like to be left alone with the affected child in case 'at some stage they get accused, you know, of doing something'. Stories of promiscuous and inappropriate behaviour tended to be from those who were care-giving for girls affected by FASD. Six of my informants described difficult situations:

When we first got her when she was young, she used to show the boys her pants and that. It was real hard thing to get her out of. We had problems at school she used to always pull down her pants. In the end I put shorts under her dress. I had to deal with it to try to stop it... She was hooked into my husband, I mean it was a real hard year for everyone.

* * *

She invades men only space. If it's a woman she will have a conversation, if it's a man she has to cling.

* * *

She was six or maybe seven. My girlfriend came up from Auckland with her husband and they were staying here. I said you watch Gay [FASD child] because, Tim [local tradesman] was out fixing the fence. I said you watch Gay she will end up in front of Tim exposing herself. We just sat back and watched. There was Gay marching off down the paddock in the opposite direction. She came way back down the paddock right up through the other paddocks in a circle. In the space of about quarter of an hour, she ended up rolling in the grass in front of where Tim was fencing with her dress up around her [pause]um.. waist, you know exposing herself.

* * *

We find that if there is a male visitor, she will come out in a nightie (sleeping garment) without a dressing gown or in some clothes that are way too small for her which show off her private parts ...you've got to be watching her all the time.

* * *

But if any boys are around you have to watch it, all the time. A stranger comes to the house and she tries to sit on his lap! Clings to his arms... No, just males. As long as he has two legs and is a male she will try it. Not so much boys her own age, it's men, adults not her same age.

* * *

No I took her to the doctor cause when she arrived back last time the CYFS rung me up a couple of days later and said "You gotta go and get a pregnancy test done on her" she's well under age... Yip I only got a phone call saying "Pauline needs a pregnancy test" and I said "What's going on" because they wouldn't tell me... So I decided to do my own hunting around to find out what had been going on. I know a lot of people who hang out with her mothers crowd and all that. Found out she had slept with more guys than I have in my entire life. I was so disgusted, CYFS knew that, that's what really pissed me off... No investigation, this is a small place I found out who it was last with her, he's 40 years old for gods sake!

This obviously is a very serious issue that can rock the very foundations of the family unit. Equally it is important that these children can be easy prey for child abusers and paedophiles, if placed in compromising situations or environments. Caregivers reported their FASD children as generally being unable to understand the concept of 'stranger danger' even after intense and repeated tuition on this subject. Most of these children and adolescents are extremely trusting of adults (unfortunately any adult) and as with any child desperately wanting to please peers or adults, 90% of the FASD children were identified by my participants (N=30) as repeatedly showed poor judgement. Many of my participants described their children as being 'too trusting' particularly with strangers a problem that does not appear to disappear with age, two caregivers reported their children as:

Her judgement is bad ... She is real trusting with men. She is still the same now as when she was young.

* * *

Her judgement is bad, she calls everyone auntie and uncle, I hate that. She is real trusting with men, she is still the same now as when she was young. I have tried to

teach her the danger stranger stuff but it doesn't seem to work .. I'm Maori, I believe in true uncles and aunties not every Tom, Dick and Harry.

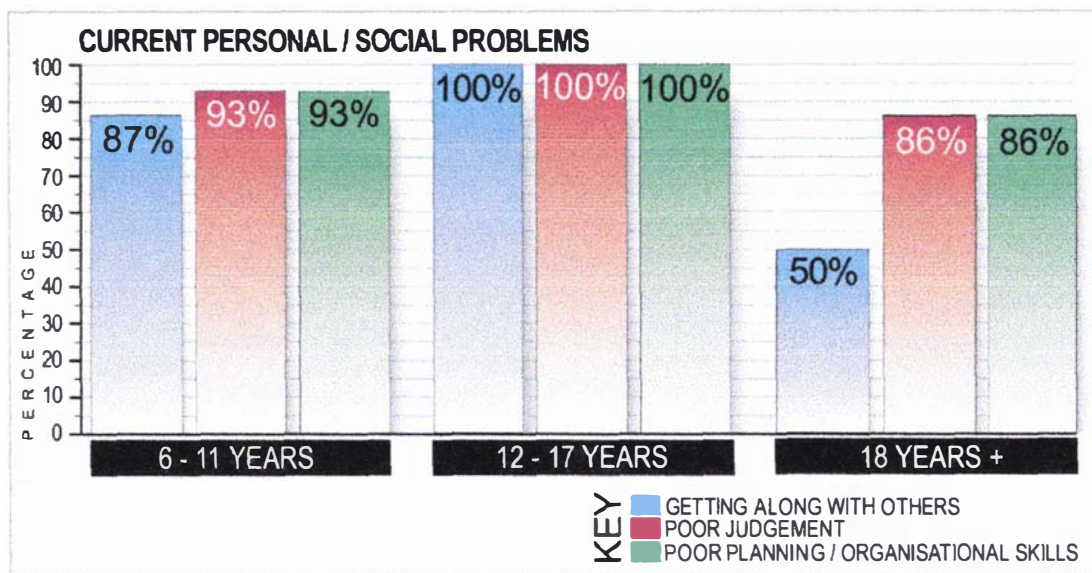


Figure 20. Current Personal/Social Problems. N=30.

Eighty three percent of my FASD subjects (N=30), were identified as have problems making and retaining friendships with their peers and are often seen as loners, 76% as having difficulties with getting on with other people,

Yeah, I think there was a real anxiety about, “will you be my friend” and kids were winding her up. Other kids get sick of her, she desperately wants friends and other kids get sick of her really quickly.

Seventy six percent were experiencing loneliness or isolation and 73% exhibited repeated incidents of a lack of initiative or boredom. Ninety three percent were reported as having poor organizational skills. One participant described her son's situation as:

Loneliness! It's a real problem for him, he's really lonely. I just don't like to think about it. He gets bored very quickly and he has difficulties in getting on with others. He's really good one on one with adults, really, really good with younger children . At school he was always in trouble because he would go over and play with (sister) cause he was not allowed to play with five year olds.

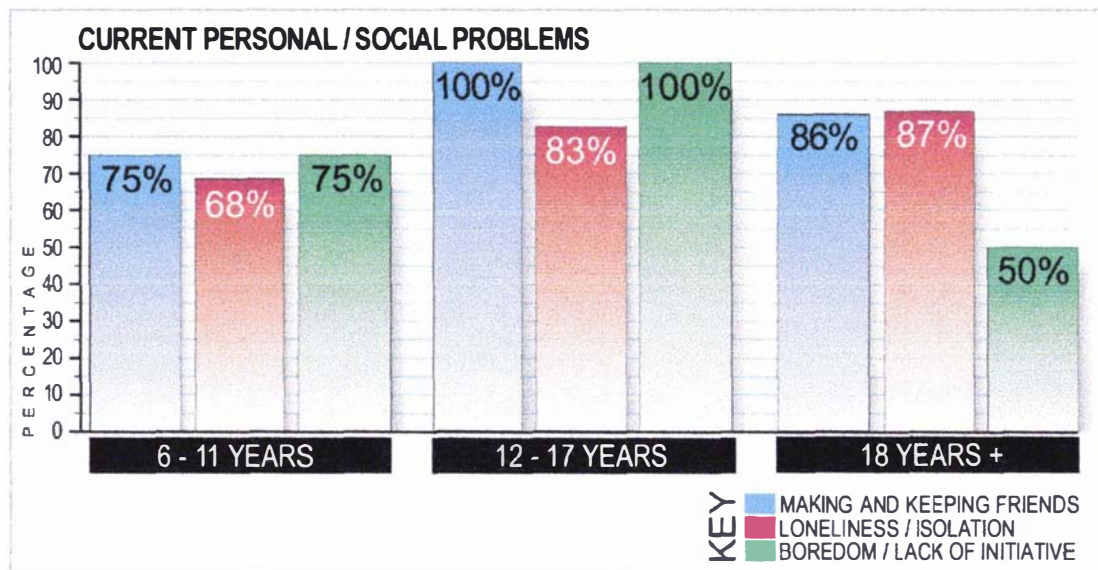


Figure 21. Current Personal/Social Problems. N=30.

These children/youths cannot be expected to fit into any environment where they are expected to conform to existing and often different rules. Ninety-six point six percent of my 15 year plus age group (N=12), reported repeatedly having problems surrounding the inability to conform to social norms with 91.6% identified as being unable to show or feel remorse for actions. These are not good figures in a society that tends to be punitive for age inappropriate anti-social behaviour. Generally in most societies if an individual shows no sign of remorse, more severe punishment is usually dealt out. It is

imperative that caregivers identify something that the child is attached to and enjoys so it can be removed as a punishment for a period of time. It is too easy for a parental smack to turn to a hit when frustration levels are reaching an all time high by what appears to be constant disobedience and defiance, particularly if the child shows no sign of remorse for actions they know are wrong. One parent described their child's lack of remorse as:

She just has no remorse. Does not care who she hurts, anyone is fair game, anyone she's annoyed with.

Another participant stated:

He shows no remorse for anything. It is always someone else's fault, never his. He just doesn't seem to be able to identify with the hurt he has caused, he has no such thing as a conscience.

My observation with those I have advocated for in the justice system is that inappropriate smiling appears to be an automatic reaction to an environment or situation they are not comfortable with such as a court room. While in court I witnessed one of my informant's FASD teenage son grinning and waving inappropriately to persons in court as if he were on an recreational outing while the charge was being read. His probation officer leaned over to whisper 'That's torn it, what is he... a Cheshire cat, no brownie points for that one'. The judge hearing the case was not amused and possibly was a little more punitive than normal with his sentencing.

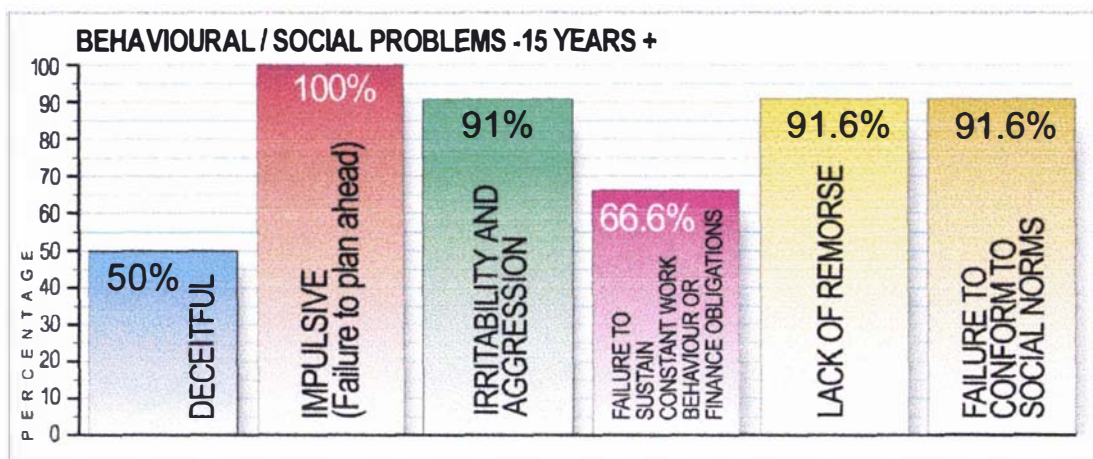


Figure 22. Current behavioural /social problems 15 years plus age group. N=12.

Educational Problems

For many diagnosed as FASD, the journey of getting a diagnosis has been driven more often than not through the inability of the current education system to deal with these children. Many recommendations for diagnosis have come via these children’s educationalist. These professionals have to deal with these children for up to six hours per day, five days a week. In recent years as part of cost-cutting measures, New Zealand has seen the closure of most special education schools, classes and adult sheltered workshops along with increasing teacher pupil ratios.

Educational services are essential for dealing with some of the extreme cases of central nervous system dysfunction presented by this population. At school behavioural problems accelerate and often the FASD child becomes more difficult to handle and

academically falls further and further behind his/her peers. Most FASD children, as with other disabled children, are in mainstream public education, a system that is often overcrowded with large teacher-student ratios and standardised funding for special needs in school. A small government Special Needs Grant is given to every school in New Zealand. The amount however is the same regardless of the number of special needs children it caters for on its school roll. This is a very inequitable distribution of public monies, particularly if a school has a high number of behavioural special needs students.

Without a diagnosis there is simply no money available and unless the parent is wealthy enough to pay for extra help out of school, these children's educational requirements are not met. For affected children from families that do not have the resources or diagnosis, the likelihood that they will be labelled as a problem child from a dysfunctional family environment grows with their age. Eighty-eight percent of my participants' FASD children (N=30), attended public schools, 5% were home schooled and 7% attended private schools. Those in private schools received more special education help than those in the public school system. The smaller the teacher-child ratio, the more one-on-one time with teacher aides and tutors and special education programmes, the greater the educational progress. School has an important role to play in these children's lives, in both academic and socialization arenas. These children are attending classes on an average of 6 hours per day and if challenging behaviour is an issue at home, you can be sure it is an issue in the classroom.

The lack of specific resources and understanding of how to teach these children is a major problem. It is not that these children cannot learn. As shown previously, these children can have serious problems with processing, storage and retrieval of information, a disability that is not very conducive to learning. Therefore these children require different educational techniques when forced to attend mainstream classroom settings. It is imperative that these children learn at their own speed, and that they be taught in the contexts of the child's daily life (Ministry of Education B.C. 1996, Ministry of Education Alberta 1997). School curricula must be tailored to suit the FASD individual, especially with the help of Ministry of Education, Special Education Services. The Ministry of Education, British Columbia suggests:

By developing learning environments that respond to the unique challenges of a student with FAS/E, teachers can provide an important link in the chain of support needed to assist these children to succeed in the school and in the community. (Ministry of Education British Columbia 1996:19)

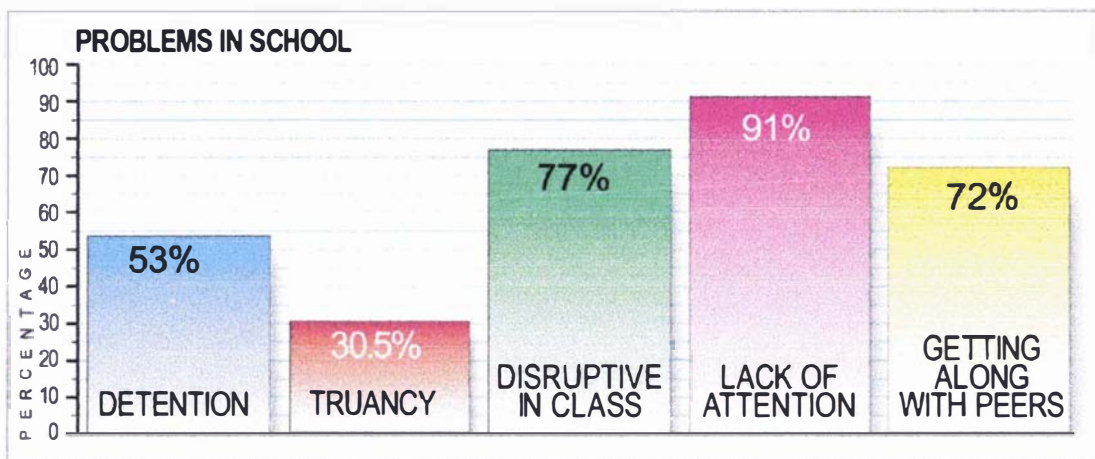
Daily academic and social goals must be placed at a level that is not necessarily age appropriate but individually appropriate. It is imperative that these children are able to achieve goals or objectives and not always fail. Educational ideology surrounding the importance of setting age appropriate academic goals often does not accommodate individual FASD limitations. Self-esteem and confidence for a large number of these children comes from achievement and if educational as well as social goals are set age appropriately, chances are these children will constantly fail. Educationalists Burg, Kinsey, Lutke and Wheway (1997) suggest that,

In school, children are expected to show initiative, on-task behaviour, compliance and be able to follow through. They are expected to adapt to, and accommodate the desires of the teacher, peers and the classroom, quietly, quickly, and with good grace. When the child is *unable* to do so, he/she may be viewed as

unwilling to do so. If this happens, school can quickly become a breeding ground for early failure, poor self esteem and secondary behavioural problems... Educational planning and pro-active interventions by parents and school staff that are cooperative, comprehensive, and on-going in nature are essential to promote and maximize potential. (Berg et al 1997:1)

The inability to cope or stay on task with school work will usually end up with the child being disruptive and high levels of frustration will generally lead to what can become disruptive or violent outburst. The most reported problem at school was lack of attention, where it was found that 91% of my FASD group (N=30), had repeated problems staying on task. Seventy seven percent were considered repeatedly disruptive in class, with 53% having experienced detention on repeated occasions. Truancy was a common problem amongst 30.5%. Yet surprisingly, only 15% had experienced suspension and only 11% experienced expulsion from school.

Figure 23. Problems in School. N=30.



When collating data on what types of trouble my participants' children were having in the classroom, 69% identified incomplete school work as a major problem. Homework can be particularly difficult for these children. For some it is necessary to have a

communication book that passes between parents and teachers so parents know what is expected for the next day of school. Directions for homework must be set to accommodate the individual student's comprehension ability. I have lost count of the amount of times I have viewed my friend's FASD child's homework sheets sent home with one essay question that contains several different directives. Most FASD children when confronted with too much written information to process in one question will not even attempt the question, as the actual ability to process and comprehend the written question is where most experience difficulty. They often have difficulty in processing more than one directive at one time, therefore it is often necessary for the teacher to set the question out directive by directive. Instead of one question it is broken down into the six smaller questions asked in the one paragraph. It is not that these children cannot learn - some have average or higher IQ's - it is just that they learn in a different way and different teaching techniques are required for success.

Many FASD children I had the opportunity to observe in the Canadian classroom, particularly primary school age, responded well to wearing a set of headphones connected to a closed circuit microphone worn by the teacher. Canadian teachers I spoke to maintained that these sets were a must for FASD children as more of what they were saying was being processed and retained by the student. These headphones play a dual role. On one hand, they stop unwanted auditory stimuli distracting the student and secondly, they insure the student can hear the teacher clearly. This sort of technology is available in New Zealand for those with a serious hearing impediment but I have never

heard of any FASD student here being given this teaching aid. Presumably school budgets cannot support these types of costs or schools are unaware of the technology.

Fighting in the classroom involved 61% of my participants FASD children (N=30). In some, these aggressive episodes have been brought on by too much stimulation.

Classrooms as learning environments are supposed to be exciting and often busy, all of which is normally conducive to learning. The problem is many FASD children suffer from sensory overload. Non-affected students subconsciously filter a multitude of sensory information received through visual, auditory, touch and smell automatically. FASD students on the other hand can quite simply overload their brain with sensory signals. They do not have the same filtering system the rest of us have, an overload can lead to the student literally shutting down. They can be observed in a trance like state, remaining in that space for several minutes without even blinking. Then just as suddenly as they shut down, they continue with their activity. One teacher I spoke to described it as a time when 'the lights are on but no one is at home'. The alternative reaction to over stimulation is that they 'spin out' and can become quite aggressive, often to other children.

A friend of mine was running a Kohanga Reo⁵⁷ in the Hokianga, and was having trouble with two local children. I knew both the children and the parents and had for several years suspected both these children of being FASD because of their odd facial features, small size for their age and their behaviour. I knew there was a history of prenatal alcohol consumption with these children as I had been present at many functions when

their mother was pregnant and drinking heavily. My friend at the Kohanga Reo was at her wit's end. Every time these children walked into the room they would create havoc in a matter of minutes. At her request I came to observe them and sure enough within a minute of their arriving, in they were punching and exhibiting totally out of control behaviour.

On inspection of the classroom I noticed that the only lighting was in the form of fluorescent tubing, similar lighting to most classrooms in New Zealand. I had been warned while in Canada about the overload effect some lighting, especially fluorescent lighting, can have on children. The person explaining it to me equated it to the effect strobe lighting can have on epileptics in causing an epileptic fit. Fluorescent lighting is a form of strobe light, the light flickers usually faster than our senses can pick up. I suggested the lighting be changed to ordinary bulbs. Several weeks later I got a phone call from my friend to say that the lighting change worked and the children were much easier to deal with and the unwanted behaviour was not immediate on arrival.

My participants identified disobeying school rules, as a problem for fifty-eight percent of their FASD child (N=30), in the classroom, and 50% of the children were in constant trouble for talking back to teachers. It appears that many of these children cannot control the impulses and become reactive unintentionally. Having a thick skin and not taking comments personally is an important asset when dealing with these children; often it is a case of mouth engaging before the brain and these children just cannot control themselves.

⁵⁷ Means a 'language nest' for preschoolers where the only language spoken is Maori.

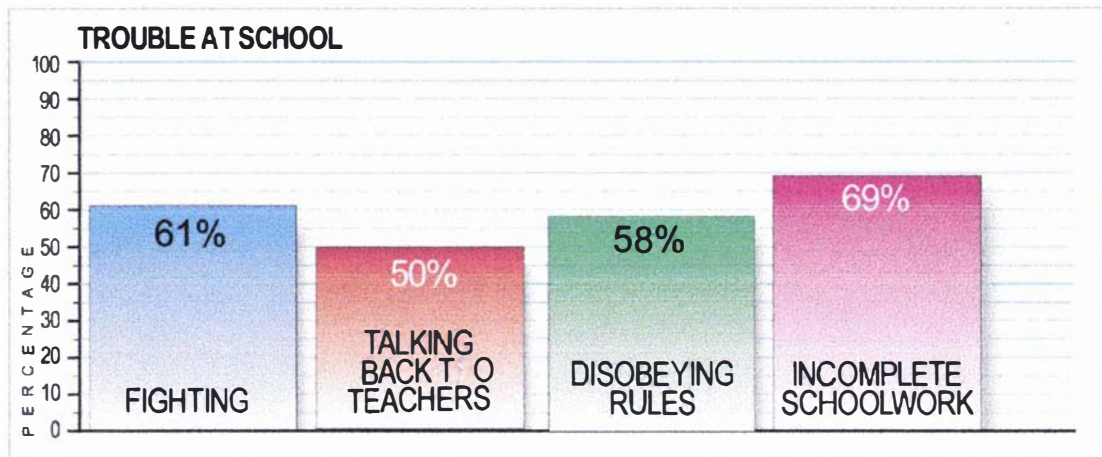


Figure 24. Trouble at School. N=30.

Appropriate discipline in the classroom must be firm, consistent and above all fair.

When talking and expressing feeling it is important to use exaggerated facial and body language accompanied by intonation in order for the child to begin to understand visual cueing and that what they have done is wrong. Consequences and rewards must be immediate or you run the risk that the student forgets what they have done wrong.

Making a FASD student wait in the corridor as a punishment is not appropriate and an open invitation for them to wander off unsupervised. It is imperative that teachers give as much positive feedback as possible, since these children operate on praise and genuinely want to please. To minimise the disruption often experienced when changing subjects it is important to give at least two warnings, one ten minutes before the change of activities and another at five, in order to prepare the student for the change over.

Routine for this student is imperative, the more structure the better.

Legal problems

Positive educational environments that identify and cater for the FASD individual's needs are important in the attainment of positive outcomes for an FASD youth/adult. Information given at the 1999 Alberta, Prairie Province Conference on Fetal Alcohol Syndrome identified a strong correlation between both trouble with the law and the failure to complete school (Streissguth et al 1996). New Zealand has no statistics available for investigation, but Canadian research by Fast et al 1999 suggests that an unacceptable and disproportionate number of these children are involved with the youth justice system. Many are known to be repeat offenders. Fast et al state:

In conclusion, we found a disproportionate number of alcohol-affected youth (23.3%) in youth remand for psychiatric/psychological assessments in the juvenile justice system. Screening for FAS and related disorders is feasible. In working with adolescents in the criminal legal system, health professionals need to be aware of this high risk population. These youth will require special consideration in sentencing, disposition, intervention and treatment. (Fast et al 1999)

However as with many sectors of our society, the New Zealand Justice Department appears to have no idea of the implications surrounding these individuals or the risk. International statistics indicate this is a large at risk group of individuals that have been identified as repeat offenders (Fast et al 1999). As yet I have not heard of FASD defendants in New Zealand justice systems as having the FASD diagnosis taken into account. One personal experience amongst many with the New Zealand Justice Department was while advocating on behalf of a family with a teenage boy who had been diagnosed as suffering FASD. When the judge was asked by the defence lawyer to take his client's FASD diagnosis into account when sentencing, the Judge's reaction was

to slide his glasses down to the end of his nose, stare at the lawyer for several seconds then almost sarcastically ask the lawyer, “Why on earth do I have to take into account the fact that his mother is an alcoholic?” The parents of this boy who were in court sitting next to me said that they felt angry and humiliated by this comment. The New Zealand justice system is sadly lacking in knowledge and in all probability housing many FASD individuals within the remand homes and prisons, where unfortunately most will not receive appropriate interventions. This situation must change.

Researchers Ladue and Dunne (1995) have identified serious issues surrounding FASD defendants as being:

- Competency: the ability to understand what they are being charged with and aid their legal defence in an acceptable fashion.
- Capability: many FASD individuals have a diminished capability, meaning they lack a specific intent to commit a crime because of their mental deficits.

Canada has set an amazing precedent. An inclusion in the judges’ handbook has been written specifically to outline the legal considerations that must be followed by judges’ when dealing with FASD offenders. Screening for FASD, particularly among repeat juvenile offenders, would be a positive start here in New Zealand. This situation would require those making court directed psychological assessments to be familiar with FASD diagnosing. To date no research has been carried out in New Zealand for the justice department concerning FASD even in light of large amounts of international research identifying these people as a high risk group for offending.

While completing this thesis I have been contacted by a birth mother who was present at an educational seminar carried out during my research, a parent who wanted to know how to go about diagnosing her child who at that stage was thirteen and getting into petty crime. After my presentation she approached me saying she needed her son diagnosed as he exhibited all the traits I had discussed and was getting more difficult to deal with as he got older. I explained that perseverance would be the strongest trait she would have to present when advocating for her child (not accept no for an answer when dealing with professionals) and learn how to go about obtaining a diagnosis. She had followed that path for the last five years with her son becoming more and more involved in petty criminal behaviour which once again ended up in court. To my knowledge this young man is the first in New Zealand to have a diagnosis originating from a court ordered FASD assessment.

CHAPTER ELEVEN

FAS/FAE/FASD Just Another Label?

When a subject such as Fetal Alcohol Syndrome is the focus of research one has to look at the labelling argument that has been presented after the creation of this new medical diagnostic terminology. I have heard the statement, ‘We don’t want to label the child’ or ‘We didn’t tell them the child was FAS, we didn’t want to disadvantage the child with a label’ on several occasions when discussing FASD. To me labelling and a medical diagnostic term are two completely different concepts. Labelling is, I believe, the result of stereotyping something and is of very little use to anyone, particularly the person directly affected. Labels such as ‘stupid’, ‘lazy’, ‘deliberately disruptive’, ‘defiant’ or “promiscuous” appear to be the most regularly used labels that tend to be attached to children suffering FASD. The parents and other caregivers are often identified and labelled as having no parenting skills, particularly by those who have no or little understanding of FASD. One parent described her experience as,

I felt like I was treated as a criminal, I mean, nobody would actually ever put into words, what you were meant to have done or anything like that. There was one particular caseworker that just about gave me a break down, I actually lost a stone and a half in weight, I went onto antidepressants... I am extrovert and unconventional, people in the community just take one look at me and sort of think.. Why has she got kids that aren’t her own?.. and then because Jan was so different – can play dumb and play manipulative. Everything that Jan did reflected that I was a poor parent and should never have that child. So every single thing they saw as not right [pause] people were making totally ridiculous complaints and CYFS were racing around trying to dig up whatever dirt they could find. I was a nervous wreck, I got to the stage where I didn’t even want to walk to the shops, I didn’t want to ride my horse around town. I didn’t want to leave my property unless I was in the car... Um...at one stage one of the complaints was so ridiculous. The kids were at swimming club and it was time to get out of the pool. I said to my other child ‘Get out of the pool darling’ then I said in a firm voice

which you have to use in public to Jan or she wont listen 'you are to get out of the pool now' . The next thing I know I'm having to explain to CYFS why I would say get out of the pool darling to one, and get out of the pool now in a firm voice to my other child. I just got so scared to take her out in public.. and yeah everyone was looking at me as if I was a bad parent and I would push her more than I should have because I was always scared that people were judging me.. some still don't comprehend it, they still think her behaviour is because of me.

A medical diagnostic term is a specific name used universally to explain a specific medical problem; a term that can open the doors to intervention and an understanding of a specific medical problem. If you don't know what a person is diagnosed with, how can you anticipate present or future requirements and needs? In relation to FASD how can one explain and deal effectively with behaviour that is being exhibited if there is no understanding of FASD and its limitations particularly in the processing, storing and retrieval of information?

Internationally the actual term Fetal Alcohol Syndrome is what appears to be in contention, not the seriousness of this condition, or its existence. The actual term 'FAS' has been seen by some feminist authors as just another discourse of patriarchal medical dominance. Keane (1996) states

Elizabeth Ettorre, for one, has questioned the political motives and social implications of a discourse which she regards as stigmatising women drinkers and increasing the medicalisation of pregnancy. She sees it as part of the widespread and invidious appropriation of women's reproductive power by male doctors. (Keane 1996: 263)

Helen Keane (1996) believes that there is merit in this argument, but deems it a far more complex issue. Keane's argument is interesting and must be acknowledged, as she presents the implications surrounding the terminology FAS from a completely different

angle to other authors. She investigates the term in relation to the female alcoholic who in many health arenas is identified as suffering a disease - a common western ideology that places alcoholism under a disease model. Keane takes the diagnostic term FAS and discusses the serious implications this term creates for women identified by most health authorities as suffering from the disease of alcoholism, suggesting,

Questions of agency are also central to the discourse of alcoholism in general... the article looks at how understanding of alcoholism as a disease works with FAS discourse to produce female alcoholics as dangerous agents of disease. (Keane 1996:263)

The title of her research 'The Toxic Womb' expresses how she views the negative discourses generated from the term FAS and touches briefly on existing public health education, critical of its current form due to the covert control exerted over the individual woman during her child bearing years (basically the do's and don'ts).

Thus the project of educating and informing free and equal individuals blurs into a realm of Foucauldian discipline, of bodies observed, classified and managed to ensure their docility and control their productivity. (Keane 1996:267)

However the author seems to pull a large number of examples from a particular book called *The Broken Cord* written by Michael Dorris, an adoptive parent of an American First Nation's child seriously affected by FASD. This parent sadly ended his own life after the death of his much loved son. The book has been made into a motion picture raising awareness particularly in America society of FAS. When reading this book it is very apparent from some very emotive negative analogies that the author was extremely bitter and angry towards the birth mother of his adoptive child, who was an alcoholic woman. His anger towards this woman appears to have extended to all women, alcoholic or not, who drank alcohol during pregnancy. Dorris's disturbing cry for the

forced sterilization of all alcoholic women and incarceration of all pregnant women who continued to consume alcohol in any form during pregnancy, was and is, a very extreme ideology. This book, although well written and moving, is defiantly the world according to Michael Dorris, his ideology and world view. His discourse and individual belief is not a collective voice that one can generalize from. Because of the emphasis on Dorris's book as a reference, I feel that Keane's (1996) argument loses some of its impact, but not to the point that it loses merit. Her argument is strong and must be acknowledged that if one places alcoholism under a disease paradigm then sadly the discourse of FAS could lend itself to the negative classification of alcoholic women as agents of disease, and bearers of what Keane describes as a 'Toxic Womb.' One can argue that this term could be seen as form of medical control, as does Keane, yet without public education there is no understanding or prevention. Correct educational techniques should involve agenda setting especially around stereotypical judgmental attitudes towards those with FASD children.

But one can equally, even from a feminist point of view, argue that by not informing a pregnant woman about alcohol consumption and pregnancy risks accurately, surely this contravenes a woman's individual rights. All women have the right to be privy to medical information surrounding birth risks. If women wish to continue drinking alcohol during pregnancy that is also their right. However if these women have been informed and educated around the dangers of alcohol and pregnancy then their decision is an informed one, rather than a decision based on ignorance and what could be termed as an old wives' tale surrounding the beneficial effects of alcohol during pregnancy. For some

women, particularly those with alcohol drinking problems, this information can be the motivational push to give up alcohol or if the individual is unable to accomplish this, knowledge can lead to treatment options. I truly believe that few pregnant women in New Zealand would deliberately place their child at risk of birth defects once they are made aware of the risks.

The term Fetal Alcohol Syndrome certainly has its own peculiarity. Within the volumes of medical texts it's hard to locate another syndrome that is named after a cause and effect, involving an element of blame by association – a Foetus is exposed to Alcohol which in turn results in a Syndrome or, in the case of FASD, a spectrum of disorders. As for the blame by association, the only one who is able to subject the foetus to alcohol is the woman carrying the foetus. The very name identifies this problem as a woman-only problem. I must mention that Dr Clarren, who knew and worked alongside doctors Smith and Jones, did not believe that there was any intention on the part of those who coined the term Fetal Alcohol Syndrome to use it as a tool of oppression or blame for birth mothers of affected children. Rather they felt it was an important way for people to be made aware of a serious disability associated with a common recreational drug used regularly and widely by many populations during pregnancy - thus the term 'Fetal Alcohol Syndrome'.

To some degree I have to agree that the term Fetal Alcohol Syndrome has created an overall rise in awareness, but a lack of accurate information has the ability to stigmatise women. Over the course of my travelling to interviews and staying in numerous motor

camps and backpackers, I was regularly asked by people from many different walks of life what I was studying. When I stated that I was researching pregnancy and alcohol many persons I talked with immediately mentioned FAS or FASD even though they did not understand what exactly it was, they knew it was somehow connected to sick babies and the mother drinking alcohol while she was pregnant. Most associated FAS with alcoholic women. Many saw it as a problem that affected those in lower socio – economic status or ethnic groups that they believed (stereotypically) had a natural disposition for this condition. I found the socio-economic status comments extremely interesting as most of the persons that made that statement I judged to be from white, professional middle to upper socio-economic backgrounds.

Interestingly, comments made to me by professionals I interviewed working out of various agencies in Vancouver mentioned a trend surrounding diagnosis. Those from higher socio-economic environments were more likely to have children diagnosed as suffering Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD) than FASD (or other terms associated with this disorder). Conversely very few children appeared to be diagnosed as ADD or ADHD from lower socio-economic environments. These children tended to be identified and diagnosed as FASD. This is a dangerous trend that can fuel incorrect public belief, creating a labelling myth that only those expectant mothers from lower socio –economic environments are at risk of having a FASD affected child. Every woman that drinks alcohol during pregnancy is placing her unborn baby at some level of risk.

I have heard the rationale from a number of professionals: ‘Why bother diagnosing these kids, there is no cure, why make the mother feel unnecessary guilt?’ Firstly, these professionals are correct, there is no cure or ‘magic pill’ that will repair the damage. However, understanding the complexities and the full spectrum of possible limitations and behavioural manifestations associated with this medical diagnosis is pivotal to managing this serious disability. Without an accurate medical diagnosis there will be no knowledge base from which interventions to manage this disability can be generated. As suggested by all international research, the earlier the diagnosis of an individual suffering FASD the better the chances of that individual achieving and realizing their full potential. All my participants (excluding two who fostered or adopted a child knowing they were FASD), including birth parents, wished they had received the diagnosis for their child earlier rather than later. Many wished they could ‘turn the clock back’, often because of the way they had punished the child for what was understood at the time as irresponsible, defiant, age inappropriate behaviour. Most felt guilt surrounding the strategies they had used to deal with the affected child prior to diagnosis, relieved to have the behaviour manifestations explained as being the result of brain damage rather than a lack of parenting skills. Two of my participants described their views on a medical diagnosis as:

I think that getting your diagnosis is so important for your family because it gives them [pause] it just helps the family feel as though they’re, um, how would I explain this [pause] it gives them a sense of self worth, it makes them feel good, it makes them realize that it’s not just bad parenting, it gives a lot of clout as far as schools go , and as far as agencies go, well it should. It’s not a label, it’s much more than that, it’s a means of understanding...because you know what you’re dealing with, then you can learn about it.

* * *

There’s lots of things I would have done differently, many, many things, and I really feel cheated at the years I didn’t have a diagnosis because I could have,

things could have been so different, they've turned out really well but that's been a lot of luck. I know now had she been diagnosed, that had I been given the diagnosis when she was a baby we would have gone through such little stress compared to what we have gone through. I didn't know what I was fighting, couldn't figure it out or get people to understand.

Most of the birth mothers involved with my study stated that they felt remorseful rather than guilty for drinking during pregnancy, and all caregivers found the diagnosis positive for both themselves and their child. Some stated when they observed their child doing something associated with FASD they felt a twinge of guilt. Without intervention both the person affected and their caregivers are walking a tightrope with no safety net every day of their lives. These brain damaged children, as with all children, very quickly grow into adults and as small children do not come with a manual. How do we expect a twenty-six year old adult male who has the adaptive functioning of a seven year old to survive in a world governed by societal laws, age appropriate expectations and norms? Without a medical diagnosis, access to intervention funding is next to impossible in New Zealand, making it difficult to achieve long-term positive outcomes for these people.

CHAPTER TWELVE

Reflections

Birth abnormalities due to alcohol consumption during pregnancy have been observed and documented through the centuries. Since 1973, when this medical disability was first formally identified and documented in America, New Zealand has been extremely slow in accepting and responding to huge amounts of international research on this subject. The ethanol contained in alcohol has been identified as being the strongest teratogen known to human-kind. Unlike most teratogens, it has the ability to interfere with the development of the foetus at all stages of pregnancy right up to birth. We no longer require any more research to support this fact, as vast amounts of global research has supported these findings and failed to disprove this fact.

Medical anthropology has been a valuable tool to gain insight as to how difficult it is for FASD individuals and their caregivers in everyday life, particularly when dealing with agency professionals within New Zealand on a personal level. This thesis has, I believe, presented this medical problem in the context of ordinary everyday life in New Zealand, giving others the opportunity to be privy to the information gathered from experiences of those care giving for a FASD person in this society. For many the journey in search of a diagnosis within New Zealand for New Zealand children is both difficult and in some cases inaccessible. Without diagnosis there are no interventions to reduce the occurrence of serious secondary disabilities. This situation requires an urgent government review. Education surrounding FASD needs to come about through direct Ministry of Health

directives. It must start from the top and work down to the grass roots population. My use of action anthropology by way of seminars (which were evaluated) received extensive positive feedback from the audiences, identifying this as an important way of educating communities and agencies on FASD, its implications and dealing with any negative stereotypes and assumptions associated with FASD. More community focused presentations need to be carried out to ensure increasing awareness is happening within the general population. On reflection, what was noticeable in my research was the lack of New Zealand agency professionals that fully understood the ramifications and implications that the FASD client can have on existing policy and procedures, and how inappropriate many of these policies are when used on this group of people and their caregivers. Procedures surrounding suspected FASD or diagnosed FASD individuals within individual agency systems need to be drafted and implemented to assure safety of both caregivers and the FASD person. All agency workers need to have a solid understanding of the issues surrounding FASD and in particular the limitations it presents to those directly affected. It is no longer acceptable in this time of public accountability (particularly social service agencies) to place a FASD child with a family that have no idea that the child is diagnosed as FASD and/or have no training in regard to FASD.

In New Zealand it appears many do not understand the implications of FASD for their agencies. FASD individuals often appear far more capable than they actually are and as adults can present themselves well. Often even with a diagnosis of FASD they are placed by income agencies in inappropriate job positions, purely because of the lack of

knowledge surrounding this disability. If a person is fired from that job due to poor performance, which is highly likely, he/she will automatically (by legislation) be placed on a six month stand down for eligibility for an unemployment grant. This is a common situation for my participants with adult FASD children. The family will be seriously affected, as they will have to provide for and financially support their FASD child until they qualify for the unemployment benefit or be directed to yet another inappropriate job. New guidelines need to be created for agency personnel to follow, ensuring the safety of agency workers from external criticism and accountability. These children do not simply grow out of it, special strategies are necessary to facilitate behavioural management. The result often has been a succession of placement disasters in which the personal safety of either the child or other family members could easily be (and in some isolated cases have been) compromised. For some of these children, respite/foster placements in an environment where there are no other children is the safest option. It is no longer acceptable that FASD children are adopted out into the community without the prospective parents being informed about the medical problem affecting the new baby. International repercussions for agencies that have continued to adopt out FASD children to unsuspecting parents are beginning to appear in the Canadian newspapers. Agencies are being held accountable and in several cases in America, being sued for this covert practise.

An environment that is stable and structured and able to adapt and be beneficial to the FASD child without too much disruption to the ongoing needs of the rest of the family is ideal. I have had numerous heated discussions when dealing with respite service

providers surrounding inappropriate placements and the importance of diagnostic information to prospective respite families. Often I have been told that to inform caregivers about this diagnosis is not fair to the child, as they will be judged, a process that the respite worker felt would hinder the new relationship. However, without this diagnosis these children are seen by others as lazy, stupid and defiant, all of which are stereotypical labels given by those with no knowledge of FASD. Rather than identifying common FASD behaviour as wilful and deliberate, most is due to the inability to process more than one direction at any one time. One can only wonder how many of our sad statistics surrounding deaths of young children in New Zealand through family violence could be attributed to either FASD parents with poor parenting skills or FASD youngsters having behaviour associated with brain damage being misconstrued as deliberate defiant behaviour.

FASD is a medical diagnosis that is not simple or uncomplicated, and it requires diagnostic procedures to be carried out by confident experts who specialise in this medical area. It is unrealistic to expect every general practitioner, psychologist and paediatrician in New Zealand to be experts in this field, however, every practitioner needs to be directed by the Ministry of Health to undertake mandatory screening of pregnant women for their alcohol consumption pattern and be required to inform them with standardised information on the dangers and risks associated with maternal alcohol consumption. The risk reduction model is excellent and appropriate for those with drinking problems but for the rest of the pregnant population totally inappropriate.

Accessibility to the few diagnostic experts is a serious problem in New Zealand; they appear to be in short supply and tend to be in two main New Zealand urban centres, Auckland and Christchurch. There appear to be no clear referral policies established. Because of the way our health system is divided with respect to funding throughout the country by health boards, it makes it almost impossible to get a referral for diagnosis by an expert operating outside each individual health board's geographical jurisdiction. There are Canadian initiatives that could easily, at little cost, be implemented in New Zealand by way of either setting two or three specialised diagnostic clinics across the country with an appropriate open referral policy where one can obtain an appointment from the closest geographical clinic, or, setting up and operating a telediagnostic service for the screening of children prior to being seen by the diagnostic expert. The longer we leave a child undiagnosed the lesser the chances of a positive outcome for that individual as an adult. Support and assistance for those with disabilities within New Zealand is often difficult to access at the best of times; to attempt to gain access without a diagnosis of a recognised disability is an impossible task.

Historically, early dominance of the macro was exerted over the indigenous Maori people within New Zealand politically and economically. Alcohol, an introduced substance to the Maori people, was introduced and proliferated by agents of the macro for economic gain (often personal) to the detriment of traditional Maori society. It is difficult to ascertain which was more devastating to Maori society – European illnesses or low grade rum. Alcohol appears to have been a major tool for the accumulation and legitimisation process - monetary accumulation in the form of taxes on the sale of

alcohol and legislation as a way of legitimising profitable capital accumulation. When one looks at early New Zealand legislation surrounding alcohol it is very apparent the state has attempted to disguise the accumulation process by ensuring that legislation in no way hindered the accumulation process yet looked as if it was for the good of the people. I believe that this is far from the truth. Alcohol was a serious problem for many European settlers as it was for the Maori people, yet no legislation was developed to deal with the European problem. Liquor has in New Zealand, both in the past and the present been a vehicle for the accumulation of vast amounts of capital gain by way of tax and excise. There is a serious chance that this historical and current monetary gathering process may have created a situation whereby Maori could very possibly have been exposed to a higher risk of experiencing intergenerational FASD among its population. Originally when I started this research, individual ethnicity was not an important component, as this problem is cross-cultural by nature. No one ethnicity has a predisposition for FASD. However, once my interviews had finished I realised that over half of my participants' children identified as being Maori.

History plays an important role in how we as a society view alcohol in the present. Alcohol was and is a cultural factor in most New Zealanders' lives. I believe this is best highlighted by the legislation created in 1946. Alcohol appears to be used as a measure of equal citizenship. Being prepared to die for your country was what it took to gain equal rights (only in regard to alcohol consumption, the revenue creator) within New Zealand society after the first and second world wars. This equal rights and equal

citizenship did not immediately appear to extend itself into equality in most other domains of New Zealand society such as health or education, until many years later.

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Bearing in mind our history with alcohol, one can perhaps understand how we in New Zealand have acquired our attitudes surrounding alcohol. A large number of pregnant New Zealand women are practising binge drinking patterns, the very pattern deemed internationally as high risk in relation to the occurrence of FASD. New Zealand specific research has identified binge drinking patterns as common practise by women within New Zealand and in light of child bearing age and the socialisation of alcohol among youth, young Maori women are at serious risk. It has taken generation after generation to create our drinking patterns, so it could be expected that change in that area could possibly take several more generations to come about. Education is prevention, without education the status quo remains and unaware pregnant women will continue to drink and public attitudes will remain the same. One must also bear in mind that educating the masses will increase awareness, which in turn could possibly result in the government being forced to treat FASD as a capital expense. There is an urgent need for Maori specific research to be carried out on FASD in New Zealand as this population has been identified as having disproportionate numbers of failure in the current education system, disproportionate numbers in prisons for alcohol related offences and serious health problems, all of which could be seriously impacted on by FASD occurrence.

FASD is a political and economic problem within New Zealand. Traditionally to legitimise its existence it appears that the state must be seen to meet various demands

and needs of those adversely affected by the accumulation process, in order to ensure a collective loyalty by the masses. O'Connor suggests that for the state to maintain its legitimacy it must balance the two functions of a capitalist state – social capital and social expense. Whenever we are informed as a nation that there is an increase in liquor tax (social capital), it is legitimised by the state as necessary for the purpose of funding initiatives dealing with the increasing negative effects from its consumption (social expense). FASD is one such negative effect, yet it is not considered serious enough to warrant it as a social expense, minimal if any monies are spent in the research of FASD in this country. The argument seems to hinge on, as the ALAC representative stated, 'no prevalence rates, no funding'. Until the Ministry of Health issues a directive, FASD will not be added to the list of disabilities that demands mandatory reporting. To my mind this lack of response from the government could in part be due to the reality that if FASD joins the list of disabilities that require mandatory reporting, then it could by virtue of statistical power become another social expense that will require the expenditure of social capital. The relationship between prevalence rates and funding is one of extreme intimacy - one obviously cannot have one without the other, in order to legitimise the spending of public monies.

The importance of notification relates to the ability to provide statistical information that identifies general prevalence rates within a given population. In light of international research on FAS over the last 30 years, a large body of internationally acknowledged information has accumulated. It is well overdue for New Zealand to become proactive and at least have an indication of the size of the problem.

Already in New Zealand we have a growing rate of diagnosed cases of FASD, due in part I am sure to a growing awareness among individual health professionals working with pregnant clients. The greater the awareness, the greater the numbers of diagnosed cases. But what is there for both the child and their caregivers after the initial medical diagnosis? These FASD individuals suffer a multitude of social, personal and behaviour problems all of which impact directly on the individual's ability to reach and sustain independent living, and the families' ability to cope with these problems. I am well aware that the 38 participants' children I used for this thesis would not be considered a scientifically statistical population sample from which to generalise, however, I believe it invites further investigation into how the existing system can be adapted to suit this client group. It is imperative that this process involve those experts who deal with FASD on a daily basis - the parents and caregivers. Without their input one can only surmise where the difficulties in existing procedures and protocols lie. Professionals must listen and take into account the expert information given by caregivers, acknowledge - not marginalize - its content.

I believe that FASD is a very real problem in New Zealand, one that impacts in all areas of New Zealand life including political and economic arenas. This is not a problem that is going to simply disappear by ignoring or denying its existence; the longer we keep our population (particularly women) in ignorance the greater will be the prevalence rate of FASD. There is no safe limit, we simply do not know enough about low dose responses to categorically state that there is such a thing as a safe limit.

Maternal alcohol consumption rate is not being affected or reduced, nor any appropriate national level of public awareness being carried out. In fact during my research I found the breweries and the Beer, Wines and Spirit Council of New Zealand having far more insight and acknowledgement of the possible serious harm FAS/FAE could cause amongst our population. Interestingly now in 2004 where New Zealand specific research into FASD is almost nonexistent, funding has been given to researchers to document and study the teratogenic effect the recreational drug 'P' has on the babies' development during pregnancy. New Zealand is currently experiencing serious crimes and anti-social behaviour directly associated with this designer drug. The same importance has not been placed on alcohol, the legal drug which has continually been identified as a factor in many New Zealand crimes.

FASD individuals are difficult to deal with and require correct management. Routine, stability, understanding and love will all go a long way to reduce the affected persons' social and behavioural deficits. This in turn will have a huge impact on each FASD individual's ability to function as an adult in an adult world. The severity and magnitude of brain damage differs as does IQ from individual to individual. The extent of brain damage and the type of environment will have the largest effect on the individual's ability to cope without ongoing support and assistance.

The medical term (regardless of the political correctness and the labelling argument) has for all my participants been likened to receiving a 'key', a key that has the ability to unlock doors that have otherwise been closed and inaccessible. In Amanda's case, as

with all cases, the first door the diagnosis opens is access to appropriate educational resources. This thesis is an attempt in a small way to have provided a voice for those who traditionally are not heard – caregivers of FASD individuals - placing this topic in the academic arena as a small but important part of bringing the issue of FASD into the public arena - one that I sincerely hope will grow in proportion as time progresses. New Zealand needs to join other western countries in being pro-active in reducing both the incidence rate of FASD and the severity of unacceptable secondary disabilities associated with FASD within our society. I believe that the type of action anthropology carried out during this research has been a starting point from which action can and has come about, particularly in regard to consuming alcohol during pregnancy. A large portion of these children can grow into adults that can contribute to our society with appropriate intervention and support. There are success stories out there from several of my informants with adult children but sadly they are a minority.

Early diagnosis is imperative for everyone involved in the FASD individual's life. To understand the behavioural manifestations exhibited and implement appropriate interventions, one has to understand what exactly they are dealing with. As Anne Streissguth (1996) suggests, a medical diagnosis can be empowering to family members of the FASD person; an effective vehicle for communication, one that enables caregivers to not only advocate for their child but importantly educate others around the special needs of their child.

New Zealand is more than thirty years behind other western countries in the investigation of FASD, and politically it is not being recognised as a problem that should be categorised as a social expense. FASD is still seen politically as a problem that rarely occurs in New Zealand. The original contribution of this thesis is that in its completed form it is an example of how action anthropology provides a tool that can bring about change whilst at the same time reveals social, political and economic processes and how they impact on ordinary people's lives. The methodology of action anthropology has enabled a dialectal process to occur, one where the wealth of information given to me by caregivers of FASD sufferers has been passed on to other caregivers and professionals alike via my seminars – the more I learnt , the more I gave back to communities. Knowledge is power. My thesis and my accompanying educational seminars have contributed to the empowerment of New Zealand women through a growing knowledgebase on FASD. This thesis offers not just information on FASD, but also a broader analysis of the dynamic political processes within New Zealand, by placing FASD into a political economic context.

This research was never intended to prove any one particular issue surrounding FASD but instead it was intended to provide up to date information on FASD as well as provide a platform for the expression of the experiences of those directly and indirectly affected by prenatal exposure to alcohol within New Zealand. Statistics used in this thesis as I have mentioned before, are not scientifically significant due to the sampling procedures carried out and cannot be used to make generalisations. However, these experiences nonetheless are accurate personal accounts from the experiences of those

care-giving for FASD individuals within New Zealand and cannot be dismissed as non-credible but rather should be seen as an indication of where the system is failing these persons.

The major contribution of this thesis process has definitely been the empowerment of individuals through education, a process that has been made available only through the use of action anthropology. This empowerment process can only grow as other researchers use this research as a basis for necessary future work on FASD within a New Zealand context. New Zealand specific FASD research is urgently required particularly in the domains of health, justice, education and social services if we are to deal with this problem efficiently and cost effectively. We have international models and programmes from which to draw ideas and evaluations that have been operating for several years. The wheel has already been invented – there is no need to reinvent it, merely adapt it to suit the New Zealand culture and context. Extensive research or at the least an inclusion of this subject in other research being carried out in New Zealand is imperative if we are going to address this problem.

According to a New Zealand Treasury Department working paper, \$580 million dollars was earned in 1999 through tax and excise on liquor imported into New Zealand. This figure does not include New Zealand locally grown and produced alcohol beverages. Alcohol has historically and currently been an important source of state funding and has over the last two years been the focus for new legislation surrounding the lowering of the drinking age from twenty-one to eighteen years and recently, the target of a new tax

structure placing higher taxes on cheaper spirits that contained lower levels of alcohol content. This increase in tax was projected to provide approximately \$14 million dollars per year of new revenue for the New Zealand economy. This figure does not include the possible revenue created through the hospitality industry generated from the lowering of the drinking age from twenty to eighteen years. FASD is 100% preventable and until realistic funding is made available for this area very little progress will be made in preventing this disability. In light of the large amounts of revenue collected by the state from alcohol and the fact that FASD is a negative result of this accumulation process, I believe that at the very least the state has a responsibility and a moral obligation to address issues surrounding FASD within its own organizations, provide access for diagnosis and ensure that every New Zealander (particularly pregnant women) is given access to accurate ongoing information surrounding the possible risks of alcohol consumption during pregnancy.

Evaluations For FAS/E Seminar Agencies – Greymouth 21/08/2002

1. As a result of attending this seminar do you feel you have a better understanding of FAS and FAE?

YES / NO

18

2. How well would you rate the information presented as being clear and understandable?

1	2	3	4	5	6	7	8	9	10
							3	2	13

Please Comment

- Very Clear and easy to follow
- Very good presentation and most interesting
- Presentation was clear and interesting
- This was fantastic – great presentation
- Good verbal presenter. Easy to listen to. Examples helped comprehension and backed up with OHP's.
- Good examples.
- Very well presented and knew topic inside out.
- Very informative and well presented. My attention was held.
- Informative, interesting and well presented. My attitude has changed as a result of increased knowledge. Thank you.
- Illustrations were very helpful in identifying problems in people.
- Information was great.

3. Are there any areas that could have been covered in more depth?

- Because of the time limit I think it was very well done.
- Adult facial signs of FAS.
- No.
- A good introduction. Obviously there is heaps more information available.
- Nil.
- Clarification re diagnosis, days of developing FAS ie day 19 etc.
- The time limit was used to the limit.
- Could listen all day!
- Managing children's behaviour. Everything.
- Illustrations very helpful in identifying problems in persons
- Probably need a longer seminar generally.
- More about the signs in under 3's, how to get it diagnosed and from whom psychologist, paediatrician etc. Names in the South Island and where to go to
- Where to from here?

4. Would you recommend this seminar to a colleague?

YES / NO

18

Any Further comments

- There definitely need to be more information made available, especially for schools.
- Written information / handouts would be good.
- Come back – talk to the education group.
- Thanks, enjoyed being present.
- Thanks Margot for coming down and to Michael for organising the seminar.
- Excellent – a huge amount of work for NZ to do.
- Do you present this in schools?
- I would like to talk to Margot (Acting Practice Manager, CYF's)
- Interesting, informative and stimulating.
- Would have liked further info about FAS and FAE and the differences.
- Some of the information needed to be directed at funding agencies – MOH etc.
The room was freezing.

Thank you

**Evaluations For FAS/E Seminar
Hokitika 30/10/2002**

1. As a result of attending this seminar do you feel you have a better understanding of FAS and FAE?

YES / NO

36

2. How well would you rate the information presented as being clear and understandable?

1	2	3	4	5	6	7	8	9	10
				1	1		7	6	21

Please Comment

- Excellent. Well presented, needs to get more funding from Public Health. Labelling on bottles in NZ, not just cigarette packets but all bottles of alcohol TV advertising also.
- Impressive speaker but we are now in a void as there is no one to refer our FAS/E students to. Impressive because of enthusiasm and commitment.
- A very eloquent and inspirational speaker.
- I would have liked to have heard about the possible affects of alcohol on sperm and the possible mutative affects of that.
- Having two girls with this problem a lot of things I never understood are clear now.
- As again a wonderful seminar
- Appreciate the depth of information you have.
- A very understandable overview of a serious problem in our society that I had "heard" about but had no information on.
- Very informative and eye opening.
- Excellent, I wish I'd had this knowledge years ago, rearing adopted children. Also I will understand several children in my class better, and many in the future.
- Very easy to understand. I spent 3 hours trying to get information - suggestions Methanone. To no avail. This has helped heaps. Thank you
- Facilitator presented seminar in a clear, focussed and easy to understand manner. She used relevant real life examples to support and explain her facts and points of reference.
- Very dynamic speaker
- Interesting speaker
- Enlightenment at last!
- Videotape next session. Very good!
- Fantastic
- Very good presenter. Good audio visual aids. Easily "understandable" information. Presenter had a high level of knowledge in the subject area.
- A lot of very disconcerting statistics presented
- Appreciated is the visual, auditory style. Easy to listen to.

- Too much content at end of session – felt rushed.
- It was very good, really enjoyed the seminar. Well done.
- Good visual displays. Clear voice.
- Really good basic information – real life scenarios for examples – great simple ideas to support and change environment. Wide range of information historical, social etc to make the big picture.
- Very articulate, easy to listen to, thank you very much. Overmuch listening, insufficient visuals.

3. Are there any areas that could have been covered in more depth?

- No
- First half was very informative. Second half was good but too long – tiring at the end of a long day – a lot to absorb.
- Information from families present relating to experiences.
- For me it was a good all round informative seminar
- Strategies for teachers to assist FAS/E children to learn and make some achievements in school.
- Not with the number of issues covered.
- Not in the time available.
- There is always more to learn, but not in the time frame here. You did really well to cover the amount of information you did.
- Responses to FAS kids.
- Enough information for an evening workshop (tired at the end of the day)
- No
- Effects of those countries where alcohol is the form of daily wine consumption is the norm eg Italy and France.
- Where do we go if we suspect a child of being FAS? ie first steps.
- A shame no midwives or other health professionals were here tonight. Primary stop for parents are the first point of call, yet none of them seem to be here.

4. Would you recommend this seminar to a colleague?

YES / NO

42

Any Further comments

- Need to go to the Police College and teach new police recruits.
Lecture to nursing and teaching students at polytech and university.
Lecture to Junior Doctors and put something in the GP studies as part of their units.
- Incorrect starting time was trying!! Finish time – not notified of.
- Relaying of times. Arrived at 4.00 expecting refreshments. Annoyed at wasting 30 – 40 minutes. Unaware of duration of the course.
- Getting too tired to do more than take it all in and process slowly.

- Just a wee bit shorter. You do a marvellous presentation but 3 1/2 hours is a long time and with people exiting it is hard too hear and concentrate. Well done though and god luck with PhD.
- Margot you give me confidence as a parent of a FAE child. Thanks.
- The community need to hear about this and the government act upon it.
- When are you coming back? I want my principal and chairperson to hear about this.
- Late start!! 4 pm??
- Carry on the excellent work.
- A later time. 4pm is impossible .Our centre doesn't close 'till 4pm in Greymouth. Thanks for letting us arrive late.
- Thank you for caring and sharing.
- Thank you for broadening my horizons with regard to this syndrome. I will be able to put my new knowledge to work in my teaching.
- Lengthy and valuable. Important to be offered to as many educationalists as possible .Sharing of what works for practitioners.
- Lots of valid useful information – could be extended into a one day course or over two nights.
- Maybe a little long – spread over two days maybe would be better concentration wise.
- Very interesting and informative.
- A very informative seminar.
- A bit long at the end of a working day. But overall a very informative and interesting presentation.
- Thank you so much, I have heard heaps and could have spent hours listening to you. Great presenter, skills and knowledge. Thank you.
- Great seminar and very interesting and informative. Would have loved a whole day instead of at the end of a busy day. Thank you. Very helpful.
- The presenter was believable, easy to listen to and presented the information well. She talked to us (it almost felt personally) not at us.
- Bit too long. Great supper.
- I would come back again. The information is very good.
- Good comments on classroom approaches, with written Repeat in folders.

Thank you

**Evaluations For FAS/E Public Seminars
 Greymouth 21/08/2002 - Reefton 20/08/2002**

1. As a result of attending this seminar do you feel you have a better understanding of FAS and FAE?

YES / NO
 22 0

2. How well would you rate the information presented as being clear and understandable?

1	2	3	4	5	6	7	8	9	10
					1		3	1	17

Please Comment

- Absolutely great. I needed this information and have enjoyed hearing the questions and feedback.
- Great
- Good background. Reinforced the info I already had with more in depth information than I had.
- Confirmed lots of things that other people thought I was neurotic about.
- Good.
- Specific examples of behaviours, responses giving an understanding of seemingly erratic behaviour.
- This was very informative and I now know why my neighbour has steam coming out of her ears most days.
- This has been absolutely awesome and Margot has made such a difference to my life as a parent of FAE children.
- Very clear
- Very clear. Some of the language may have been a bit technical for some parents.
- Really good to enforce what I thought I knew and I learnt so much more as well.
- Well prepared. Good examples and information.

3. Are there any areas that could have been covered in more depth?

- Heaps, because it was so interesting.
- No. Very good.
- Probably, but I will read the information pack.
- Possibly more tables of symptoms and key behaviours.
- No.
- Don't know.
- It was very thorough.
- Behaviour management.

4. Would you recommend this seminar to a colleague?

YES / NO

22

Any Further comments

- Thanks. Excellent!
- Soft drinks and breaks??
- A short break half way through would help.
- Thanks.
- Maybe some day there will be a difference made. Hopefully people can come out of their shells and make the change.
- Thank you.
- Too much information in a short time. Could have been more condensed and simpler presented.
- Thank you. Very interesting especially the statistics. Great to see your passion.
- Excellent, informative seminar.
- We need to get this information out to mothers before they get pregnant.
- A comment that behaviour management was effective and not behaviour modification. More information on this would be useful as behaviour modification is behaviour management.

Thank you

Evaluations For FAS/E Seminar Teachers Group – Greymouth 19/08/2002

1. As a result of attending this seminar do you feel you have a better understanding of FAS and FAE?

YES / NO

41 / 1

2. How well would you rate the information presented as being clear and understandable?

1	2	3	4	5	6	7	8	9	10
		2	1			4	11	6	18

Please Comment

- Please emphasise that there is a lot of guilt associated with FAS and FAE and seldom closure.
- A lot of information to comprehend.
- Really interesting and informative.
- Great presentation. Very informative.
- Good. Generally very clear.
- Thank you for enlightening me and helping me realise that I have a FAS child in my class.
- Although very clear presentation. May need to read a bit more about the difference between FAS and FAE.
- Excellent. It gave me some good ideas for strategies.
- Clear and concise (especially given the shorter presentation time)
- Learnt a lot and confirmed a lot.
- Exceedingly wide ranging yet compact because of limited time available.
- Explains the behaviour of a significant number of students – that's scary.
- Very clear and concise.
- Very clear information.
- Very quick, but we had heaps of information.
- Informative.
- Impressive range of information. Episodic in my understanding. Probably a result of time frame.
- I thought the seminar was going to cover FAS/FAE from a classroom teacher's perspective. The historical background/medical aspects were interesting however it seemed to take a long time to get to the recommendations. Helpful ideas – unfortunately hard to implement given the constraints of timetable, limited resources and frequent movement in secondary schools.
- Very interesting. Good food for thought.
- Well presented.
- Well presented, extremely interesting and informative.
- Very clear and informative. Information to take away would be good.
- Fantastic. I want to give up teaching and become a medical anthropologist.

- Lack of time to fully cover.
- Hard to hear – noises/echoes, accents. Hard seats. Time of day.
- A lot of text to read and go through.
- A lot of information to take on board.
- Clear at first. Then I got rather confused.
- Insufficient time and opportunity for interaction.

3. Are there any areas that could have been covered in more depth?

- How FAS/FAE is assessed.
- Great presentations. Very informative.
- Yes I'm sure, but not in the time available.
- No.
- Everything – though a good coverage given time.
- More strategies for dealing with these but I realise there wasn't enough time.
- More pointers for recognising children with syndrome – differentiate between naughtiness and FAS/E.
- Secondary age – coping with 4 to 5 students that are FAE in each class and feed off each others behaviour. Can't effectively deal with one because the others then go ballistic.
- No.
- The strategies on what to do.
- What strategies can we use in the classroom (real situations)? Discussion with other teachers who have experienced FAS/E children.
- Not in the time available.
- Carry on! Touching strategies. Identification so that we are more aware.
- Yes. Years 9-11 at high school. Photocopies of teaching strategies.
- Is there much research being done about the incidence of this on the Coast? What should we as teachers do if we are concerned? Is there any point in labelling the students if there are so many of them? Or is it better to put resources in to assisting the students?
- No.
- Symptoms in terms of behaviour. Ways of dealing with it as a teacher.
- Yes, however the limited time restricted the speaker.
- Dealing with adolescents in the school setting.
- Heaps of information delivered in an informative manner.
- Strategies for coping with teen FAS/E children while coping with 29 other differently demanding souls.
- Shame there wasn't more time.
- Strategies – all suggested are now recommended as good teaching practices.
- The strategies to deal with such children and where to go If you think you have a FAS/E child in your class.

4. Would you recommend this seminar to a colleague?

YES / NO

42

Any Further comments

- Great presenter with a lot of experience and great ideas to help the children.
- Thank you.
- I hope the parent Of an FAS/E child in my class will attend Wednesday's seminar. Fingers crossed.
- Thanks very much.
- A real eye opener. Answered many questions raised recently about FAS/E that I've been hearing without understanding. As a teacher I would have liked more information what they (FAE students) are capable of academically.
- Recommend (as a teacher) that school management do more to identify FAS/E and pass on information to classroom teachers (with advice on how to deal with them).
- Excellent detail.
- More discussion with peers regarding personal experiences.
- More visuals would be great.
- A fascinating topic and one that is of concern in the schools.
- I liked the emphasis on 1) avoid judging the behaviour 2) avoid judging the parents.
- Breaks to maintain attention.
- More time needed to work out how we can implement these ideas in our classrooms, but a good introduction. Thank you for the strategies to try.
- Very knowledgeable presenter – really good visual information.
- A great amount of information presented and a clear understanding gained.
- Lovely afternoon tea!
- Rather than a presentation could we use something more interactive?
- Thanks.

Thank you

Evaluations For FAS/E Seminars

Westport 23/08/2002

1. As a result of attending this seminar do you feel you have a better understanding of FAS and FAE?

YES / NO
20 0

2. How well would you rate the information presented as being clear and understandable?

1	2	3	4	5	6	7	8	9	10
							2	6	12

Please Comment

- It was very clear and straightforward. I found the whole talk great
- Well presented
- Excellent overview and explanations.
- Excellent introduction.
- Professional well thought out, confident and sure of material.
- An excellent presentation with plenty of up to date and useful resources. Great clear voice.
- I enjoyed the clarity and passion of the presentation.
- So enlightening, shocking and clearly presented.
- Very clear and very easy to follow.
- I think the information came across very well with the hand movement and also the humour put into the speech.
- Started a bit slow but warmed up well.
- Good verbal presentation, reinforced with good examples. Good overheads. Also drawing on participation as well.
- Would have liked handout during the talk so I could have written on it.
- Great information well delivered.
- I found this most easy to understand a mine of information. Well read knowledgeable and practical.
- Was very pleased with everything I heard.

3. Are there any areas that could have been covered in more depth?

- I found that your talk helped me understand a lot about the way people think. Thank you.
- No.
- No. It was excellent.
- Info on who to refer to if FAS is suspected.
- Everything.
- I would love to study more about this area.
- No- really well covered. Not that I can think of.
- I don't really know much about FAS/E so I don't think that there was much more you could have given.
- Behaviour and management of.
- Some treatment ideas.
- I thought that in the time allowed I had more than enough information and will be able to access any more that I may need.
- Ways to cope and help FAS/E individuals to cope with their problems.
-

4. Would you recommend this seminar to a colleague?

YES / NO

20

Any Further comments

- Thanks. Excellent!
- Soft drinks and breaks??
- A short break half way through would help.
- Thanks.
- Maybe some day there will be a difference made. Hopefully people can come out of their shells and make the change.
- Thank you.
- Too much information in a short time. Could have been more condensed and simpler presented.
- Thank you. Very interesting especially the statistics. Great to see your passion.
- Excellent, informative seminar.
- We need to get this information out to mothers before they get pregnant.
- A comment that behaviour management was effective and not behaviour modification. More information on this would be useful as behaviour modification is behaviour management.



13 July 2001

Margot Symes
C/- Fetal Alcohol N.Z. Trust
PO Box 13385
Onehunga
AUCKLAND

Tena koe Margot

I have just completed the report for the 2001 PAFT Ongoing Training and am congratulating myself on putting together such a worthwhile programme for all the parent educators throughout New Zealand. However, I do have to admit that the calibre of facilitators and the wonderful information imparted was the vital key to 'my' success. So I'm writing to you to express my sincere thanks for your great session.

As you know from your own evaluations participants at all sites were very satisfied with the session. Our evaluation forms indicate an extremely high rate of satisfaction. The only dissatisfied response was someone who was tired and grumpy from a long day travelling, and was critical of ECD's organisation rather than your session.

Here are some of the comments from the evaluation forms. Parent educators' words express the true appreciation for your work,

Shona and Margot's presentation was absolutely excellent!

Keep better records if women have had a drink of alcohol during pregnancy. It can make a difference.

Early Childhood Development • National Office • Tari Matua
Level 7, CMC Building, 89 Courtenay Place, PO Box 9951, Wellington, New Zealand
Telephone 0-4-381 9800 Fax 0-4-381 9801
Email info@ecd.govt.nz Internet <http://www.ecd.govt.nz>

Be more assertive regarding pregnancy/alcohol and attempt to let people know the disastrous effects.

Be more observant in looking for possible FAS/FAE mothers and babies.

Everybody should know about FAS/FAE

Scary stuff.

The first time I've heard this talk. Absolutely amazing, scary as to the implications – short term/long term.

Not to be judgemental about families.

This is a topic that needs to be brought to the attention of every person in the country.

Thank you for giving us wonderful facilitators and their knowledge is awesome.

My aim is to focus on our mothers who drink, especially our Maori mums. Vitally important.

A fascinating but very disturbing and moving presentation.

This is the biggest issue facing the women of NZ.

I didn't know anything about this so I feel to me a book has just been opened and now I have to keep reading.

Be more skilful in my home visit observation recording.

Brilliant thank you, so much more real than anything I did in my degree.

So there you have it. One hundred and seventy nine happy participants and one very happy training coordinator. The sessions exceeded my expectations and I am so grateful to you for your role in getting this extremely important information across to parent educators who have such a positive influence on young parents.

Margot, I hope your thesis is going well and I look forward to reading it when it's completed. Thanks again for everything. No doubt our paths will cross again soon.

Heoi ano. Naku noa, na

A handwritten signature in blue ink, appearing to read 'Lorraine Tarrant', with a stylized flourish at the end.

Lorraine Tarrant
Parenting Programmes



Hibiscus Coast RTL B

★ Red Beach School ★ 20 Albert Hall Drive ★ Red Beach ★ Hibiscus Coast 1 462 ★
★ Phone & Fax 09 426 8921 ★ email: hibiscustrlb@xtra.co.nz ★

Margot Symes
Albany Village Gallery
239 Main Highway
Albany

Dear Margot

My sincere thanks for delivering the RTL B and Staff Professional Development Sessions on Foetal Alcohol Syndrome at Wainui recently. We all enjoyed your presentations which were very informative and most helpful in working with children with FAS.

There has been very positive feedback from the Resource Teachers Learning and Behaviour who attended the sessions on 1 May, and from the teachers at Wainui School. Your preparation and depth of knowledge are evident and we are grateful that you were willing to make time to share this.

Wainui school have expressed an interest in some follow up with you in the future as they are concerned to do their best for students with FAS/FAE.

Enclosed are the resources we borrowed as well as something towards your expenses and travel.

Regards

Julie John
RTL B

Home Telephone (09) 424 5992
Cell Phone 021 106 1008

19/01/1997 Sex: M 5 yrs.

Rosie Marks
Developmental Paediatrics

GP: Dr [REDACTED]

CLINICAL NOTES

DATE
TIME 24/11/03

CLINICAL NOTES

OUTPATIENT REVIEW

PROBLEMS

1. Attention deficit disorder.
2. Prenatal alcohol exposure/heavy alcohol consumption to 9/40.
3. Active challenging behaviour.
4. Facial features consistent with fetal alcohol syndrome.
5. Recent URTI with middle ear involvement.

Current Medication

Magnesium and Ambrotose prescribed by Dr Ian McDonald.

ACTION PLAN/RECOMMENDATIONS

1. To see General Practitioner in one to two weeks for review of middle ears and tympanogram.
2. Discharge from developmental paediatric follow-up see on parental or GP request.

[REDACTED] who is now aged 6 years, 10 months attended the developmental paediatric clinic at Wilson Centre today for review. He was accompanied by his mother [REDACTED]

Educational Progress & Programme

[REDACTED] describes [REDACTED] as being "200% improved". Margot Symes has been actively involved and has supported [REDACTED] coming into the school and providing information and ideas for [REDACTED]'s management. [REDACTED] brought a copy of the report from the RTLB and I understand that Special Education have also been involved. [REDACTED] is attending [REDACTED] Primary School and making pleasing progress.

Attention Deficit Disorder

The Connors questionnaires done last year confirmed a diagnosis of attention deficit disorder. We discussed the possibility of using stimulant medication at that time but [REDACTED] decided against this because she was concerned about side effects. We agreed today that in view of [REDACTED]'s pleasing progress he should remain off medication.

General Health

[REDACTED]'s general health has been reasonably good. He had a recent viral upper respiratory infection for which he saw his GP and there was concern that his middle ears were inflamed. He was not treated with antibiotics and today both tympanic membranes have good light reflexes but some peripheral injection consistent with a resolving viral upper respiratory tract infection.

Don't kid yourself,



**...it may be fun for you but
alcohol can permanently
damage your unborn child**

Fetal Alcohol Syndrome and Alcohol Related Effects
are preventable ... just have an Alcohol Free Pregnancy!



Alcohol can permanently damage your unborn child.

Kava malohi oku he hanga o' fakatupu a palapalema ki he pepe te'eki fanau.

Make he kava ke fakamatematekelea tukulagi e tama nakai la fanau ha u.

Ka riro te kava kona ite akakino ite oraanga o ta'au peepe i te tuatau te nui ra koe.

E maua i ni afaina tumau se pepe ae lei fanau mai , pe a inu ava malosi le tina ae o mamafa.



Alcohol can permanently damage your unborn child.

Kava malohi oku he hanga o' fakatupu a palapalema ki he pepe tē'eki fanau.

Make he kava ke fakamatematekelea tukulagi e tama nakai la fanau haau.

Ka riro te kava kona ite akakino ite oraanga o ta'au peepe i te tuatau te nui ra koe.

E maua i ni afaina tumau se pepe ae lei fanau mai , pe a inu ava malosi le tina ae o mamafa.

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