

# **FETAL ALCOHOL SPECTRUM DISORDER: NEW ZEALAND BIRTH MOTHERS' EXPERIENCES**

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## **ABSTRACT**

The aim of this study was to describe the 'lived' experiences of New Zealand birth mothers, from pregnancy onwards, of a child/ren diagnosed with Fetal Alcohol Spectrum Disorder (FASD).

## **Method**

A qualitative paradigm was utilized so that the participants could tell their stories through words and text rather than collecting statistical data which is the domain of quantitative research. The adoption of a feminist standpoint theory bridged a communication gap, adjusted the balance of power within society and gave visibility and voice to the women. Eight New Zealand-resident multipara biological mothers ages 18 and over, who had nurtured or were still living with their affected offspring, were studied. Their ages ranged from 29 to 64. The mothers were interviewed in depth, face-to-face, using unstructured, open-ended questions. Data were analyzed using the constant comparative method.

## **Results**

The mothers described a range of issues of concern for their disabled offspring and themselves (as advocates) relating to health, social, educational, judicial systems, lack of knowledge by professionals and problems in diagnosis, to being oppressed and stigmatized. Cognitive concerns for the offspring included attention-deficit, absence of fear, diminished memory and comprehension and inability to acknowledge and understand consequences. Behavioural issues included excessive crying or no crying as a baby, lying, stealing, hyperactivity, aggressiveness, destructiveness, sexual promiscuity and few friends. Other issues of concern were delayed milestones and numerous health problems. All mothers stated that the pregnancy, labour and delivery of their child with FASD were different from their other non-compromised pregnancies/labours/deliveries. Most mothers said that the doctors used medical language which they did not understand, thus giving power to the former. Seven mothers were either married to or partners of alcoholics when they conceived their offspring with FASD. All mothers had been drinking alcohol before becoming pregnant. Six mothers came from drinking families. Most mothers continued to consume alcohol because they did not know that they had conceived. All mothers were unaware of FASD and its effects on the unborn child. Eight babies had low Apgar scores with an average of 6 (out of 10) and low birth weight (average 6lb 2oz). An Apgar score is a numerical expression of an infant's condition, usually determined at 60 seconds after birth, based on heart rate, respiratory efforts, muscle tone, reflex irritability and colour. All women were of middle to high socio-economic status. Seven mothers experienced family breakdown as a result of alcohol consumption by the biological father of the child with FASD. All women feared for their child's future.

## **Conclusion**

Health, social, educational, judicial professionals, policy-makers and agencies, need to understand and be educated in the daily realities and complex problems that children with FASD and their families face. Only then will the correct diagnosis be made so that these individuals can receive the nurturing, needs, education, funding and support they require in order to live full and meaningful lives and have the quality of life they deserve.

**Keywords:** *Fetal alcohol spectrum disorder, behaviour, cognition, education, health, judicial system*

Pregnant women, worldwide, continue to consume alcohol which freely crosses the placenta at the full concentration that is ingested by the woman, entering the circulatory system of the fetus. Because of the baby's small size and under-developed liver and enzyme system, it cannot eliminate the alcohol at the same rate as the mother can, so that the fetus is exposed to alcohol for longer periods than the drinking mother.<sup>1</sup>

This teratogen plays a very important part in New Zealanders lives, because of its strong culture of heavy alcohol use where alcohol abuse is considered to be normal social drinking, so amongst its pregnant women, there are high levels of alcohol consumption (>4 standard drinks per week) as well as 16-24 year-old females.<sup>2,3</sup> There is also evidence of an increase in excessive drinking amongst young women. Nearly a quarter of those young women aged between 18 and 19 years who drink, consume sufficient to feel drunk at least once a week.<sup>4</sup> Consequently, women are most likely to be drinking heavily at ages when fertility (and sexual activity) is high – perhaps because medical and health advice on drinking during pregnancy continues to be inconsistent despite the official New Zealand guideline to avoid alcohol whilst pregnant, planning pregnancy and when breastfeeding.<sup>5</sup>

However, this has implications far beyond the acute risk of harm to the individual drinker and the immediate risk that it may also pose to the fetus should the drinker be pregnant at the time of consumption. Also, there are currently, no reliable means to confirm maternal drinking using biochemical markers in pregnancy.<sup>6</sup>

### Drinking Behaviour

The drinking behaviour of New Zealand women during pregnancy is as follows:

- A 1994 national study in New Zealand showed 41.6% of pregnant women consumed alcohol during pregnancy. Hazardous drinking was not confined to any one socioeconomic group.<sup>7</sup>
- A 1999 nutrition report on 500 pregnant women in New Zealand showed that 29% continued to drink alcohol after their pregnancy was confirmed.
- Of the 24% of women who regularly drank to intoxication before pregnancy recognition, 11% continued to do so throughout pregnancy.<sup>8</sup>
- A survey of midwives reported that 36% of

pregnant adult clients and 82% of pregnant teenage clients drank during their pregnancy.<sup>9</sup>

- A 2002 study reported that a quarter of pregnant New Zealand women at 24 weeks report consuming alcohol in the previous 7 days.<sup>10</sup> The study found that women who were older, had previous pregnancies, a tertiary education and higher income levels, were more likely to drink.
- In 2004, 82.4% of women drinkers reported having stopped alcohol intake during pregnancy. No significant differences were found between Maori and non-Maori.<sup>3</sup>
- A 2006 study on the awareness of the effect of alcohol use during pregnancy<sup>11</sup> showed that more than 50% of women were of the opinion that if a pregnant woman wanted to drink, then some alcohol was safe in pregnancy. Nearly 20% of all women had binged at least on one occasion in pregnancy, most having done so before they realised they were pregnant.

In the absence of individual assessments, it is unclear whether drinking during pregnancy in New Zealand is actually decreasing or whether fewer women are reporting it owing to their awareness of the issue and possible stigma if admitting to drinking. Clearly if 50% of women believe that some alcohol during pregnancy is safe, then some will be more likely to drink themselves.<sup>12</sup> Certainly, general directions for limiting the harm caused by alcohol were set by the National Alcohol Strategy 2000-2001<sup>13</sup> in which a number of initiatives were directed specifically towards reducing the consumption of alcohol by pregnant women.<sup>14</sup> Four years later ALAC suggested that drinking pattern, rather than the average number of drinks per week, was likely to be the most significant factor affecting adverse pregnancy.<sup>15</sup>

In Australia the issue of FASD has not been the subject of policy development or of extensive research. There is a lack of knowledge, both in the general community and by health professionals, of the nature of the risks associated with heavy alcohol consumption during pregnancy and the factors that increase this risk.<sup>16</sup> A survey carried out by the Salvation Army found that more than three million women were not convinced it was necessary to stop drinking while pregnant and one million said they strongly disagreed that drinking during pregnancy

was dangerous. 1.2 million Australian women aged between 25 and 49 drink or have drunk alcohol during pregnancy, with those aged between 25 and 34 more likely to drink than other expectant mothers.<sup>17</sup> Researchers have commented on the clinical under-diagnosis of FASD in Australia, referring to ARBD (alcohol-related birth defects) as the 'great paediatric imitator', meaning that true alcohol-related defects may often be diagnosed as another condition for which symptoms are similar.<sup>9</sup>

### How Much Alcohol?

Importantly, there has been confusion over how much alcohol a pregnant woman could safely consume. Whereas mothers who are alcoholic or abusing alcohol during pregnancy are at highest risk of having children with FASD, even social-drinking women are at risk of having children with subtle, yet long-lasting neurodevelopmental problems. Because medical researchers have not been able to say for certain what the safe level of alcohol use is for pregnant women, many service providers argue that any alcohol use must be considered risky behaviour.<sup>18</sup> In this respect, the New Zealand Government in 2007, erring on the side of caution, called for 'zero' consumption of alcohol by pregnant women. This, in contrast to the statement made by the United States Institute of Medicine (IoM)<sup>19</sup> which says "While alcohol is the necessary teratogen, it alone may not be sufficient to produce FASD in humans or birth defects in animals. As with most teratogens, not every fetus exposed to significant amounts of alcohol is affected. The outcomes might be modulated by numerous biologic and environmental factors".<sup>20</sup>

Interestingly, whilst the Royal College of Obstetricians and Gynaecologists (UK) in 2001<sup>21</sup> recommended limiting alcohol consumption to no more than one standard drink per day, Sood et al,<sup>22</sup> in the same year, suggested that prenatal exposure to small amounts of alcohol – as low as one standard drink per day, where a standard drink contains about 0.5 oz of ethanol alcohol (e.g., 360 mL [12 oz] of beer, 150 mL [5 oz] of wine or 45 mL [1.5 oz] of spirits – has some neurobehavioural effects on the offspring. Since the precise lower threshold for ethanol embryopathy is unknown, pregnant women should be advised to abstain from all alcohol use if possible.<sup>23</sup> In Australia, there is also differing recommendations as to what is a safe level of alcohol

consumption when pregnant. For example, the Australian National Health and Medical Research Council (NHMRC) guidelines differ from those of the American Centers for Disease Control (CDC), the latter being fully restrictive and the NHMRC ones being described as unnecessarily complex and leading women to believe that it is safe to consume alcohol during pregnancy.<sup>24,25</sup> Of note, is that the Australian Drug Foundation has called for more warning labels on alcoholic drinks, highlighting the health effects of harmful use.<sup>26</sup>

### Risk

Although some sources state that the risk is highest in the early stages of pregnancy, the actual severity of the effects of prenatal alcohol exposure depends on interactions between maternal and fetal physiology and genetics, timing and duration of fetal exposure, pattern of maternal drinking and a number of maternal lifestyle factors, including higher maternal age, lower education level, cocaine use, smoking, custody changes, lower socio-economic status and paternal drinking and drug use at the time of pregnancy<sup>22</sup> as well as reduced access to pre- and post-natal care and services, inadequate nutrition and a poor developmental environment (e.g. stress, abuse, neglect). However, evidence shows that binge drinking (5 drinks or more on an occasion) creates the greatest risk of FASD.<sup>27</sup> Importantly, Pierce and West<sup>28</sup> demonstrated that blood alcohol level rather than the amount of alcohol consumed, is critical for producing fetal damage

### Terms and Meanings

The term FASD is not a clinical diagnosis. The diagnostic term coined in 1973 by Jones and Smith<sup>29</sup> (who laid claim to the discovery of the disability), was fetal alcohol syndrome (FAS), but this condition was first reported by Lemoine et al (1968)<sup>30</sup> in Nantes, France. The US IoM 1996 nomenclature (to reflect current knowledge in the field) had previously eliminated the term fetal alcohol effect (FAE) (atypical FAS)<sup>31</sup> because it lacked specificity and sensitivity,<sup>32</sup> proposing instead an establishment of a category for assigning the FAS diagnosis without maternal history.<sup>33</sup> The term FAE was first used in 1978 in reference to the cognitive or behavioural problems, growth aberration or physical (dysmorphic) deviations that occurred at higher frequencies in alcohol-exposed populations than in

unexposed populations.<sup>34,35</sup> The full FAS diagnosis describes three primary characteristics occurring together: a pattern of facial abnormalities (generally defined as short palpebral fissures [eye slits], a flat mid-face, a short upturned nose, a smooth or long philtrum and a thin upper lip), growth deficiencies (pre- or post-natally) for height, weight or both and central nervous system (CNS) impairment; other criteria being a specific pattern of minor anomalies, including microcephaly.<sup>36</sup> Facial signs of FAS are most evident between eight months and eight years of age; hence, their vague appearance in the newborn should not be misinterpreted. Other physical malformations may also occur in FASD, although the frequency and occurrence of these malformations is poorly defined. These can range from cardiac, skeletal, renal, ocular and auditory.<sup>37</sup> It is stated<sup>32</sup> that partial fetal alcohol syndrome (pFAS) requires a confirmed history of prenatal alcohol exposure, facial dysmorphology and either growth retardation or CNS abnormalities, that alcohol related neurodevelopmental disorder (ARND) requires a confirmed history of prenatal alcohol exposure and evidence of CNS abnormalities and that ARBD (which denotes the presence of congenital anomalies, as referred to above<sup>37</sup>), requires a confirmed history of prenatal alcohol exposure. It is also stated<sup>32</sup> that FAS without confirmed maternal exposure requires evidence of facial dysmorphology, growth retardation and CNS dysfunction.

The CNS is often the most debilitating of the three areas of impairment and may include structural abnormalities of the brain, neurological problems such as impaired motor skills, poor coordination and visual problems and behavioural and/or cognitive problems such as mental handicaps, learning difficulties, poor impulse control, problems in social perception and problems in memory, attention, reasoning and judgment.

In 1999, Astley and Clarren<sup>38</sup> drew up the 4-Digit Diagnostic Code to reflect the magnitude of expression of the four key diagnostic features of FASD in the following order:

1. Growth deficiency;
2. The FAS facial phenotype;
3. CNS damage/dysfunction;
4. Gestational alcohol exposure.

The magnitude of expression of each feature is ranked independently on a four-point Likert scale with 1 reflecting complete absence of the FAS

feature and 4 reflecting a strong 'classic' presence of the FAS feature. It offers an intuitively logical digital approach to reporting outcomes and exposure that reflects the true diversity and continuum of disability associated with prenatal alcohol exposure. The 4-Digit Diagnostic Code is fully comprehensive. It can be used to diagnose individuals of all ages and races who present across the full spectrum of exposure and outcomes.<sup>38</sup>

### **Cost of the Disability**

FASD is irreversible and is said to be the leading known cause of mental retardation in the Western World. It is also said to be the leading cause of developmental and cognitive disabilities among Canadian children and has surpassed Down syndrome, spina bifida and cerebral palsy in estimated prevalence in the United States.<sup>31</sup> FASD is stated to be 100% preventable, but according to the Public Health Agency of Canada,<sup>39</sup> this is an oversimplification of the problem, suggesting that any woman can 'just say no' to consuming alcohol, ignoring the dynamics of addiction and the burden of other health and social problems that many women face.<sup>40</sup>

The cost of failing to prevent FASD is significant. New cases of FASD could conservatively be costing New Zealand \$3.5 million annually in extra medical, educational and social services. This does not include the cost of secondary disabilities<sup>90</sup> that can develop if the individual is not receiving adequate and appropriate care according to need.<sup>12</sup> International estimates vary. The US estimates the life-time health-care costs for one individual with FAS at 1.4 million.<sup>41</sup> In Canada, using an estimated life-time care cost of \$1 million per person, the calculation for FAS alone costs Canadian taxpayers an extra \$4 billion every year across all systems.<sup>42</sup> This estimate is based on the annual Canadian birth rate and a FAS prevalence rate of 1 per 1000 live births (4,000 babies born with FAS). Of note and by way of comparison, May et al<sup>43</sup> found a FAS rate of 3.7-7.4 per 1000 and a FASD rate of 20-40 per 1000 in 5-6 year old pupils in Italian schools. Without appropriate knowledge and skill for services and families to manage the needs of persons with FASD appropriately, the unmet needs of individuals will inevitably result in increased cost and duplication of ineffective services across lifetimes and generations. The cost of

diagnosis, early intervention and ongoing support by appropriately trained personnel within services would likely be much less than the cost of not identifying and treating appropriately individuals affected by FASD. If lifetime care costs for FAS and FASD were calculated together with a higher estimated prevalence rate (which is quite likely given the current drinking culture in New Zealand), then it can be assumed that FASD is costing New Zealand an enormous amount of avoidable revenue expenditure, not unlike that now recognised in Canada and the US.<sup>12</sup>

### **Incidence and Prevalence**

Incidence and prevalence rates of FASD vary widely<sup>32</sup> and are difficult to estimate in many countries. This is equally true of New Zealand, where a national registry of such cases is not held, the New Zealand Ministry of Health stating that 'there is no such thing as a notifiable disability'.<sup>44,88</sup> Interestingly, a lack of evidence of the prevalence and incidence of FASD in New Zealand has been cited as the reason why health policy and programmes have not been developed to prevent and/or treat FASD in this country,<sup>12</sup> yet FASD is not routinely screened for in infancy and early childhood. In contrast, all newborns (2,500 per year) are screened for FASD in France, with selected infants examined by a neonatologist.<sup>45</sup>

The Alcohol and Public Health Research Unit<sup>46</sup> stated that they believed FASD was under-recognised and under-reported in New Zealand with low public awareness of risks. Only about half GPs and obstetricians routinely advise women about alcohol consumption at the first antenatal contact.<sup>47,48</sup> Of note, is that the majority of affected children in New Zealand are in foster home/adopted care and adopted Russian orphans comprise a significant proportion of the affected children.<sup>47</sup> However, a report drawn up in 2006<sup>11</sup> argues that the incidence of FASD in New Zealand has not yet been established or estimated. Similarly, in Victoria, Australia, research indicates that FASD is almost certainly under-reported to the Victoria Birth Defects Registry which may be due to under-diagnosis or late diagnosis of the syndrome, suggesting a lack of knowledge of this condition in both the general community and the health professions or poor reporting of alcohol use in hospital records, particularly in investigation of

microcephalic babies. Also highlighted by research is the need for better health education and promotion policies and programmes to raise awareness of the syndrome.<sup>49</sup>

The first study to report the possible prevalence of FASD in New Zealand was performed in 1993 by Leversha and Marks.<sup>47</sup> They reported 63 children (under the age of 10) in paediatric care diagnosed with FAS based on maternal alcohol abuse and dysmorphic features in the child. An additional 78 children were diagnosed, but were not under paediatric care. 130 children with recognised ARBD were under paediatric care. Compared to the incidence rate of FAS in overseas studies, Leversha and Marks<sup>47</sup> estimated the actual number per year of FAS cases to be 20-114 (0.3-1.9:1,000), ARND 354 (5.9:1,000), cerebral palsy 120 (2:1,000), Down syndrome 60 (1:1,000) and cystic fibrosis 20 (1:3000). The FAS figures are in keeping with those reported by the New Zealand Paediatric Surveillance Unit (NZPSU)<sup>50</sup> in 2004 who predicted between 20 and 112 children are born each year in New Zealand with the disability. This figure is considerably less than the expected rate from overseas figures and it is not clear whether New Zealand does actually have a lower prevalence than overseas or whether the estimate is just low and thus falsely reassuring.

A 2 ½ year study performed by the NZPSU ending December 2001,<sup>91</sup> concluded that there were 62 valid reports of new cases or suspected FAS (97% were from the North Island and New Zealand born)- 39% of cases were New Zealand European, 45% Maori, 8% Pacific, 8% Unknown and 8% Other (predominantly Russian). Information received on 24 (83%) stated: 9 definite cases of FAS were reported; the remainder were suspected FAS but awaiting further investigation or assessments over time; the diagnosis was usually suspected by the notifying paediatrician: however, other agencies also suspected the diagnosis facilitated referral (2 by Special Education Services, 2 by Child, Youth & Family services [CYF], 2 by mental health professionals and one by the child's parents); 20 children were born in New Zealand and the remaining 4 in Russia; 7 of the 24 were living with their biological parents, 7 living with family and the remainder adopted or in foster care; of the 20 children born in New Zealand, 11 were of Maori and 9 of European ethnicity.

Prevalence figures for FAS in Australia have

come from Western Australia (WA) and the Northern Territories (NT).<sup>49</sup> In Victoria, the prevalence of FAS was calculated at 0.006 per 1,000 live births. Four additional possible cases of FAS increased this to 0.014 per 1,000 live births. Six cases were defined as 'unable to categorise' as alcohol use was unknown, but other features of FAS were evident. Including these cases, plus five where some low-level alcohol use was reported, increased the prevalence to 0.03 per 1,000 live births. Twenty-eight per cent of the audit population and 39% of the microcephalic cases had no information about maternal alcohol use recorded in the antenatal or babies' records.<sup>49</sup> In WA, FAS prevalence is reported to be 0.18 per 1,000 births. The prevalence rate for the non-Indigenous population was estimated at 0.02 per 1,000 and for the Indigenous population was 2.76 per 1,000.<sup>51</sup> Another study recorded the incidence of FASD in WA as 0.06 per 1000 live births. There are no published data on the prevalence of FAS in Victoria,<sup>49</sup> where it is a notifiable condition. However, there were three reported cases of FAS notified to the Birth Defects Register among 498,016 live births between 1995 and 2002, giving a prevalence of 0.006 per 1,000 live births. Using the lowest reported prevalence from WA (0.02), 9-10 cases could be expected to be reported in Victoria during this time.<sup>49</sup>

The prevalence of FAS in the US has been estimated to be 0.5 to 2 cases per 1,000 live births and FASD as 9.1 cases per 1000 live births.<sup>39</sup> It is also recognized that there are higher rates in Indigenous populations<sup>16</sup> and in North America, Aboriginal heritage is a risk factor for FAS and ARBD, creating methodological problems.<sup>20</sup> Of note, Hoffman & Shanske<sup>52</sup> stated that many factors must be considered when discussing incidence, i.e., maternal age, socio-economic and health status, race, drug use, the rate of abortion, educational background, as well as factors affecting data reporting. Also, of course, FASD epidemiology data<sup>92</sup> can be confounded by inconsistencies of diagnostic criteria, reluctance to diagnose, lack of diagnostic expertise, surveyed population, migration, whilst other individuals go undiagnosed. However, although there is no clear national data available to indicate the likely FASD incidence and cost burden to New Zealand services and families, anecdotal evidence suggests that individuals with FASD are continuing to come to the attention of health,

educational and social service professionals and are being referred to other services for ongoing assistance, most of which are not equipped to respond adequately or appropriately.<sup>53,54</sup>

### **Cognitive and Behavioural Functioning in Individuals with FASD**

FASD is a birth defect that has its primary effect on the brain. Because so many vital regions of the brain are affected, individuals with FASD display a wide variety of difficulties including intelligence, memory, problem-solving and attention. Estimates indicate that 90% of people suffering from FASD have mental health problems.<sup>55</sup> People with FASD can have intelligence quotients (IQs) that range from normal to being severely handicapped<sup>56</sup> as depicted by the following studies:

LaDue's study in 1993<sup>57</sup> of adolescents and adults found intellectual functioning in the mild to moderate range of impairment, with 46% scoring an IQ of less than 69. There was a marked discrepancy between a mean verbal IQ of 65 and a performance IQ of 79, with significant specific deficits in academic and adaptive function. Even with a normal IQ, learning tended to be compromised in alcohol-exposed children. Features included poor short-term memory with intact long-term memory, difficulty establishing routines in infants (Brazelton Scale),<sup>58</sup> decreased academic performance, especially with 'binge' drinking, problems with verbal memory (recalling Word List)<sup>59</sup> and defects in spatial memory, with poor retention of learned tasks. Mattson and Riley's 1996 survey of FAS case reports between 1973 and 1996 in which an exact IQ estimate was provided, found a mean IQ of 65.73 (SD = 20.2) with a range of 20 to 120.<sup>60</sup> The Mattson et al study in 1997<sup>61</sup> demonstrated that the average IQ for a child with FAS was 74. However, Steissguth et al study in 1996 ascertained the mean IQ for individuals with FAS as 79 (range from 20 [indicating severe mental retardation] to 120 (indicating above average intelligence) with an IQ score ranging from 49 to 142 (mean of 90) for those individuals with FAE, pFAE or ARND.<sup>62</sup>

Some people with FASD can live fairly normal lives if given adequate and structured support. Each person with FASD has his or her own special needs, problems, behaviour or cognitive disorders and capabilities. Sometimes other disorders can co-exist with FASD such as autism, conduct disorder and

oppositional defiant disorder (NCBDDD, CDCP, DHHS).<sup>63</sup> Because children with FASD are reportedly extremely active, the most common behaviour associated with this disability is attention-deficit hyperactivity-disorder (ADHD) which was first identified in Heinrich Hoffman's 19<sup>th</sup> century descriptions of 'Fidgety Phil'.<sup>36,64</sup> ADHD has been diagnosed in about half of children with FASD, becoming apparent usually at or near school age. Frequently these children exhibit impaired social adaptive ability and impaired executive functions, which reflect prefrontal cortex dysfunction.<sup>37</sup> Individuals with FASD also tend to have difficulty with the encoding of information and flexibility (shifting) aspects of attention whereas children with ADHD typically display problems with focus and sustaining attention (NCBDDD, CDCP, DHHS).<sup>63</sup> This is not to say that individuals with FASD do not appear to display hyperactivity – because their impulsivity may lead to increased activity levels.

Some research, however, has shown that the attention problems for children with FASD do not seem to fit the classic pattern of ADHD and O'Malley and Nanson<sup>64</sup> argue that there may be no link between FASD and ADHD. They further state that the clinical quality of ADHD in children with FASD often differs from that of children without FASD. For children with FASD, ADHD is more likely to be the earlier-onset, inattention subtype—as defined according to DSM-IV 314.00, 314.01 (American Psychiatric Association Diagnostic and Statistical Manual for Mental Disorder) – with comorbid developmental, psychiatric and medical conditions.<sup>64</sup> Children with FASD are commonly not mentally retarded but present complex learning disabilities, especially a mixed receptive-expressive language disorder with deficits in social cognition and communication (reminiscent of sensory aphasia and apraxia), working memory problems and frequently, a mathematics disorder. Secondary disabilities are those believed to occur as a result of primary disabilities and are revealed as mental health problems, school dropout and trouble with the law.<sup>37</sup> Comorbid psychiatric conditions include anxiety, mood, conduct or explosive disorders.<sup>64</sup> Incidences of inappropriate behaviours are poor judgment and difficulty perceiving social cues.<sup>65</sup>

### **Neurological Characteristics of Individuals with pFAS and ARND (previous term FAE)**

As noted earlier, the diagnoses pFAS and ARND require a minimum of three CNS impaired domains, the difference being that no facial anomalies are present in individuals diagnosed with ARND compared with pFAS.<sup>23</sup> ARND refers to various neurological abnormalities such as problems with communication skills, memory, learning ability, visual and spatial skills, intelligence and motor skills.<sup>66</sup>

Individuals who are affected neurologically by prenatal alcohol exposure, including those who lack 'the face of FAS', often experience developmental delays, attention deficits, learning disabilities, self-injurious behaviours, impulsivity and emotional and social adaptive disturbances.<sup>45,62</sup> They typically exhibit specific characteristics that may increase their risk for criminal behaviour. Examples include poor impulse control, information processing deficits, inability to relate behaviour to consequences, lack of a sense of connection to societal rules, poor short-term memory, poor sense of personal boundaries, confusion under pressure, difficulty grasping abstract concepts, inability to manage anger and poor judgment.<sup>67</sup> In addition to the characteristics mentioned above, other potential domains that can be affected include sensory problems (e.g., tactile defensiveness and oral sensitivity), pragmatic language problems (e.g., difficulty reading facial expression, poor ability to understand the perspectives of others) and difficulty responding appropriately to common parenting practices (e.g., not understanding cause-and-effect discipline).<sup>63</sup> These individuals may also exhibit naïveté and a tendency to be easily led by others.

### **OBJECTIVES**

An in-depth literature search revealed no research relating to the experiences of biological mothers of children diagnosed with FASD. The closest study appeared to be that performed in California by Gardner in 2000.<sup>36</sup> Gardner's study interviewed in-depth, using unstructured and open-ended questions, eight foster-mothers who were living with a collective total of 17 children aged between two and 16 years diagnosed with FAS. The study used content analysis to analyse the data and describe the women's experiences. This present study aimed to address that paucity of knowledge on the topic.

## METHODS

The methods and protocols were designed so that the 'lived experiences' and perspectives of the biological mothers would be included and form the basis of the results. The protocols in this project were approved by the University of Otago Human Ethics Committee and involved consultation work with a sub-group of mothers.

### *Sample*

Purposive sampling was used with participants being identified through a FASD agency in Hamilton, New Zealand; other biological mothers being found through the 'snowballing' technique. Letters of invitation to participate in the study, information sheet and a pre-paid envelope were sent to all the mothers identified. Of the 10 biological mothers located, eight agreed to participate - five in the North Island and three in the South Island. The birth mothers had nine affected offspring amongst them aged from 8 ½ to 30 years - two males had FAS, three males had FAE, two females had FAS, one female had FAE and one female had pFAE plus ADHD. Eight of the affected individuals had been diagnosed by a medical professional.

### *Data Collection*

Written consent having been obtained, each interview lasted up to an hour, was generally in the participant's home and consisted of questions such as, "Please tell me about your experiences of your pregnancy with your child with FASD": other topic areas related to labour, birth, post-partum period and onwards. Interviews were audio-taped and transcribed verbatim for analysis. The mothers were told that they could stop the interview at any time and could decline to answer any question. As data collection progressed, additional themes were added,

as new areas of interest emerged. All mothers received a copy of their transcript for review, but no alterations were made.

### *Data Analysis*

Interviews were analysed using the constant comparative method<sup>68</sup> which is a continuous process of reading, re-reading, memoing and comparing transcript with transcript (as they become available) so that categories and themes emerge, which are then compared with other interview data, literature, field notes and participant dialogue. Codes were used to organize data into core categories, categories and themes for analysis and interpretation. Analysis continued until the data were saturated, each segment of the transcripts being coded, thus allowing related data to be grouped accordingly. Interview data were aggregated to give demographic information. Where topics over-lapped, similarities and differences were noted. Validity was informed through triangulation, participant-checking and closeness of 'fit'.

## RESULTS

This study produced several emergent hypotheses. Of the fifteen sub-themes which emerged, four were categorized as key themes with all women responding to lack of knowledge for the syndrome, maternal guilt/blame laying and diagnosis, support networks, education, health, the policing and judicial systems, employment and independence (Table 1). The forty-eight recurring themes/words which were identified (Table 2) are inter-related with each other to some degree. The participants' characteristics are documented in Table 3. All names used in Table 3 are fictitious.



**TABLE 1** The Study's Core Categories, Categories & Recurring Themes/ Words

Core Category - Category	Recurring Themes/Words #
<b>1. It's the mother's fault</b>	
<i>*lack of knowledge</i>	34, 35, 36, 38, 40, 42, 44, 46
<i>*the mothers drank in pregnancy</i>	34, 35, 37, 38, 40, 42, 46
<i>*pregnancy/labour/birth different</i>	34, 35, 38, 41, 42, 44
<b>2. Medical and health professionals abandon the mothers</b>	
<i>*mothers left 'to it'</i>	33, 34, 35, 36, 37, 39, 42, 43, 44
<i>*mothers viewed subjectively/violation of rights</i>	34, 35, 36, 37, 42, 43, 44
<i>*mothers not listened to</i>	34-37, 39, 42, 43, 44, 47
<i>*mothers want a diagnosis for their child</i>	34-39, 42, 43, 44, 45, 46
<i>*mothers learn to cope with child's neurodevelopmental problems</i>	1-17, 19-21, 24, 26, 28, 34, 35, 37, 44, 46, 47
<b>3. Birth Mothers and their children are unsupported in the educational system</b>	
<i>*mothers not listened to by teachers</i>	4-7, 9, 13, 14, 18, 23, 27, 28, 31, 33, 34, 36, 37, 39, 42, 43, 48
<i>*child's behaviour not understood by teachers</i>	1, 2, 4, 5, 6, 9, 13-17, 19, 20, 22- 26, 28, 29, 31, 34, 36, 37, 39, 48
<i>*children should be taught according to their educational needs</i>	22, 23, 24, 25, 27-31, 33, 34, 39, 42, 43, 48
<i>*child is frustrated and not included in classroom</i>	1, 2, 4, 5, 6, 9-18, 20-37, 39, 48
<i>*child has few friends</i>	1, 2, 22, 32, 34
<b>4. Birth Mothers are the cause of criminal behaviour</b>	
<i>*police blame the mothers for the child's behaviour</i>	1, 4, 6, 9, 14, 17, 23-26, 32, 33, 36, 37, 39,45
<i>*police have little or no knowledge of the syndrome</i>	1, 2, 4, 6, 9, 14, 15, 16, 17, 19, 20, 23-26, 32, 33, 36, 37, 45, 46, 48

**TABLE 2** Recurring Themes/Word List

1. Odd /different /not normal /retarded /dumb
2. Sexually promiscuous
3. Perfect/good baby
4. Spoilt/lazy/naughty child
5. Lack of concentration
6. Difficult behaviour
7. Sensitive
8. Floppy/rigid
9. Missing link
10. Cries++
11. Sleep pattern disturbance
12. Lazy suck /feeding problems
13. Delayed milestones
14. Learning problems
15. No sense of time
16. Fearless/ risk taker /no fear of heights
17. Lack of foresight /poor judgement
18. Special
19. Truant
20. Restlessness
21. Tactile defensiveness
22. Child's feelings ignored
23. Gets in with wrong individuals /attracted to other FASD individuals
24. Alcohol /drug use by child
25. Child's lack of trust in the professionals
26. The child steals /crook /liar
27. Child held back in school system
28. Child doesn't fit in at playgroups/kindergarten
29. Child viewed as 'clown' in mainstream schooling
30. Homework/overload/'special'/not set at correct academic level of child
31. Separation/integration within the educational system
32. Animals /cars /young children
33. Violence against child
34. Social workers /health professionals /teachers
35. Language /power of the medical professionals
36. Burden on society
37. Labelling
38. General Practitioner surgeries/ante-natal clinics hold no literature on the syndrome
39. Violation of the child's rights
40. Women didn't know they were pregnant
41. Fast /shock birth
42. Frustration of the mothers in relation to the professionals/systems
43. Women didn't know about FASD
44. Women's intuition
45. Male doctors
46. Police /policing system /legal system

47. Alcohol /drug use by other family members
48. Violence against mothers
49. Employment /job stability

### 1. FASD is the Mother's Fault

It is because of the mothers' responsibilities and proximity to their children which have tended to make them the prime suspects when things go wrong in their children's lives. Most mothers said that they felt others blamed them without cause. All mothers felt responsible for their child's disability, although some did not experience guilt.

### *Lack of knowledge*

The multipara women's ages were between 19 and 35 when they delivered their affected child. All women had never heard of FASD prior to or during pregnancy. All women stated that had they have known about the disorder prior to or during pregnancy, they would never have drunk or continued to drink, alcohol. None of the mothers was aware that their partner's or husband's heavy drinking could affect his sperm (low testosterone levels) and its count (DNA [deoxyribonucleic acid] permanently altered), which is a marker for neurodevelopmental abnormality of the fetus(e.g., learning problems, small baby). The eldest woman said:

*"Nobody had ever heard of FASD".*

One woman said:

*"Just wish that back when I was pregnant the emphasis was made don't drink any alcohol, as I was into heavy drinks. There was definitely not any mention of FASD back then".*

### *The mothers drank in pregnancy*

All women consumed alcohol during their pregnancies, with some not aware that they had conceived until the end of the first trimester. One woman said:

*"When I got pregnant with the girls, I was drinking quite heavily, as you do when you've just turned 18...it's a normal thing for teenagers to do...and I didn't know I was pregnant until I was 3-4 months".*

Another woman who became pregnant as a teenager, said:

*"I drank every night of the week".*

Two of the women believed that they suffered contraceptive failure as a result of binge-drinking. One woman was on Depo-Provera (lasts for three months and given via injection) and the other was taking the Pill religiously. One of the two women stated:

*"...I had a binge when I was about three-and-a-half to four weeks pregnant with him. My husband and I were both drinking heavily. I didn't know I was pregnant until I was eight weeks. I was on contraceptives..." (sigh).*

The other woman said:

*"I obviously conceived him over...festivities time. In fact, I remember the night I fell pregnant with him, in which I had actually been drinking tequila...my birth control pill did not obviously work because I was violently ill, but I didn't actually know I was pregnant until another six weeks later, when I thought ghee, I haven't cycled...so I didn't drink right from the time I knew, but there would have been a portion I would have drank probably five-six weeks after conception before I realized I had been drinking pre-pregnancy, quite heavily obviously, married to an alcoholic – did the same thing!"*

## **2. Medical and Health Professionals Abandon the Mothers**

During pregnancy, labour, delivery and the post-partum period, the women found themselves in the midst of many different medical and health professionals. The women expected that these professionals would show empathy and support as well as knowledge. However, the women said that they did not experience this, being left to cope the best way they could with their 'different' child.

### ***Mothers left 'to it'***

All mothers said that they felt unsupported, with the health and medical professionals unable to meet the special needs of their children. The women were also unsupported because the medical professionals did not give any information or explanation for why certain things were happening to their children, especially when witnessing for the first time their child's unpredictable behaviour. Many mothers stated that it was the experiences of other parents which represented almost the major source of help. Five of the mothers stated that their child was viewed as 'different' by other people, the difference generally being seen in the child's behaviour, since physical disparities are 'invisible' to the lay-person.

Many of the mothers said that they had witnessed oppositional defiance and aggression from their child, with three women experiencing violence from their sons. One mother recalled that after she split-up from her alcoholic husband, she was at her 'wit's end' trying to cope with her son. She went to the Department of Child, Youth and Family (CYF) and found them to be unsupportive and ineffective. Another mother frustrated in her efforts stated:

*"...we'd stopped going to ask people about what to do with this kid, because the system didn't help anyway".*

### ***Mothers viewed subjectively/violation of rights***

Because the biological mother of the disabled child drank in pregnancy, they believed that the medical and health professionals with whom they came into contact, tended to view them judgmentally and with a somewhat negative attitude. Two women stated that they received negative remarks from their GP when consulted regarding their child with FASD, with one being regarded as "neurotic" and "to take a pill and go home" and the other as a "hyperchondriac". The experiences within the hospital system for another woman intensified when she discovered that a male doctor had given her teenage allergy-suffering son, a tetanus injection without her prior knowledge. She felt this to be a violation of her rights as the child's carer. She stated:

*"...I was his caregiver, therefore, I should have been consulted, but they didn't take that into consideration... This is a 14 year-old boy, who's not that good with conversation. So that actually blew my faith of..."*

### ***Mothers not listened to***

Because of the mothers' general lack of knowledge within the medical and health arenas, the mothers said that they were generally not listened to by the professionals. This appeared to be especially so when the mother encountered a health conversation with a male doctor. One mother became so frustrated with the negative conversations she had with her GP in relation to her offspring's disabilities that she said to him:

*"I'll find a real doctor who knows what he's talking about...so it's really frustrating".*

Another mother, recalling the extremely negative response from a social worker following her call because her daughter had been sexually abused at school by a boy pupil, stated:

*"She didn't believe it - she thinks my daughter was making it all up. From November, when it happened, right through December, she made my daughter go to school with him and in late December, early January, she tried to take an overdose of pills here. I rang the social worker and asked her to come out and talk to my daughter two days before she did it. She came out and said to me "There's nothing wrong with the child - she's just attention-seeking!"*

### ***Mothers want a diagnosis for their child***

Since there is a close link between ADHD, the birth mothers were frequently given this diagnosis by the medical professionals for their offspring with FASD. One offspring was given three different diagnoses. All women had experienced great difficulty in obtaining a diagnosis for their child from a diagnostic medical professional, creating much frustration, as they were constantly fighting the system. When the women did receive what they believed to be the correct diagnosis for their child, they expressed much relief, because as well as knowing what was actually wrong with the child, it also made sense of confusing behaviours they had observed and had thought were the consequences of their own poor mothering skills. For appropriate recognition and intervention strategies to occur, the child with FASD requires to be diagnosed correctly, which also bodes well for the future, reducing the risk for later secondary disabilities, such as dependent living, confinement, addiction and mental health concerns. It was also common for the professionals to confuse FAS with Down syndrome (because of the similar facial characteristics) or ADHD. One woman recalled this happening to her son back in the 1980's when she consulted a paediatrician, in keeping with her alcohol consumption:

*"I said to him that I had a binge with him and that I drank with the youngest one and told him about their behaviours. I took photos because it's quite evident, particularly with the youngest one - his eyes wide apart, no philtrum, thin top lip - and he said to me "I don't like to put that guilt on mothers".*

Another mother stated that she had had one

psychologist say to her:

*"Why would you want to label your child with that?"*

She answered:

*"Why do you want to label my child ADHD?"*

### ***Mothers learn to cope with child's neurodevelopmental problems***

Since alcohol freely crosses the placenta, the brain of the developing fetus is devastatingly affected which can, as stated, create neurological, physical, mental, health, social and behavioural problems. Evidence of CNS neurodevelopmental consequences may be decreased cranial size at birth, structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia), neurological hard or soft signs (as age appropriate) such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, impaired vision, poor eye-hand coordination. Evidence of a complex pattern of behaviour or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, may be learning difficulties, deficits in school performance, poor impulse control, problems in social perception, deficits in higher level receptive and expressive language, poor capacity for abstraction or metacognition, specific deficits in mathematical skills or problems in memory, attention or judgment.<sup>69</sup> Importantly, children with and without physical features of fetal alcohol syndrome display qualitatively similar deficits.<sup>70,93</sup>

The present study revealed that one child could not see properly, most babies had a 'lazy' suck, one child was asthmatic as well as having extensively chalky teeth and one child had a high pain threshold to the extent of having a tooth capped without anaesthetic. Seven of the children experienced delayed milestones, five children experienced delayed speech/language, so that verbal communication was problematic. Two children suffered hearing problems. Six children suffered problems getting to sleep whilst others slept for extensive periods of time and had to be woken up to be fed. Other children did not like certain foods in their mouth. Some of the children did not dress according to the prevailing climate. One child remembered to do his homework, but never remembered to hand it in. Another child, at the age of seven, could never remember to catch the bus to

school. All women stated that their offspring suffered memory problems.

Wall-hanging charts and lists were used by the mothers as aide's memoir in an attempt to keep daily structure within the household. Most of the children were secretive, not scared of things or people, had no fear and did not fear consequences. It was through the mothers' intimate relationship with their offspring, that they realized that the child's behaviour was not of its own conscious making and thus came to understand and learn from their child, so becoming the experts. The eldest mother said of her son:

*"He cried, he cried and he cried...he would only sleep for a couple of hours. He was hyper...It went on and on and on...he just wasn't a normal baby. Even feeding him was difficult. He crawled about 14 months and he got into everything. Nothing was a danger! And he kept having accidents".*

Another mother said:

*"...it was freezing with a really cold, bitterly wind and it was raining. He came out of his bedroom with his shorts, T-shirt and sandals on...and it was only 12 degrees inside..."*

The same mother stated:

*"He took a knife off to school...Lighting a bag of cement in the garage to see how well it burns".*

### **3. Birth Mothers and their Children are Unsupported in the Educational System**

All women said that they believed their children had suffered as a result of poor or incorrect educational facilities, programmes and teachers being unable to meet the child's special and individual needs. This created much frustration and stress amongst the children and their families. Consequently, the children suffered a disrupted school experience.

As Streissguth et al<sup>59</sup> posit "Students who inappropriately express their needs are often misunderstood and ridiculed or goaded by fellow students and viewed as troublemakers by administrators and teachers". These comments strengthen and support the experiences of the birth mothers and their children. The mothers are also supported in the literature by Ballard who firmly stated that "Those children who have a disability (including intellectually), their needs are often not met, or at least not met without there having to be seemingly endless advocacy by parents, disability groups and other professionals."<sup>71</sup>

#### ***Mothers not listened to by teachers***

Since the women and their disabled children were seen as a burden on the educational system, they were generally viewed negatively and without empathy by school teachers. The teachers took no interest in the child and could not be bothered to listen to the birth mothers. Consequently, the child had no interest in the classroom situation, became unmotivated, disruptive and ultimately, a truant. One mother stated that her child had had problems ever since he started school. Another mother recounted:

*"He couldn't spell 'cat' or 'dog' but he could spell 'hippopotamus' and 'rhinoceros'. The teachers couldn't be bothered, so he didn't do good at school...He was a truant, he was known by the police...So he left school at 15".*

Another mother stated:

*"She [teacher] said 'Oh, well, she doesn't look like a FASD child' and I said 'Well, I know she doesn't, but she's been in reading recovery ever since she started school here and now she's on her second year of teacher's aide. It's doing nothing at all. She's still not even reading. She doesn't know the alphabet and she's eight. She can only count probably to 30 and that's it".*

#### ***Child's behaviour not understood by teachers***

The women said that since the teachers had little or no knowledge of FASD, the disabled child was labelled as lazy, naughty, spoilt, dumb. They appeared unable to comprehend that the child's behaviour was not of his or her own making - that it is a neurodevelopmental and cognitive disorder and that the children have very short attention-spans and visual, hearing and memory deficits. Because the teachers do not give the affected child the attention required, he/she attempted to gain it by causing classroom disruption. One mother, whose son was believed by school teachers to be very naughty said:

*"That particular very old male teacher decided to teach him some lessons and apparently made him pick up his desk and chair on top of each other, carry them to the foyer and then the kids could file past and laugh at him".*

Another mother said:

*"He'll snap his pencil or roll it to get attention. He'll throw bits of paper at the kids to distract them if they're working. He'll crawl underneath his desk and make silly noises and more noises and tell the teacher he needs to go to the toilet and take half-an-hour to come back because he's in the toilet throwing paper on the roof".*

***Children should be taught according to their educational needs***

Because the teachers failed to recognise that the child's cognitive ability does not equate to the child's chronological age, the individual was given schoolwork which was not in keeping with his or her educational age. One mother stated:

*"They were sending her home with homework she couldn't do..."*

Another mother said of her daughter:

*"Just completely overwhelmed...she just can't do it. But to get her to sit down for that long anyway...is very hard". As the child said to her mother "It's too hard, Mum. I just can't read, I can't learn. It's too hard".*

***Child is frustrated and not included in classroom***

Because the disabled child appears not to fit into the classroom scene, he or she tends to become frustrated, a result of which, is that the individual is excluded by the teachers and the other children. Five mothers believed that their children were frustrated in mainstream schooling. One mother said:

*"He was in intermediate school and he was terribly tormented by these children and so frustrated at one stage - he was locked out of the classroom by other children".*

Another mother stated that the teacher had said to her daughter:

*"You're not doing that right!"*

Her daughter said in reply:

*"I don't know how to do it".*

The teacher's reply:

*"You're just being lazy and I don't like lazy children".*

A distraught mother said:

*"The teacher...unbeknown to me - was giving my daughter hell and she broke down in tears one night and said 'Mum, am I dumb?'*

***Child has few friends***

Owing to the disabled child's behavioural problems, other children tended not to include them amongst their friends, so they sought comfort from animals, collecting items or bonding with much younger children. One mother recounted that her daughter said:

*"I have no friends. Nobody likes me".*

Another mother said:

*"Throughout his school life, he's never been able to settle with friends and I remember as a pre-schooler, he came home early one morning and said 'Mummy, those are my friends - I collect snails now'".*

Yet another mother stated of her son:

*"Oh, he loves kids, loves them. He'll make friends, but he can't keep them".*

**4. Birth Mothers are the Cause of Criminal Behaviour**

Children with FASD can easily get into trouble with police because they lack the cognitive ability to relate cause with effect. They are unable to learn from previous experiences, have a high need for social interaction, but lack the social and cognitive skills for such long-term relationships. Because they know little about the world in which they live, they are unaware that there are laws and systems put in place by the government to protect citizens. According to Streissguth et al<sup>59</sup>, however, it is the lack of appropriate intervention and structures not put in place early in life and maintained across the life-span which is the cause for children with FASD to become involved in the legal system since many of these individuals are at high risk from birth through to their adult years.

***Police blame the mothers for the child's behaviour***

Although the mothers tried hard at controlling, influencing and educating their children in the differences between right and wrong and their consequences, their efforts generally failed to have the desired effect. It is not uncommon for the child with FASD to participate in petty crime, for which the mother is blamed. The eldest mother, who was working full-time, recalled her encounter with the police:

*"I'm trying to work and he was pinching my car and pinching my little scooter...Taking off at nine and of course, they said "Why aren't you watching him?" and I said "You have to sleep sometimes".*

***Police have little or no knowledge of the syndrome***

While there has been much progress in the identification and understanding of FASD, the legal system has been slow to grasp its impact on juvenile crime, leaving little room for those whose capacity to control their actions has been impaired by prenatal exposure to alcohol. Many professionals who work within the juvenile justice system are unable to deal appropriately with individuals with FASD because they lack critical knowledge and training about the disorders. The result is a failure to recognize individuals with FASD and to ensure that they

receive appropriate services and support, from arrest through re-entry into society.<sup>66</sup>

These comments are consistent with the police who believe that all children at some stage in their lives may steal, so the FASD child is put into this group, the law usually being unaware that the offending individual is suffering from the effects of the disorder. Consequently, the courts are unlikely to recognise the person's cognitive disability and behavioural problems so that the individual is misunderstood and misinterpreted, labelled as stubborn, obnoxious, lazy, having anti-social personality disorder or given other judgmental and inaccurate labels. The mothers believed that the individual's unpredictable memory lapses and gains happened just often enough to convince those who were not au fait with FASD, that they were deliberate 'behaviours' made manifest under the control of the affected offspring. The reality is very different. The mothers stated that although children with FASD know right from wrong, they cannot relate cause with effect, so have no regard for the consequences of their actions. The individual may become involved with gangs, but more often as a 'fringe' member or 'gopher'. Four mothers stated that their children repeatedly stole money. One mother said of her offspring:

*"He joined the local gang...he was very excited - 'But they've given me adventure, Mum and a Triumph motorcycle!' Real criminal gang and the reason they gave him the bike was so he'd do their drug running...you see, mm and...he was in a terrible state.' I don't like this, Mum'. Well, you were told, weren't you? 'They don't let me sleep'. He was a Prospect - that's the ones that want to be a gang person, you see. So he ran away, but being Jamie, he forgot he had the King Pad's keys with him and he had his patch on and that patch is their sacred mark...Mmh, he came in that window one night - he'd run away. One of his jobs that made him run away was they were making cannabis oil and they sent him up to the airport to pinch four huge drums of isopropylene..."*

Other gaps identified by the mothers and which require addressing by public policy and practice<sup>72</sup> are:

- Lack of provincial/territorial government commitment, policy directives or leadership.
- Lack of financial support and human resources to put the needed programmes and services in place.
- Lack of structure or mechanisms for sharing information.
- Lack of research activity and funding.
- Lack of recognition and practice regarding coordinated and integrated service delivery.
- Challenge of dealing with a complex issue that cuts across many disciplines.
- Lack of national coordination.

**TABLE 3** Participant's Characteristics

	Age	Alcoholic Partner	Professional Occupation	Birth Mother's – Father Alcoholic	Birth Mother – Alcoholic
<b>Oldest Group 1970's birth</b>					
1975 Mary	64	Yes	No	No	No
1975 Miriam	52	No	Yes	No	No
<b>Middle Group 1980's birth</b>					
1980 Martha	42	Yes	No	Yes (+brother)	Yes
1988 Rebecca	41	Yes	Yes	No	No
1987 Esther	38	Yes	No	Yes	No
<b>Youngest Group 1990's birth</b>					
1993 Ruth	32	Yes	No	Yes	No
1995 Sarah	31	Yes	No	No	No
1996 Naomi	29	Yes (+drugs)	No – medical problem	No	No

## DISCUSSION

The sample size, typical of qualitative research, was small and the results are not generalizable to wider populations in a statistical sense. However, generalizability is of no real concern to this research which adopted a feminist lens, because each project is seen as illustrating a partial view of the world, the whole picture being made up of many differing perspectives. In fact, the collection of data was a basis on which to start asking questions and to draw attention to issues that needed to be further researched.

Through the use of a feminist perspective,<sup>73</sup> some of the mothers in the present study demonstrated how they finally found their voices in amongst the knowledge-power relationships of the doctors, medical practitioners, health workers and teachers. The mothers found that they were able to make sense of their lived experiences with their disabled child and therefore, their actions by

virtue of their interactions and connexions with the medicalization and socialization processes and those professionals working within them.

Interestingly, the women's narratives as presented reflect and support the findings of Gardner<sup>36</sup> whose study participants described many difficult issues relating to children with FAS. Cognitive concerns included diminished memory/comprehension, lack of understanding of consequences and the absence of fear. Behavioural management was a problem owing to the frequent occurrence of hyper-activity, aggressiveness, destructiveness and high pain tolerance. The foster mothers also described problems in coping with the daily realities of life with a child with FASD, including the necessity of providing consistency, coping strategies and fears for the child's future.



The birth mothers raised issues relating to the incorrect behavioural conception of the cognitively-disabled individual by the policing and judicial systems, violation of mothers' and children's rights, the importance of appropriate and adequate support networks for the family of a child with the disability and issues concerning labelling, child abuse, promiscuity, stealing, lying, risk-taking, daily structuring, unpredictability, lapses in memory, adoption and fostering together with lack of printed information on the syndrome within society. There may be a general awareness in the public at large of adverse effects of alcohol consumption by pregnant women, but as the study has shown, people generally do not know about FASD. As a result, most of the women participants continued to drink even though they were pregnant.

The women were dismayed and frustrated by the medical and health care professionals who were unwilling or unable to respond to their needs, their offspring's needs and their compassion for their children. The medical and health support networks were viewed as a failure with many gaps being identified, the major one appearing to be a lack of diagnostic professionals and services – in particular, medical diagnosis and neurodevelopmental, behavioural and psychological assessment. Even where a service might exist, coverage and access is uneven and often does not extend to rural or remote communities.

The birth mothers stated that it was the experience of other parents which represented almost the major source of help and understanding regarding what is needed, what is not needed, what works and what does not work and who understands FASD in each community and who does not. In other words and as Landsman<sup>74</sup> stated; "The women get to know who the experts are". This idea was supported by Wright<sup>75</sup> who said "The affected child's family will need ongoing supportive services to help them disentangle the host of emotions they will feel and effectively confront the difficulties of living with a child with FASD".

Because the birth mothers realized that they could not change the cognitive impairment and behavioural issues of their child, they intuitively changed their attitudes toward the individual, so that he/she too became a valued member of the

family unit – the 'special one'. It was through the mothers' intimate relationship with their offspring that they became aware the child's behaviour was not of its own conscious making and thus came to understand and learn from their son or daughter, ultimately becoming an earnest advocate and mediator in amongst the many medical and health encounters they experienced.

A major issue of much concern to the birth mothers was of the consequences for the child of incorrectly identifying the syndrome. For appropriate recognition and intervention strategies to occur, the individual with FASD requires to be diagnosed correctly, which also bodes well for the future. All of the women participants stated that they had experienced great difficulty in obtaining a diagnosis for their child from a diagnostic clinician, creating much frustration for the mothers who were constantly fighting the system. This issue is commented upon in the literature by Leslie and Roberts<sup>1</sup> who said that "even when children are suspected of being affected by FASD, getting a diagnosis is a major challenge". When the participants did receive a proper diagnosis (as they believed) for their child, they expressed much relief because as well as knowing what was actually wrong with the child, it also, as Landsman<sup>74</sup> believed "made sense of confusing behaviours they had observed and had thought were the consequences of their own poor mothering skills". In New Zealand, individuals with FASD need to be correctly diagnosed in order to receive the educational and welfare services that are necessary for his/her survival within society.

However, there are still many difficulties and uncertainties for the medical professionals involved in making the FASD diagnosis because of the complexity of morphological and behavioural characteristics as opposed to a single, unifying observable feature; being further complicated by a lack of a single biological marker.<sup>76</sup> Of note, is that this study has demonstrated a medical practitioner may not make the correct FASD diagnosis because he/she does not wish to 'label' the child, since this brings about a possible issue of guilt and blame-laying on the mother. Interestingly, Clarke et al<sup>77</sup> argue that the primary reason for lack of diagnosis is lack of specific training. Disagreements and

conflicts of interest over appropriate education within the disability arena are commonly reported by mothers of disabled children.<sup>78,79</sup> In keeping with this statement, all of the women participants, even through their 'battling' experiences believed that the educational systems had, overall, failed to meet the needs of their children, so that each individual, after entering mainstream schooling, experienced a disrupted education. The mothers' narratives clearly state that a major concern was lack of progress by their offspring. The mothers' beliefs and concerns are supported in the literature by Streissguth<sup>62</sup> who stated that students with disrupted school experiences had twice as many learning and behaviour problems as those without disrupted school experiences. Of note, is that all children in this present study, suffered a disrupted school experience.

Niccols<sup>80</sup> stated that some researchers have claimed it 'essential' to identify the specific and specialized needs of children with FASD and develop a set of educational and developmental strategies tailored to meet these needs. This has not transpired within New Zealand and the teachers still tend to remain reliant upon educational practices drawn up for children with other developmental disabilities, which are generally unsuccessful.<sup>81</sup> The mothers recognizing these issues stated that the disabled child should be taught according to its educational needs and not its chronological age: this because the teachers are still not au fait with the spectrum of cognitive and neurobehavioural challenges which FASD encompasses.

Frequently, the mothers found that the structure which they put in place within the household was not counter-balanced by that of the classroom. A structured environment is vital to a child with FASD, as is only being given small tasks at a time by teachers. Unless the child is totally structured in the classroom and receives the attention and help that is required with school-work and especially mathematics, he/she becomes frustrated, followed by a tendency to 'act out' which culminates in much classroom disruption, as the mothers' stories bear witness to. The child is consequently, viewed as a troublemaker, a time-waster and ineducable. These findings support those made by Oliver,<sup>82,83</sup> which shows that within New Zealand, the educational system

appears not to have changed much from the UK in 15 years. Consequently, instead of appropriate teaching strategies being drawn up to meet the slow-learning child's needs, the individual is ridiculed by some of their contemporaries and teachers. These experiences are supported in the literature by Turnbull and Turnbull,<sup>84</sup> further indicating that the New Zealand educational system's attitudes towards disability have not changed over the past 26 years.

Even though the mothers themselves became the experts in FASD by virtue of nurturing and advocating for an offspring with this disability, they worried about their child's future, especially since none of them was given an early diagnosis (<6). They feared that their offspring, on finding independence, would violate the law and that the disabled individual would be unemployable because he/she lacked the necessary social and communication skills. However, the study showed that of the four children of the mothers' who left school seeking paid employment, all found positions within the workforce, albeit of low job status, with one offspring still in his first job after 2½ years. This finding is in contrast to Reid and Bray's<sup>85</sup> statement that "Traditionally people with intellectual disabilities have been excluded from paid work", but in keeping with Barnes and Mercer<sup>83</sup> who said that "...disabled people are over-represented in low-skilled, poorly paid, less secure jobs".

An interesting issue which this study has raised is that all the birth mothers, except for one, experienced family breakdown, felt to be by the participants, as a result of the consumption of alcohol by the father of the child affected with FASD. This finding is in contrast to the study findings of Ballard et al<sup>86</sup> which explored 15 fathers' experiences of children with disabilities, when they concluded that family breakdown was not prevalent in the group and the evidence that a child with a disability significantly increases the chances of marriage breakdown<sup>79</sup> is equivocal. It should also be noted that the role of fathers in reproduction is understudied and should be of great significance to disability studies.

Finally and of note, is that many of the above-described issues are also in keeping with the experiences of birth mothers' of children with other disabilities, e.g., Lesch Nyhan syndrome,<sup>87</sup>

Down syndrome, Rett syndrome, autism, Fragile-X, as found in the plethora of literature on disability. It must be emphasized, however, that FASD is not genetically constructed, as is the case with many other intellectual disabilities.

In summary, these findings represent an important step in furthering the understanding of the lives of children with FASD in the midst of societal prejudice, stigmatization, oppression, discrimination and justice. Some of these issues find wide support in the literature such as the lack of teaching strategies available, the primary and secondary disabilities, the importance of an integrated teaching approach and the complexities involved in making a diagnosis of FASD. The mothers' personal experiences, as reported here, provided order and a measure of cohesion in terms of the experiences that mothers with a child/ren with FASD undergo to nurture and educate their offspring so that it has the best possible opportunity of fitting into and being a valued member of society. As a result, these various relative issues and problems associated with the child with FASD and his/her family have been raised, thereby confirming, as well as adding to, the existing body of knowledge in this field. It is hoped that this emancipatory research study, which has given voice to the birth mothers' of a child/ren disabled by FASD, may advance the knowledge of professionals working with individuals and their families within the field as well as providing an impetus for future work in this area.

## CONCLUSION

It is essential that all women (especially birth mothers), are heard if progress is to be made in this field and that all women require an awareness of the adverse effects of alcohol upon the unborn child. It is also important when raising awareness of an issue as sensitive and as preventable as FASD, to reduce any stigma or guilt and to ensure that adequate follow-up support is available. In general, the amount a woman drinks before she is pregnant can be an indicator of whether she will continue to drink during pregnancy. Therefore, simple screening questionnaires such as T-ACE, TWEAK, CAGE and AUDIT which have shown moderate evidence as effective tools for

identifying women who may be at risk of drinking alcohol during pregnancy, can be used.<sup>20</sup> Ensuring individuals with FASD are appropriately supported, will reduce the likelihood of secondary disabilities and add value to multiple sectors. Comprehensive early intervention programmes with pregnant women at high risk of alcohol abuse,<sup>89</sup> provide an opportunity to reduce the risk for both the mother and child. The closest New Zealand has come to an integrated service for substance abusing mothers is the Pregnancy and Parental Service of Community Alcohol and Drugs Services (CADS) in Auckland. However, it does not have an integrated child assessment service.

Ultimately, medical and health professionals, including nurses, social workers and medical students also require to be educated in and understand the presenting symptoms of the disorder, so that a realistic and early diagnosis can be made and the individual's challenging behaviours and abilities understood, so that his/her needs are provided for appropriately and more effectively.

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