Review topic:

Fetal alcohol spectrum disorder

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Citation for review topic:


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Cover Artwork: New Zealand Sea Lions - by Karen Davis
Introduction

There is substantial evidence from both observational studies of humans, and experimental studies in animals, that fetal alcohol exposure can cause physical malformations, growth retardation and brain damage.\textsuperscript{1-5} Alcohol exposure in pregnancy is commonly cited as the leading preventable cause of intellectual disability.\textsuperscript{6,7}

Fetal Alcohol Spectrum Disorder (FASD) is the umbrella term used for the range of physical, cognitive, and developmental disabilities caused by exposure to alcohol in utero.\textsuperscript{8}

The Ministry of Health has recently published an Action Plan \textit{Taking Action on Fetal Alcohol Spectrum Disorder 2016 to 2019}\textsuperscript{7} which is New Zealand’s first attempt at taking a coordinated and strategic national approach to FASD. The plan recognises that FASD contributes to many poor outcomes for New Zealand’s young people including early mortality, abuse and neglect, poor educational achievement, engagement with the criminal justice system, benefit dependence, and mental health and alcohol and drug problems.

Features of FASD

The effects of prenatal alcohol exposure include malformations, growth retardation and central nervous system dysfunction of varying severity.\textsuperscript{9} For a child’s long term future the most devastating effects of prenatal alcohol exposure are the cognitive and behavioural problems caused by alcohol-induced brain damage.\textsuperscript{9}

Facial features

Facial anomalies are characteristic of fetal alcohol syndrome (FAS) and a diagnosis of FAS requires (in addition to other criteria) that the following three facial features are present: short palpebral fissures (the distance from the inner corner to the outer corner of the eye), a smooth philtrum (absent or shallow vertical groove between the upper lip and the nose), and a thin upper lip.\textsuperscript{6} Assessment of these facial features requires specialised training and these features can become less noticeable as children grow up.\textsuperscript{10,11} Only a small proportion of children with FASD have the three facial features, but their presence is highly specific to FAS.\textsuperscript{12}

Studies of the effects of alcohol on mouse and chick embryos have indicated that the period of vulnerability for these anomalies corresponds to the human gestational stage between three and six weeks after fertilisation and that there is a general trend for the facial anomalies to become more pronounced as alcohol exposure increases.\textsuperscript{13}

It is often stated that FAS is the most severe form of FASD but cognitive and behavioural impairments can be of similar severity in people with FAS and people with FASD who lack the facial features of FAS and it is the cognitive and behavioural deficits rather than the facial abnormalities that have the greatest impacts on life outcomes.\textsuperscript{14,15}

Neurodevelopmental problems

Children exposed to alcohol in utero at any stage of gestation can have impairments of variable severity in many areas of central nervous system function.\textsuperscript{16} Their cognitive and behavioural problems can seem similar to those of other neurodevelopmental conditions such as ADHD but specialised assessment can distinguish FASD from other conditions.\textsuperscript{17} Cognitive problems that children with FASD may have include:\textsuperscript{16,17}

- Lower than normal intellectual ability. The average IQ of children with FASD is in the cognitively impaired to low normal range but there is a wide variation\textsuperscript{18}
- Difficulty with sustaining attention
- Difficulty with executive function in both cognition-based and emotion-based tasks (problems with coordinated planning and execution of tasks)
- Difficulty with language
- Difficulty with mathematics
- Difficulty with memory
- Deficits in visual-spatial perception and construction
- Slower than normal information processing

Overall, these problems can be summarised as a generalised deficit in processing complex information.\textsuperscript{17} Mathematics is a particular area of weakness in children with FASD, and deficits have been found even in
studies that control for IQ and other potentially confounding variables. It is the cognitive weakness that is most highly correlated with the amount of prenatal alcohol exposure. 19

The effects that these problems have on everyday life can be profound. Memory problems and difficulties with information processing make it hard to follow instructions and to learn new skills. Teachers may report that children with FASD are disorganised, tactless, distractible, lack persistence, and have poor processing and reasoning abilities.17,20

People with FASD commonly have problems with adaptive and social behaviour and their deficits in these areas are more severe than those of people with similar verbal IQs who were not exposed to alcohol.21–24 Social problems include impairments in social competence and relationships, being inappropriately friendly as children, and difficulties in perceiving and responding to social cues, exhibiting consideration for others, following social norms, and forming reciprocal friendships.25 These problems often result in social rejection, which contributes to poor self-esteem, aggression, anxiety, depression, trouble at school, mental health problems and anti-social behaviour.25

Standardised tests of adaptive functioning, such as the Vineland Adaptive Behavior Scales, may not fully capture the extent of the difficulties experienced by a person with FASD since they include only a few questions relating to poor decision making and dangerously impulsive behaviours that pose risks both for the person themselves and those around them.26 Functioning as an independent adult requires not only being capable of shopping, cooking, cleaning and laundry but also being able to deal with problem associates who may enter your home, steal your belongings or cause property damage that results in you being evicted.26 The Vineland scales have questions covering the former but not the latter skills.26

Social impairments in people with FASD are life-long and tend to become more pronounced with age. Some adults with FASD have been reported to have the social functioning of a six-year-old child.27

**Growth retardation**

Prenatal alcohol exposure is associated with intrauterine growth retardation with smaller weight, length and head circumference at birth.28 A number of cohort studies have found growth deficits to persist through childhood into adulthood.29–32 Most of the international diagnostic guidelines include growth retardation in the diagnostic criteria for FAS and other FASDs,10,33–36 although the latest Canadian and Australian guidelines have adopted the term FASD as a diagnostic term and deleted growth impairment as a diagnostic criterion due to the fact that many children with prenatal alcohol exposure and central nervous system dysfunction do not have growth impairment. A population-based cohort study done in Western Australia found that, although infants of mothers with moderate to heavy alcohol consumption in pregnancy had increased odds of being born small for gestational age, this effect was eliminated after adjustment for smoking status.39

**Comorbidities of FASD**

A recent systematic review aimed to estimate the pooled prevalence of co-morbid conditions in people with FASD (using data from 33 studies with 1728 participants) and to highlight conditions that were much more common in people with FASD than in the general US population.40 There were 18 disorders that were found to be present in more than half of those with FASD, including conduct disorder, visual problems and refractive errors, speech and language deficits, premature birth, hearing loss, alcohol or drug dependence, and ADHD.40 The prevalence of hearing impairments was estimated to be 100 times higher in individuals with FASD than in the general population, the prevalence of visual impairments at least thirty times higher, and the prevalence of mental and behavioural disorders due to multiple drug use around twenty times higher.

**Life course consequences of FASD**

Over the lifespan, the primary impairments of FASD interact with environmental risks to produce secondary problems. Infants exposed to alcohol in utero tend to be more irritable than other infants and often have disturbed sleep patterns and feeding problems.21 These problems can disrupt mother-infant attachment, which is believed to be fundamental to later social interactions, especially interactions between two people.21

As pre-schoolers, children with FASD may be hyperactive, excessively friendly and fearless, and have poor motor coordination and delayed speech, language and other developmental milestones.41 They may be prone to temper tantrums and non-compliant.42 When they go to school, children with FASD struggle with cognitive,
academic and social, emotional, and behavioural challenges that have negative effects on their ability to learn and function in the school environment.\textsuperscript{43} 

The University of Washington’s Secondary Disabilities Study conducted life history interviews with all available caretakers or informants of 415 individuals with FAS or fetal alcohol effects, whose ages ranged from six to 51 years.\textsuperscript{44} The most important findings from this study were:

- 90% of all study participants had experienced mental health problems, most commonly attention deficit and behaviour problems in young children, and depression in adults
- 60% of those aged 12 or more years had been suspended or expelled from school, or dropped out of school
- 60% of those aged 12 and over had been in trouble with the law
- 50% of those aged 12 and over had experienced loss of liberty (23% because of psychiatric disorders, 15% via compulsory admission for drug or alcohol dependency, and 35% because of imprisonment by the criminal justice system)
- 50% of those aged 12 and over were reported to have a history of inappropriate sexual behaviour
- 30% of those aged 12 and over had drug and alcohol problems
- 80% of the 90 individuals aged 21 years or more were not living independently
- 80% of those aged over 21 had problems with employment

The University of Washington study noted that many of the people with FASD had come from dysfunctional, transient and abusive living situations which may have contributed to their secondary disabilities.\textsuperscript{44} It found that 72% of those aged 12 years and older had experienced violence (physical or sexual abuse, or domestic violence) and that having experienced violence was by far the strongest risk factor for inappropriate sexual behaviour. It also found that half of those aged 12 years or more had not stayed in each living situation for an average of more than two years, and half had spent at least 30% of their lives living with a person who had an alcohol or drug problem.

There have been few longitudinal studies of people with FASD.\textsuperscript{45-49} A study done in Finland followed up children born to eighty-two pregnant women who had attended a special clinic aimed at reducing heavy drinking in pregnancy.\textsuperscript{47} Of the 69 surviving children who could be followed up at 12 years, 41 had FASD (FAS, fetal alcohol effects or alcohol related neurodevelopmental disorder), 10 had growth retardation but no other signs of FASD, and 18 had normal development. Of the 41 children with FASD, 21 were receiving mainstream education, seven were in a mainstream class with either a personal assistant or adjusted requirements in some subjects, and 13 were in a special education class.

In this study there was a high rate of children being taken into care because of parental alcohol abuse and inability to provide adequate daily care for their child, often in combination with psychosocial problems.\textsuperscript{47} Only 11 of the 42 children with FASD and 18 of the 28 children without FASD had lived only with a biological parent by the age of 12 years. Behavioural problems were common: families of 24 of the 41 children with FASD, and nine of the 28 children without FASD had sought help for behavioural problems. According to the examining psychologist/child psychiatrist behavioural problems were associated with one or more of the following factors: poor quality of early attachment and daily care; repeated experience of neglect; physical and/or sexual abuse; having observed a frightening experience (abuse of mother or sibling); not being liked by peers – loneliness and poor understanding of social rules; and difficulties in learning capacity, attention and impulse inhibition. Eleven biological parents of study children (eight mothers and three fathers) had died. Their deaths were due to alcohol abuse and/or psychological problems. Eight biological parents (four mothers and four fathers) had been in prison.

Another prospective longitudinal study\textsuperscript{50} which assessed 24 children of alcoholic mothers in Sweden at the age of 12–14 years had similar findings. A later Swedish study,\textsuperscript{51} which included some of the same participants as the previously mentioned study, used national registers to follow-up a group a 79 Swedish adults with FAS at a mean age of 32 years and compare their educational, social adjustment and mental health outcomes with those of a comparison group of 3,160 individuals matched on age, gender and place of birth. Compared to the comparison group, the FAS group were much more likely to have received special education (25% vs 2%), be unemployed (51% vs 15%), and receive a disability pension (31% vs 3%), but they had similar levels of criminal offending. They had higher rates of hospital admission for alcohol abuse (9% vs. 2%) and psychiatric disorders (33% vs. 5%) and were more likely to have been prescribed psychotropic drugs (57% vs. 27%).
The Swedish register-based study\textsuperscript{51} noted that 81% of the adults with FAS had been placed in state care in their youth (compared to 4% of the general population) so the authors attempted to account for the effects of this difference. When the outcomes for the 79 adults with FAS were compared to those for a matched group of 122 adults who had been placed in state care before the age of 18 years it was found that although the FAS group were more likely to have attended special education (25% vs. 3%), there were no significant differences between the two groups in terms of completed education, income, self-support, or hospital care. Compared to the state care group, the FAS group were less likely to have received a criminal conviction (28% vs. 55%) and much less likely to have been convicted of a severe crime (6% vs. 30%). The study authors noted that the study subjects had full-blown FAS and had received their diagnosis early in life and had therefore received financial support and had close contact with social workers during childhood. They suggested that these factors might have contributed to the relatively high rates of completed secondary education and employment of the individuals with FAS.

A German study which was a 20-year follow-up study of 37 adults with FASD (out of a cohort of 52 eligible subjects originally diagnosed as having FAS or FAE in infancy and childhood) found that, although the facial features of FAS were less marked in adulthood, only a very small proportion of the study population were living a normal adult life.\textsuperscript{27} Eighteen (49%) had received special education only. Only five (13%) had ever held an “ordinary” job, despite 25 (69%) having received at least some preparatory job training and 21 (58%) having either started or progressed to formal occupational training. Assessment of living situations revealed that 27% lived in institutions, 35% were in a dependent-living situation, 14% lived independently alone, 8% lived with a partner, 8% had their own family and 8% lived with their father plus a mother surrogate. Study subjects had higher than normal rates of emotional and behavioural problems, especially attention difficulties and aggressive, intrusive and delinquent behaviour. Their mental and behavioural problems were independent of intellectual impairment and whether they had been diagnosed with FAS or with fetal alcohol effects.

**Epidemiology of FASD**

There is no New Zealand data on the prevalence of FASD but it has been conservatively estimated to be at least one percent in the general population and around 50% in children and youth in Child, Youth and Family (CYF) care.\textsuperscript{7} Ospina and Dennett’s 2013 systematic review of 54 FASD prevalence studies, mostly conducted in North America and Europe, found that FASD rates have been examined in a variety of settings including the community, schools, foster care settings, prisons and correctional settings.\textsuperscript{6} The review found considerable variation in prevalence estimates. Some of this was due to factors such as differences in methods of case ascertainment, diagnostic criteria and study participants’ ages, but variation in prevalence estimates is also likely to reflect genuine variation between different geographic and other population groups.\textsuperscript{7}

Ospina and Dennett’s review found the reported prevalence of FASD in the community ranged from 0.2 to 5 per 1,000 population across five studies.\textsuperscript{52} The prevalence of FAS in non-South African school settings ranged from 0.2% to 0.8% giving a pooled estimate of 0.4% (4 per 1,000). The prevalence of partial FAS in schools, based on a pooled estimate from the four studies that assessed prevalence in either random samples or the whole population, was 2.9%. The prevalence of FASD in special education settings ranged from 2% to 9%.

The prevalence of FASD was found to be much higher in certain population groups. In foster care settings the prevalence of FASD ranged from 30 to 50%.\textsuperscript{52} Studies in the US and Canada estimated the prevalence in prisons and correctional facilities as being between 10% and 23%. Prevalence estimates for FASD in aboriginal populations in Canada, the US and Australia were highly variable, but a pooled estimate of FAS prevalence in Aboriginal peoples was calculated from six studies as 0.2%, not substantially higher than that found in community samples from the general population.

**Diagnosis of FASD**

It is important that children with FASD are recognised early in life because they can then receive the understanding and support that will increase their chances of having the best possible outcomes in later life and help them avoid some of the secondary problems that can result from their primary neuropsychological impairments, such as exclusion from school, criminal offending and mental health problems.\textsuperscript{53-55}

Making a diagnosis of FASD can also enable a child’s mother to get help to address her alcohol problem and associated difficulties, and avoid having more children with FASD.\textsuperscript{56} It may lead to the identification of siblings with FASD. Early diagnosis is helpful for parents because it gives them an explanation for their
child’s behavioural problems and their parenting skills can increase with greater understanding of their child’s disabilities and impairments. Professionals often fear that mothers will feel judged and shamed when their child is diagnosed with FASD but the New Zealand birth mothers interviewed by Jenny Salmon reported that they were relieved when they finally received what they perceived to be the correct diagnosis for their child because, as well as knowing what was actually wrong with the child, they could make sense of the confusing behaviours that they had observed and had thought were due to their poor mothering skills.

Without the capacity to diagnose FASD it is impossible to determine how many people in a community have FASD and whether prevention or mitigation efforts are having any effect.

**Diagnostic criteria**

There are a number of international guidelines on the diagnosis of FAS and FASD and there are well-established diagnostic criteria for FAS. There is less international consensus on how to diagnose FASD but there is a consensus that a comprehensive physical and neurodevelopmental assessment is needed to understand the full impact of fetal alcohol on a child’s development. Such an assessment requires input from educators, social workers and a multidisciplinary team of health professionals.

According to the Australian diagnostic guidelines for a child to receive diagnosis of FASD he or she must have:

- severe impairment in at least three of the following ten neurodevelopmental domains: brain structure; motor skills; cognition; language; academic achievement; memory; attention; executive function, including impulse control and hyperactivity; affect regulation; and adaptive behaviour, social skills or social communication

AND either

- All three of the sentinel facial features OR
- 0,1 or 2 facial features plus confirmed prenatal alcohol exposure

Confirmed prenatal alcohol exposure is not required if all three facial features are present (small palpebral fissures, smooth philtrum and thin upper lip) because it is then unlikely that some other condition is the cause of the child’s examination findings.

Because there is no pattern or type of CNS dysfunction that is specific to FASD, it is never possible to say for certain that a child without the facial features of FAS has an alcohol-related neurodevelopmental disorder, only to say that, on the balance of probabilities, given known prenatal alcohol exposure and observed CNS dysfunction consistent with the diagnostic criteria for FASD, it is likely that he or she does.

The diagnosis Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE), has been proposed for inclusion in DSM-5, The Diagnostic and Statistical Manual, 5th edition, from the American Psychiatric Association, to encompass the range of neurodevelopmental disabilities that can be associated with prenatal alcohol exposure. According to the proposed definition of ND-PAE, diagnosis requires confirmed prenatal alcohol exposure plus impairment in all three of the following domains:

- neurocognitive (as indicated by impairment in one or more of: intellectual function/global development; executive functioning; learning; memory; visual spatial reasoning)
- self-regulation (as indicated by one or more of: impairment in mood or behavioural regulation; attention deficit; impairment in impulse control)
- adaptive functioning (as indicated by two or more of the following, with at least one of the first two symptoms: communication deficits; impairment in social communication and interaction; impairment in daily living; motor impairment)

**Practical difficulties in diagnostic assessment**

While guidelines recommend that children suspected of having FASD be assessed by multidisciplinary teams who have specific training in assessing children prenatally exposed to alcohol, there are few specialised FASD diagnostic services. An international survey conducted in 2006 identified 34 FASD diagnostic clinics: 29 in North America, two in Africa, two in Europe and one in South America. The UK currently has only one specialist FASD clinic. A 2011 Canadian survey of clinical capacity for diagnosing FASD found that, based on an estimated FASD prevalence of one percent, diagnostic capacity would need to increase seventeen-fold to be able to diagnose all cases of FASD. A US expert estimated that the US would need another 200
multidisciplinary teams and the UK would need 39 fulltime teams to identify all new cases of FASD\textsuperscript{55} and he cited the view that the current diagnostic criteria for FASD are so complex that even expert clinicians have difficulty applying them.\textsuperscript{56}

Another Canadian study estimated that a multidisciplinary diagnostic FASD assessment used between 23 and 33 hours of staff time (costing between $2,650 to $3,750) and that the total cost for one individual to be screened, referred, admitted, and diagnosed ranged from $3,110 to $4,570 (32 to 47 hours per person).\textsuperscript{57}

Many clinicians lack the training and experience to confidently diagnose FASD.\textsuperscript{67,69} The Ministry of Health’s 2015 survey of a wide range of New Zealand clinicians found that those who felt extremely confident about this diagnosis were definitely in the minority.\textsuperscript{7} A 2004 survey of paediatricians in Western Australia found that, while 81\% knew that abnormal facial appearance was a feature of FAS, only 19\% knew all of the essential diagnostic features of FAS, and only 23\% routinely asked about alcohol use in pregnancy when taking a pregnancy history.\textsuperscript{78} Most admitted having suspected but not diagnosed FAS and almost 70\% thought that diagnosis could stigmatise a child or family.\textsuperscript{78} The provision of educational resources did little to change these paediatricians’ knowledge of the essential diagnostic features of FAS or their confidence in making the diagnosis.\textsuperscript{70}

Most children with FASD do not have the characteristic facial features of FAS. Of 1,270 patients seen at clinics belonging to the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network during 1993–2005 who had confirmed prenatal alcohol exposure (or all of the features of FAS) and CNS dysfunction, and would therefore meet the criteria for FASD, only 59 (4.6\%) could be diagnosed with FAS.\textsuperscript{71}

Making a diagnosis of FASD in the absence of the facial features characteristic of FAS requires confirmation of maternal alcohol intake during pregnancy.\textsuperscript{53} This can be difficult to obtain. Midwives and other clinicians may be reluctant to ask a pregnant woman about the details of her alcohol intake for fear of alienating or stigmatizing her, because they lack knowledge about the amounts of alcohol and the patterns of alcohol consumption that are especially harmful in pregnancy, or because there is a lack of services to refer a woman to if an alcohol problem is identified.\textsuperscript{72} Women may be reluctant to disclose their alcohol intake because of embarrassment, guilt or fear that they may lose custody of their children.\textsuperscript{77} A woman may not be able to recall the details of her drinking in pregnancy if she is asked only years later when her child is being evaluated for developmental and/or behavioural problems suggestive of FASD, and she is likely to be especially vulnerable to feeling judged if she did drink during pregnancy and knows that there is a possibility that her drinking has contributed to her child’s problems.\textsuperscript{73} For children in foster care or international adoptees it may be impossible to obtain information on their mothers’ alcohol consumption.\textsuperscript{74}

Children exposed to alcohol in utero often have other adversities in their backgrounds so it can be hard to determine the whether a child’s emotional and behavioural problems are primarily due to prenatal alcohol or to other environmental or possibly genetic factors.\textsuperscript{74} Children of alcohol abusing parents have been found to be more likely than other children to experience emotional, physical and sexual abuse; emotional and physical neglect; exposure to domestic violence; substance abuse or mental illness within their household; parental separation or divorce; and incarceration of a household member.\textsuperscript{75,76} Parental substance use disorders have been reported to be a contributing factor for between one-third and two-thirds of children involved with child protection services in the US.\textsuperscript{77}

Given their often difficult family environments it is not surprising that children with prenatal alcohol exposure often meet the diagnostic criteria for one or more mental health conditions including reactive attachment disorder, posttraumatic stress disorder, learning disabilities, depression and anxiety, conduct disorder, and attention deficit hyperactivity disorder (ADHD).\textsuperscript{74,78,79} It can be hard to decide whether these disorders are independent of, secondary to, or comorbid with any effects of prenatal alcohol exposure on neurodevelopment.\textsuperscript{74,80} This may be why some clinicians are reluctant to make a formal diagnosis of FASD.\textsuperscript{74} New research may develop more specialised assessment tools that will help with discriminating the impairments of FASD from those due to other conditions.\textsuperscript{74,81}

It is important that mental health professionals consider the possibility of FASD in someone with a mental health problem because it may be the reason they are not responding to medications and psychosocial therapies, and an indication that they need on-going psychosocial support.\textsuperscript{78}
New Zealand experience with FASD diagnosis: The FASD assessment pathway in the Hawke’s Bay DHB

The Hawke’s Bay District Health Board (DHB) has a Developmental Assessment Programme (DAP) that provides multi-disciplinary diagnostic assessments of children with complex developmental and behavioural concerns. It also provides training in developmental and behavioural conditions for people working in health, education and social service settings. One component of the DAP is a FASD Assessment Pathway for children whose developmental and behavioural issues are possibly related to pre-natal alcohol exposure. The Health Promotion Agency (HPA) commissioned an independent process evaluation of this FASD Assessment Pathway to learn more about this service model and explore considerations related to replication of this programme in other regions. A brief summary of the findings from this evaluation, which took place during April to June 2015, is presented below.

The FASD Assessment Pathway is provided by a multidisciplinary team. Paediatric, speech language, psychological and social work assessments are combined in a diagnostic assessment based on Canadian guidelines. Key aspects of the pathway are: assessment at home, school and clinic; collaboration with families, caregivers, teachers, referring paediatricians and others; presentation of synthesised assessment findings and recommendations in a single report, and provision of feedback sessions to the family and to school personnel involved with the child.

The evaluation found that the FASD Assessment Pathway is successfully identifying children with FASD, engaging families living in low decile areas, and engaging many Māori whānau. It is reaching into homes and schools. Factors identified as being linked to the success of the pathway were categorised as relating either to the service model or to the workforce, infrastructure and service context.

Essential aspects of the service model were:

- Shared vision and values
- A best practice multi-disciplinary approach
- A synthesised report and feedback sessions
- A team approach
- Close working relationships with paediatricians
- Strong and effective relationships with other services
- Building capacity through training

Regarding the workforce, infrastructure and service context, the evaluation found that the DAP FASD Assessment Pathway is provided by a highly skilled and experienced professional team supported by strong leadership. The Pathway is part of a broader assessment programme that is located within a child development service. This was viewed as contributing to the programme being sustainable and of high quality. The evaluation noted that locating the specialised FASD assessment pathway within a child development service is widely viewed as a way of providing an effective continuum of service for children, enabling a flexible and efficient use of resources, and helping to ensure programme sustainability. It also noted that the people delivering such a programme need specialist training in FASD assessment. (Three of the Hawke’s Bay team members travelled to Canada for this.)

The evaluation highlighted a number of important factors relevant to the replication of the FASD Assessment Pathway. The most significant was a general consensus that the effectiveness of the pathway is limited by the lack of post-assessment support for children identified as having FASD, and their families. Effectiveness would be improved if support could be provided, similar to that provided for children diagnosed with Autism Spectrum Disorder (who are also diagnosed within the DAP). Extra funding would be needed for this. Additional on-going challenges were:

- Waiting times
- A need to keep refining assessment reports so they are both as comprehensive and as user-friendly as possible
- Ensuring cultural responsiveness. Stakeholders suggested that Māori and Pasifika input should be obtained in the programme set-up phase to ensure that cultural responsiveness is maximised from the outset.
A mismatch between the perspectives of the health and education sectors: health focuses on diagnosis but education is more concerned with functional impact in the learning environment

The need to develop and maintain a team culture characterised by strong professionalism, collaboration, collegial respect and openness. This requires ensuring that team members have opportunities for on-going professional development

The DAP team aims to provide 40 assessments per year (one a week during school terms), and data indicates that approximately one third of these are FASD assessments. The average number of professional hours used per FASD assessment (excluding paediatrician, administration and management hours) was 34.5. The FASD Assessment Pathway does not accept children until they reach the age of eight years so any child younger than eight must wait under the care of a paediatrician until they are old enough to be assessed. Most children assessed for FASD receive general health oversight from a paediatrician both before and after assessment. During 2010-2015, 74 children accessed the FASD Assessment Pathway. Seventy-four percent were boys and 26% girls. Most were Māori (73%). The ages of children (at referral) ranged from three to fifteen years and around 61% were aged eight or older. Most children lived in high deprivation areas and only 26% lived with two parents (birth parents, adoptive parents or whangai parents).

Of the 42 children with data on FASD assessment outcomes, all but one child met the criteria for at least one disorder and 38 (90%) met the criteria for FASD. Most children had more than one disorder: 29% had two disorders and 64% had three or more disorders. The other disorders included attention deficit hyperactivity disorder, intellectual disability, language disorder, attachment disorder, adaptive behaviour limitations and cerebral palsy.

**Interventions for children and families living with FASD**

There is little point in investing in improving capacity to diagnose FASD without also being able to provide services that will make a meaningful difference to the lives of children with FASD and their families, both in the short term and the long term.

There is a small but growing evidence base for interventions for children with FASD, children at risk of FASD because of known prenatal alcohol exposure, and parents who are themselves affected by FASD.82-84 Intervention studies in humans have mostly aimed to improve specific cognitive or adaptive skills such as language, literacy, mathematics, self-regulation, working memory and social skills. Kodituwakku’s 2011 review identified only 12 papers reporting on scientific evaluations (RCTS or quasi-RCTS) of interventions for children pre-natally exposed to alcohol.83 While some of these studies found positive effects, only two interventions had been evaluated more than once, and none were considered to be well established. Because each person with FASD (or prenatal alcohol exposure) is not affected in the same way or to the same degree, a thorough assessment of a person’s deficits and strengths is necessary to determine what kind of specific intervention might be beneficial for that person.84 Cognitive and behavioural interventions often require time and effort from families and therefore they may be ineffective for children in chaotic families.83 Such interventions are more likely to be successful when they include both direct child intervention and parent support.82,83

The 2015 review by Reid et al.85 had broader inclusion criteria and included studies if they reported quantitative measures of functioning so that comparisons could be made about potential gains, regardless of the study design or type of outcomes. It identified 32 studies, most of which targeted aspects of neurocognitive functioning in early to middle childhood although there were two studies which aimed to improve developmental outcomes in infants born to substance-abusing mothers, four studies of education and advocacy for parents and caregivers (two studies), and teachers or child welfare workers (one each), and two studies of support for parents who were themselves affected by FASD. The studies were generally small, at some risk of selection bias, and of variable methodological quality. Nineteen were considered to have a “strong” study design (randomised controlled trial or controlled clinical trial).

The only studies with long term follow up (six months or more) were two studies of home visiting programmes for substance abusing mothers, neither of which found clear benefits for children’s development at two to three years of age.85 The review authors suggested that standard developmental measures may not be the best tools for measuring intervention effects in infants and toddlers with prenatal alcohol exposure. Other findings from the review were: a number of small studies have found positive effects from interventions to improve self-regulation or attentional control; interventions aiming to improve some specific areas of cognitive difficulty in children are promising; there is strong evidence for the utility of structured programmes that include both parents and

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Adams J. Fetal Alcohol Spectrum Disorder in *The Health of Children and Young People with Chronic Conditions and Disabilities in New Zealand 2016*, [www.otago.ac.nz/hrxyes](http://www.otago.ac.nz/hrxyes)
children in improving social skills; there is promising evidence that parents and caregivers benefit from support in managing their children’s behaviour and that improvements in children’s behaviour are associated with improvements in parents’ wellbeing; and support, education and advocacy services for parents, caregivers, and child welfare caseworkers can be beneficial both for these adults (increasing confidence, decreasing stress) and for the children they support (decreasing school problems, reducing number of changes in foster care placement). The two small cohort studies of support for parents with FASD (all mothers except one), found benefits including decreased drug and alcohol use, and improvements in mental health, finances, housing stability, parenting, use of contraception, and use of medical and mental health services.

A modification of the Alert Program®, which was used in three of the studies in the Reid et al. review, and found to have positive effects, is being trialled with Aboriginal children attending schools in remote communities in Western Australia. The estimated prevalence of alcohol-related neurodevelopmental disorders among these children is almost 20%. The Alert Program®, which was designed by occupational therapists, teaches children about self-regulation (the ability to change the arousal state of your nervous system so it is appropriate to the task or situation). There has been very little published research on interventions for adolescents or young adults with FASD but a recent review identified two recently completed trials in the US. One of these, Project Step-Up, found that a six-week intervention aimed at reducing or preventing alcohol and substance abuse that was delivered to adolescents with FASD and their parents (separately and concurrently) led to reductions in drinking, risky drinking, and negative consequences from drinking in the adolescents. The other trial, of a multi-component intervention for 13–25 year olds with FASD and their families called Partners for Success, did not find any positive effects on youth outcomes, but did find changes in parent positive coping and self-controlling behaviours. This trial’s capability for finding positive effects may have been compromised by problems with recruitment and implementation.

Animal studies have found a number of substances that, when given to alcohol-exposed pregnant mothers, mitigate the effects of alcohol on their offspring. These substances include 5-HT1A agonists, neuroprotective peptides, anti-oxidants, and choline and other nutrients. Some studies of rats with prenatal alcohol exposure have found benefits from post-natal nutritional supplementation suggesting that these approaches might be of benefit to children with, or at risk of, FASD. Investigating the efficacy of these approaches in humans could be difficult because women who drink heavily in pregnancy are probably unlikely to reveal their drinking habits to health professionals.

Maternal undernutrition may exacerbate the effects of prenatal alcohol exposure on the developing fetus. A case-control study done in South Africa found that the mothers of children with FAS were significantly smaller than control mothers as indicated by height, weight, head circumference, and BMI. There has been very little research on nutritional supplements for pregnant women to reduce the impact of prenatal alcohol exposure on their children but one study of micronutrient supplementation in pregnant Ukrainian women suggested that choline supplementation, administered together with routinely recommended multivitamins and minerals, may improve basic learning mechanisms involved in encoding and memory of environmental events for infants from both alcohol-exposed pregnancies and non or low alcohol-exposed pregnancies.

Children with FASD often have ADHD. There have been only two very small randomised controlled trials of pharmacological treatment of ADHD symptoms in children with FASD. It appears that, while there is considerable individual variability in response to medication, psychostimulant medication, such as methylphenidate or dextroamphetamine, improves hyperactivity but not inattentiveness. A recently published consensus guideline from the UK on the identification and treatment of individuals with ADHD and associated FASD, the first such guideline, warns that side effects from medication may be more marked (though similar) in individuals with ADHD and FASD than in those with ADHD alone and that the use of short-acting stimulants in adolescents with FASD and ADHD may potentially contribute to the development of addictive disorders during the teenage years.

The long term outcome for a child with FASD depends on the interaction of the child’s individual characteristics with the broader ecological context, including the family, social systems and culture to which the child belongs. Being raised in a stable and nurturing family who are aware of the child’s diagnosis and can adapt to the child’s limitations and advocate for his or her needs reduces the risk of adverse life outcomes. Many children with FASD, however, experience difficult caregiving environments with adversities such as maternal alcohol and drug abuse and depression (resulting in less responsive and less stimulating parenting), abuse and neglect, poverty, family violence and multiple foster care placements.

There is very little systematic research on the impact of raising a child with FASD on the family, on how parent and family variables influence outcomes for people with FASD, or on interventions for families affected by FASD. For this reason, Olson et al. drew on the findings from both systematic research, and the informal literature based on parents’ accounts on raising a child with FASD, to highlight important childcare and family issues.

The issues identified from the informal literature included guilt and shame (for birth mothers), financial stress, the lack of knowledgeable professionals, the time needed to advocate for the child in the education and justice systems, the need for respite care, difficulties in determining the causes of a child’s misbehaviour, the value of parent support and self-help materials from parent support organizations, and the need for formal intervention services.

Issues identified from research studies included the impact of maternal substance abuse and/or depression on infant attachment and maternal responsiveness, child externalising behaviour as the most significant cause of parental stress, the need for foster parents who can provide structure and a high level of organisation and are well supported by a care team knowledgeable about FASD, parents’ need for respite care and support in dealing with negative emotions regarding their child, the risk of caregiver burnout and depression, and the difficulties of dealing with multiple service providers, such as mental health, education, medical and social services, who may not agree on the best way of helping the child.

Given the lack of research on interventions specifically for families affected by FASD, Olson et al. suggest that useful insights can be gained from the more general developmental disabilities literature, and the literature on traumatic brain injury, as families of children with these conditions face many problems that are similar to those facing families of children with FASD.

Petrenko suggests that the lived experiences of people with FASD, their parents, and caregivers, and service providers are a valuable source of information for those developing interventions for people with FASD. A qualitative study done in up-state New York asked 25 parents of children with FASD (only one of whom was a biological parent) and 18 service providers for their views on desirable characteristics for intervention programmes aimed at preventing secondary conditions, such as mental health problems or trouble with the law. Study participants reported that their children did not qualify for special education or disability support services because their IQ scores were too high although some were able to obtain such services after multiple appeals and advocacy. The study identified five key characteristics for FASD intervention programmes: availability across the lifespan; having a prevention focus; being individualised; being comprehensive; and being co-ordinated across systems and developmental stages. The study authors stated that the five key characteristics are consistent with the positive behaviour support framework which focuses primarily on adapting the environment to improve an individual’s quality of life with reduction of problem behaviours as a secondary goal.

**Drinking in pregnancy as a public health issue in New Zealand**

Alcohol is pervasive in New Zealand society. The 2012/2013 New Zealand Health Survey (NZHS) found that 76% of New Zealand women aged over 15 years had drunk alcohol in the past 12 months and that one quarter of women drinkers drank alcohol regularly, at least three to four times per week. Almost half of all women drinkers had drunk to intoxication at least once in the past year and around five percent reported drinking to intoxication at least weekly.

The NZHS included 565 women aged 15–54 years who had been pregnant within the past 12 months and 19% of them reported having drunk alcohol at some time during their most recent pregnancy. Younger women were more likely to have drunk alcohol during pregnancy: 28% of 15–24 year olds compared to 17% of 25–34 year olds and 13% of 35–54 year olds.

Of the women who had been pregnant in the last year, 31% reported that they had stopped drinking before becoming pregnant, 55% that they stopped drinking as soon as they learned they were pregnant, and 15% that they continued to drink while pregnant. Of those who continued to drink, the majority reported reducing their drinking while pregnant.

Binge drinking or heavy episodic drinking is the pattern of drinking recognised as the most harmful to the developing fetus. For this reason, the NZHS enquired about past year risky drinking, defined as drinking four or more standard drinks on one drinking occasion, in women who had been pregnant in the last year and who...
reported drinking alcohol in their most recent pregnancy. It needs to be understood that rates for past-year risky drinking among women who drank during pregnancy are not necessarily the same as the rates of risky drinking during pregnancy. Of the women who reported drinking during pregnancy, 78% also reported risky drinking during the past year, including 11% who reported risky drinking at least weekly and 16% who reported risky drinking at least monthly.  

Another New Zealand survey, which was a retrospective survey of 723 post-partum women across New Zealand, found that overall, 34% of women reported drinking in pregnancy and that 12% of pregnancies were at high risk of heavy alcohol exposure in early gestation. The percentage of pregnancies with heavy alcohol exposure in early gestation was almost five times higher in Māori women and 3.4 times higher in Pacific women, than in New Zealand European women.  

This survey found that 44% of pregnancies were unplanned and that pregnancy confirmation occurred later for women with unplanned pregnancies (7.3 vs. 5.3 weeks gestation). Three quarters of pregnancies in Māori and Pacific women were unplanned. The authors of this study suggested that this indicates that alcohol policies that facilitate the reduction of heavy episodic drinking throughout Māori and Pacific communities—not just among women planning a pregnancy and pregnant women—need to be adopted.  

Keriata Stuart conducted in-depth interviews with ten Māori women with the aim of understanding how Māori women negotiate decisions about alcohol in pregnancy. She used a grounded theory methodology to analyse the information gathered and she proposed that Māori women make decisions about drinking during pregnancy using a process of Trading off. This process was considered to be individually based but to exist within a complex social context; a fluid process that continued throughout pregnancy. Māori women learned social rules about alcohol consumption within their whānau and social circles; their beliefs about alcohol consumption in pregnancy were acquired in much the same way. Māori women regarded health professionals as a less trustworthy source of information. Reasons why women continued drinking while pregnant included fitting in (it is hard to be the only non-drinker in a social group), releasing pressure (drinking to relax) and carrying on as normal. Supportive partners, friends and whānau surrounding a pregnant woman could make a major contribution to a Māori woman’s resource bank making it easier for her to refuse offered drinks and change her drinking habits, and also helping her to deal with stresses in her life, maintain a positive self-image, take control, and act with self-determination.  

The Growing Up in New Zealand study interviewed 6,822 expectant mothers in either their last trimester of pregnancy or soon after the birth of their child and asked them to recall their alcohol consumption in three periods: before becoming pregnant or before being aware they were pregnant; in the first three months of pregnancy; and after the first three months of pregnancy. Data from this study suggested that 71% of women drank alcohol before becoming aware of their pregnancy, 23% drank during their first trimester after becoming aware of their pregnancy, and 13% drank after their first trimester. The proportions of women drinking four or more drinks per week were 29% before becoming aware of pregnancy, 7% in the first trimester and less than one percent after the first trimester. The women who reported drinking in pregnancy were very heterogeneous in regard to their socio-demographic characteristics but the heavy drinkers were more likely to be younger women, Māori women, women with no secondary qualifications, smokers and women whose pregnancy was unplanned whereas the women who reported light drinking (three or fewer drinks per week) were more likely to be older women, European women and women from socio-economically advantaged backgrounds.  

A 2005 survey of a random sample of 1,109 non-pregnant New Zealand women aged 16–40 years aimed to assess New Zealand women’s opinions on the safety of alcohol consumption in pregnancy and the sociodemographic and lifestyle factors associated with these opinions. It found that 44% of women in the study were of the opinion that no alcohol is safe in pregnancy and 45% that one standard drink or less on any one day is safe. Only 10% thought that more than one standard drink was safe. The moderate and heavy drinkers, who made up 55% of the study sample, were more likely than abstainers or light drinkers to be of the opinion that more than one standard drink on a typical drinking day during pregnancy is safe.  

In summary:

- Most New Zealand women drink alcohol (as do most New Zealand men)
- A sizeable minority engage in risky (binge) drinking
- Most women stop or reduce their drinking once they are aware they are pregnant

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• Nearly half of all pregnancies are unplanned
• There is heavy alcohol exposure in early gestation in at least 10% of pregnancies
• Binge drinking and unplanned pregnancies are more common in younger women and Māori women
• Women have mostly got the public health message to stop drinking when they are pregnant
• Women have not got the message not to drink if they are planning to get pregnant or could get pregnant

Patterns of drinking associated with FASD

The earliest studies of the effects of pre-natal alcohol exposure, done in the late 1970s and early 1980s, involved identifying children with the facial features of FAS whose mothers who were chronic alcoholics.116 The amounts of alcohol consumed by the mothers in these studies were considerable: for example, a study done in the west of Scotland reported alcohol intakes during pregnancy in the range from six measures of vodka daily to one bottle of vodka daily.112 An early US study of 23 children of alcoholic mothers found that four infants died in the perinatal period (a mortality rate of 17%) and that 44% of the surviving children had borderline-to-moderate mental deficiency and 32% had enough features on physical examination to suggest fetal alcohol syndrome.113

A prospective study which began in Boston in 1974 questioned 633 women on their alcohol consumption at their first prenatal visit and classified women into three groups: abstinent and rare drinkers (326 women), moderate drinkers (249 women) and heavy drinkers (58 women, 9%).114 The heavy drinkers were women who consumed five or more drinks on occasion and they also had a consistent daily intake of more than 45ml of absolute alcohol daily: the average daily intake in this group was 174 ml. A standard drink is defined in New Zealand as 12.7 ml (10g) of alcohol and is equivalent to one 330 ml can of beer or one 100ml glass of wine115 so these women were drinking an average of around 14 standard drinks per day. Moderate drinkers were women who drank more than once per month but did not meet the criteria for heavy drinking. The babies were given detailed paediatric, neurological and developmental examinations two or three days after delivery by a physician with no prior knowledge of the mothers’ or infants’ histories. The infants of the heavy drinkers had significantly higher rates of congenital anomalies than the infants of mothers in the other two groups. Thirty-two percent of infants of heavy drinkers had congenital anomalies of any kind and 17% had major anomalies (compared to 3% and 2% in the other groups). Ten of the fifteen (67%) heavy drinkers who significantly reduced their alcohol intake during pregnancy had apparently normal babies but only two of the 27 (7%) women who drank heavily throughout pregnancy did.

While it soon became clear that daily heavy drinking by a pregnant woman was very hazardous to the fetus, attempting to determine exactly what level of alcohol consumption was dangerous was more difficult. Studies done in humans usually rely on mothers honestly and accurately recalling their alcohol consumption during a specific period and they often do not ask sufficiently detailed questions to establish the amounts and timing of drinking in relation to gestation or drinking patterns.5

In animal studies researchers can control the size, number, pattern and timing of alcohol doses given to the mother and so examine the effects of variations in alcohol exposure on the developing fetal brain. Animal studies have established that peak blood alcohol concentration is highly correlated with the degree of brain damage (as indicated by reduced brain weight). High blood alcohol concentrations are achieved by ingesting a large quantity of alcohol over a short period of time, a pattern of drinking known as binge drinking.5

Populations that have the highest rates of binge drinking tend to have the highest rates of FASD, and the highest ratio of FAS rates to partial FAS rates.116 May and Gossage116 compared rates of FAS and partial FAS reported from seven community studies and found the highest the highest ratio of FAS to partial FAS rates was in in South Africa, where mothers of children with FAS and partial FAS drank heavily (an average of 6.6 standard drinks per night) almost every Friday and Saturday evening.

The timing of maternal drinking determines which anatomical features of the fetus are affected. The facial features characteristic of FAS are the result of heavy drinking between the sixth and ninth weeks of gestation.117 The central nervous system is developing for the whole nine months of pregnancy therefore brain damage can result from drinking at any time during pregnancy. It is possible that the specific pattern of behavioural and cognitive deficits seen in a child with FASD is related to the timing of the mother’s drinking episodes and future research may determine which regions of the brain are linked to particular deficits and behaviours.4,117
Factors that modify the risk of FASD

Even if two pregnant women, or one woman during two different pregnancies, have a similar quantity, frequency and timing of drinking, the resulting children may not be affected to the same degree.\textsuperscript{117} The incidence of FASD among the children of women who drank heavily in pregnancy is far from 100%. A 1995 review of 29 prospective studies estimated the incidence of FAS among heavy drinking women (defined as those who had average of 2 or more drinks per day, or 5 to 6 drinks per occasion, or a positive score on the Michigan Alcoholism Screening Test, or clinical diagnosis for alcohol abuse) at 4.3%.\textsuperscript{118}

Maternal factors that have been found to increase the risk and severity of FASD are higher maternal age, higher number of previous pregnancies, higher number of previous births, smaller body size, undernutrition, low socio-economic status, smoking, other drug abuse and depression.\textsuperscript{117}

Genetic factors are probably involved in susceptibility to FASD and there is continuing research in this area.\textsuperscript{119} There has been found to be greater concordance of FASD diagnosis and IQ in identical than non-identical twins of alcoholic mothers.\textsuperscript{120}

Women who have children with FASD frequently come from heavy drinking families, have heavy drinking partners, move in social circles where heavy drinking is common, and are socially isolated from the mainstream economy and society.\textsuperscript{117}

Is light or moderate drinking in pregnancy hazardous?

Government agencies in developed countries, including New Zealand’s Ministry of Health,\textsuperscript{121} commonly advise that even low levels of alcohol intake may be harmful to unborn babies and that pregnant women should abstain from alcohol.\textsuperscript{122-124} There is conflicting evidence about whether occasional or light drinking in pregnancy is a risk factor for later mental health or learning problems in exposed children but most studies have not found any significant detrimental effects.\textsuperscript{125-132}

A 2007 systematic review of 46 studies looking at the effects of low to moderate alcohol intake on miscarriage, stillbirth, intrauterine growth restriction, prematurity, birthweight, small for gestational age at birth and birth defects including fetal alcohol syndrome found no convincing evidence for any of these outcomes. This review’s authors stated that many of the studies had methodological weaknesses therefore the evidence precludes concluding that low to moderate drinking in pregnancy is safe.\textsuperscript{133}

All studies of prenatal alcohol in humans rely on maternal self-report and most have not taken into account the amount, timing and pattern of maternal drinking.\textsuperscript{134} If studies classify women’s drinking according to average alcohol intake per week then many women who are heavy or binge drinkers on the occasions when they do drink may be classified as light drinkers because their average intake is less than one standard drink per day.\textsuperscript{134} This may have contributed to some studies failing to find differences between different groups of drinkers. An Australian study examining the association between prenatal alcohol exposure and fetal effects compared the results of using three different published methods of quantifying maternal alcohol consumption with a composite method of categorisation that combined total quantity, dose per occasion and frequency.\textsuperscript{134} It found that effects of moderate and binge drinking were only evident when the composite method was used but effects from heavy drinking were evident and similar with all methods.

A 2012 review of animal studies of moderate alcohol intake found that it was associated with long lasting neuro-behavioural deficits including alterations in learning, memory, motor coordination, social behaviour, and stress responses.\textsuperscript{135} It was also associated with CNS changes that could account for these behavioural effects including alterations in neuronal migration, adult neurogenesis, neurotransmitter receptor function, synaptic plasticity, and intracellular signalling pathway. The review defined moderate alcohol intake as that producing a blood alcohol level of \( \leq 0.17 \) g/dl, which has been assumed to model human moderate alcohol intake. (New Zealand’s drink drive legal alcohol limit is 0.05 g/dl.\textsuperscript{136})

Prevention of FASD

Prenatal brain damage caused by alcohol is irreversible but totally preventable. Heavy drinking and drinking to get drunk are a significant part of New Zealand’s drinking culture.\textsuperscript{137} Compared to previous generations young women are drinking from an earlier age and drinking greater quantities when they drink.\textsuperscript{138} Fetal damage is only one of the many individual and community harms produced by alcohol abuse.\textsuperscript{137} There is not space here to

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discuss in detail strategies to reduce alcohol-related harm in the whole population. The Law Commission’s 2010 report *Alcohol in our lives: Curbing the harm*\textsuperscript{139} states that the international literature indicates that there are seven major policy levers for regulating alcohol-related harm:

- Regulating the physical availability of alcohol through restrictions on time, place and density of outlets
- Regulating conduct in commercial drinking establishments
- Taxing alcohol and imposing controls on price
- Regulating advertising, promotions and marketing
- Imposing penalties for alcohol-related anti-social behaviour such as drink driving
- Education and persuasion with the provision of information
- Increased availability of treatment programmes with screening and brief interventions in health care.

Only the last two of these are within the ambit of the health system and will be considered here.

**Communication and education strategies**

A 2014 literature review for the Health Promotion Agency, entitled *Drinking alcohol in pregnancy*,\textsuperscript{140} considered, among other things, research on primary prevention communication strategies. These strategies aim to influence knowledge, beliefs and attitudes about alcohol use in pregnancy and they can support clinical strategies, such as brief interventions, that may be used in maternity or other healthcare settings.\textsuperscript{140} Communication strategies include media campaigns, social marketing approaches, educational materials, messages for healthcare providers and health warning labels on alcohol containers.\textsuperscript{140}

Although there have been many communication campaigns addressing alcohol use in pregnancy, these have rarely been based on theory or on formative research that could help identify the target audience, the target behaviours, and the factors that influence the behaviours of the target audience.\textsuperscript{141} Campaign evaluations have tended to be of only fair to poor quality and have often not drawn any meaningful conclusions.\textsuperscript{141} There is therefore a lack of evidence to inform the design of campaign strategies and messages.\textsuperscript{141} Despite this, some best practice approaches have been identified from reviews of Canadian campaigns,\textsuperscript{142-144} as follows:

- Campaigns should be carefully planned with objectives that are specific, realistic, attainable, measurable and time-specific
- Campaigns should be one component of a broader strategy and should involve a wide range of partners
- Campaigns should be carefully designed for a specific group or groups. Campaigns are most likely to be effective in larger, well-defined lower-risk groups
- Campaigns should assess the current levels of awareness in the target audience and focus messages on areas where awareness is low
- Campaigns should have good exposure and reach to make messages more likely to be heard and remembered.

There is limited evidence on the specific elements that make a campaign message effective.\textsuperscript{140} It has been suggested that messages need to take a positive and supportive approach and avoid the use of blame, shame and fear-based strategies.\textsuperscript{143} They can link people to further information, services and support.\textsuperscript{143} The Ministry of Health’s Action Plan notes that women are currently receiving mixed messages about the risks of drinking during pregnancy and it emphasises the need to disseminate a clear, consistent and unambiguous message that women should stop drinking alcohol if they could be pregnant, are pregnant or are trying to get pregnant as there is no known safe level of alcohol consumption during pregnancy.\textsuperscript{7}

The Health Promotion Agency’s review describes a number of international communication campaigns aimed at reducing or preventing alcohol use among pregnant women that have been evaluated through assessing campaign recall, changes in awareness and knowledge, and intended changes in behaviour in the target audience. It also provides brief details on some recent non-evaluated campaigns including the *Babies and Booze* social media campaign developed in Auckland.\textsuperscript{145}

There is a lack of evidence for the efficacy of public health campaigns in changing behaviour (as opposed to knowledge or intentions) regarding consumption of alcohol in pregnancy.\textsuperscript{146-149} There is also little evidence that mass media campaigns have been effective in modifying alcohol use in the general population, except in relation to drink driving.\textsuperscript{150-152}
Identifying at-risk women

Interventions to prevent FASD need to be directed both at the general population of women of childbearing age (universal prevention) and at the women at highest risk of having a child with FASD such as women with alcohol addiction, women who themselves have FASD, and women who already have a child with FASD (targeted and indicated prevention). It is necessary to identify women with risky drinking patterns and women who are alcohol-addicted so that they may be helped to reduce or stop their drinking, to deal with the factors that underlie their drinking, and to use effective contraception. Research studies have consistently identified high levels of pre-pregnancy drinking as being predictive of drinking during pregnancy.153

Women may not disclose their alcohol abuse to health practitioners for various reasons including embarrassment and denial. The Ministry of Health recommends that primary care health professionals ask women who are planning a pregnancy or are pregnant about whether they drink alcohol; provide brief advice about not drinking alcohol when planning a pregnancy or when pregnant and explain why; and assist women who are having difficulty stopping, or whose drinking is problematic, by directing them to addiction treatment services.154 A Pregnancy and Alcohol Cessation Toolkit155 has been developed to support health professionals in this.

There are a number of standardised screening questionnaires that can be used to identify problem drinking.156,157 A 2010 systematic review158 looked at cohort or cross-sectional studies that had compared one or more brief alcohol screening questionnaire(s) with reference criteria obtained via structured interviews to detect ‘at-risk’ drinking, alcohol abuse or dependency in pregnant women receiving prenatal care. The review authors identified five studies that evaluated the sensitivity, specificity and positive predictive value of seven brief screening questionnaires. They concluded that three questionnaires showed promise for screening for risky drinking in pregnant women: T-ACE (Take[number of drinks], Annoyed, Cut down, Eye-opener), TWEAK (Tolerance, Worried, Eye-opener, Amnesia, Kut down), and AUDIT-C (Alcohol Use Disorder Identification Test – Consumption). They stated that AUDIT-C might also be useful for identifying alcohol dependency or abuse.

Once a woman has been identified as having an alcohol problem, depending on the severity of the problem, she can be offered advice, a brief intervention, or referral to an alcohol treatment service.157

Interventions to reduce alcohol-exposed pregnancies

Brief interventions for pregnant women typically involve from one to four short counselling sessions with a professional trained in motivational interviewing, such as a midwife, GP or social worker, followed by personalised feedback.157 There have been a number of randomised controlled trials of brief interventions for alcohol use in pregnant women158–162 and the results of these suggest that brief interventions may be useful in reducing pregnant women’s alcohol consumption. The Cochrane review that assessed these trials found that the evidence is insufficient to determine the type of brief intervention that is likely to be most effective.163

O’Connor and Whaley examined the effectiveness of a brief intervention in helping low-income minority women in Southern California achieve abstinence from alcohol during pregnancy. The intervention consisted of 10–15 minute counselling sessions guided by a scripted manual. It was delivered in accessible community-based settings by nutritionists from the Public Health Foundation Enterprises Management Solutions Special Supplemental Nutrition Program for Women, Infants, and Children (PHFE-WIC). Twelve 12 PHFE-WIC centres were randomised into assessment only or assessment plus brief intervention and this yielded 255 pregnant drinkers as study participants. Women who received the brief intervention were five times more likely to report abstinence at third trimester follow-up than the women who received assessment only and their infants had higher birthweights and birth lengths, and a lower mortality rate (0.9% vs. 2.9%).

Since almost half of all pregnancies are unplanned,104 there is a need for preconception interventions that help drinking women to use effective contraception and/or help women who might become pregnant to reduce or stop their drinking. In the US, randomised controlled trials have indicated that several motivational interviewing-based interventions targeting risky drinking and ineffective contraception are effective in reducing alcohol-exposed pregnancies (AEPs).164

CHOICES165,166 is a motivational interviewing plus feedback counselling intervention designed to reduce AEPs among community women.164 It involves four 30–75 minute counselling sessions and a medical contraception counselling appointment. A multi-site RCT that compared CHOICES to provision of an informational brochure found a significant 18% reduction in AEP risk (due to reductions in risky drinking, increases in contraception effectiveness, or both) in participants who received CHOICES.165
BALANCE was a modification of CHOICES that contained the same components as the original intervention condensed into a single session pre-conception motivational interview plus assessment feedback counselling intervention. It was tested in a RCT among college women aged 18–25 at risk of AEP. The intervention recipients were encouraged to have a contraception counselling visit with a medical provider through student health services but this was not a formal part of the intervention as it had been in CHOICES. At four-month follow-up 80% of BALANCE recipients, vs. 65% of participants who received the information brochure, reported no AEP risk, a 15% absolute risk difference.

EARLY was an adaptation of CHOICES and BALANCE for community women. It was recognised that the college women involved in the BALANCE trial were typically younger and less likely to have already given birth than community women, and also less likely to have other psychosocial risks associated with increased AEP risk including a history of tobacco smoking, recent drug use, a history of inpatient treatment for addiction or mental illness, multiple sexual partners or recent physical abuse. While CHOICES had been shown to be efficacious in community women it was resource-intensive which made it challenging to implement on a large scale. EARLY aimed to address both these issues. EARLY was a 60-minute, face-to-face, individual, one-session, motivational interview plus assessment feedback counselling intervention.

During the intervention counsellors built rapport, discussed reactions to the baseline assessment, elicited views on drinking and use of contraception, provided personalised feedback, showed that participant a video about AEP and FASD an elicited the participant’s response, discussed drug use and other mental health issues pertinent to prevention of AEP if indicated, selected and performed at least one intervention activity, encouraged a contraception visit with a reproductive healthcare practitioner, and summarised the intervention. The intervention activity addressed the issue (contraception or drinking) that appeared to be most relevant or of greater interest to the participant through addressing ambivalence, readiness, tempting situations or goal setting.

A three-arm RCT involving 217 participants compared EARLY, an informational video, and an informational brochure. All three interventions were associated with significant decreases in ineffective contraception rates at six months and small decreases in drinks per drinking day. Compared to the other two interventions in this trial, EARLY led to greater reductions in ineffective contraception and AEP rates (although the differences were not significant) but not in drinks per drinking day. Compared to previous RCTs of CHOICES and BALANCE, EARLY produced smaller risk reductions, and, unlike CHOICES and BALANCE, it did not perform better than the comparison interventions in its RCT. The study authors suggested that raising women’s awareness of their drinking habits through assessment seems to reduce women’s drinking even if no further intervention is provided. Other studies have also found this to be the case. This phenomenon may lead to RCTs that rely on assessment underestimating the effects of interventions.

A program of screening and alcohol brief interventions (ABIs) has recently been implemented in antenatal care settings in Scotland. A qualitative study was undertaken to explore midwives attitudes and practices regarding alcohol screening and ABI. The study involved semi-structured interviews with 15 midwives and a focus group of six midwifery team leaders. Interview transcripts were analysed in a thematic analysis. Midwives were positive about being involved in the screening and ABI programme but they were not completely convinced of the programme’s value in antenatal care. They felt that, at the first antenatal appointment, they had not established sufficient rapport with a pregnant woman to be able to discuss alcohol issues with ease although they recognised that early in pregnancy was the best time to do this. They pointed out that many women were already not drinking or drinking very little prior to the first antenatal appointment. Midwives were concerned that the women who had not reduced their drinking were the group most likely to be alienated by discussion of alcohol issues. They thought that pre-pregnancy preventive measures would have a greater impact on reducing alcohol-exposed pregnancies.

**Conclusion**

Fetal alcohol spectrum disorder is a significant threat to the health and well-being of New Zealand’s children. Prenatal exposure to alcohol can have devastating life-long consequences both for the individual child and for those he or she comes into contact with. Fetal alcohol spectrum disorder is exceedingly costly for the health, education, child welfare, justice, mental health and social welfare systems.

Although early identification and support is helpful for children with FASD and their families the evidence base for interventions to ameliorate the cognitive and social deficits resulting from alcohol-induced brain damage is

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limited. Even with the best care during childhood and adolescence, many of those with FASD will still need continuing support to manage their daily lives in adulthood. It is vital that we change New Zealand’s drinking culture from one that encourages and tolerates alcohol abuse to one that supports moderation as normal drinking behaviour.

Health services need to ensure that women of reproductive age do not face barriers to seeking help with alcohol and drug problems or associated mental health issues, and that women who have difficulty moderating their alcohol consumption have access to effective contraception.


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