20

Addressing Fetal Alcohol Spectrum Disorder in Aboriginal Communities

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OVERVIEW

This chapter begins with a description of Fetal Alcohol Spectrum Disorder (FASD) and examples of reported prevalence of FASD in the international context. It then draws on international and Australian studies to describe the burden of FASD, including studies relevant to the Aboriginal population. The section on the Australian context provides a description of some of the action that has been taken in Australia to address FASD. The section on the Life Cycle model includes stories of Aboriginal people, from a major city and rural and remote communities in northern and southeast Queensland, on their experiences and perceptions of alcohol. These stories, collected by Hayes in 1997 and 1998, led to the development of the Life Cycle model. This model can be adopted to address the complexities of FASD in the Aboriginal population. The final section describes initiatives driven by local Aboriginal communities, and accepted as best practice, for addressing FASD in their communities. The chapter concludes with questions for reflective practice and FASD.

INTRODUCTION

Concern about the use of alcohol in pregnancy dates back to biblical times,[1] but it was in 1968 that Paul LeMoine, a French paediatrician, provided the first description of dysmorphic facial features and growth delays that were similar in infants born to mothers who drank alcohol during their pregnancies.[2] Five years later, the term Fetal Alcohol Syndrome (FAS) first appeared in two papers by a team of clinicians from Seattle at the University of Washington.[3, 4] This team described characteristics in eight unrelated infants from three different ethnic backgrounds born to mothers who were chronic alcoholics. These children showed a similar pattern of craniofacial, limb, and cardiovascular defects associated with prenatal-onset growth deficiency and developmental delay.[4]

Research conducted on the effects of prenatal alcohol exposure has shown that FAS is part of a spectrum of disorders. FASD was adopted as an umbrella term to cover the range of outcomes associated with all levels of prenatal alcohol exposure.[5] There are a number of guidelines used to diagnose FASD internationally[6-8] and Australian guidelines are currently being developed.[9] According to the Canadian Guidelines, conditions under the umbrella include:

- FAS – includes central nervous system abnormality or dysfunction, three characteristic facial features, growth restriction and confirmed (or unconfirmed) alcohol exposure;
- Partial FAS (PFAS) – includes changes to the brain, proven prenatal alcohol exposure and two out of three facial changes;

- Alcohol related neurodevelopmental disorders (ARND) – includes changes to the brain and confirmed prenatal alcohol exposure; and
- Alcohol related birth defects (ARBD) – describes body changes due to prenatal alcohol exposure, often including kidney problems, or heart septum problems.[7] These guidelines recommend that the diagnosis of ARBD should be used with caution.[7]

Prevalence of FASD in International Contexts

Establishing population-based prevalence of FAS and FASD is challenging as the studies are small in number and vary in methodology, therefore limiting the generalisability of the study population to the general population.[10] Higher rates of FAS are reported in studies using active case ascertainment methodology when compared to clinic-based studies or studies using a passive surveillance system.[11]

Despite this, there have been efforts to estimate population prevalence of FAS and FASD. In the United States, it is estimated that the prevalence of FAS in a 'typical' population is 2 to 7 per 1,000 births[10] while other studies using active case ascertainment have reported rates ranging from 1.8 to 9.8 per 1,000 births.[11]

In-school studies, which have been rare until recently, are more likely to be representative of the local population.[10] A study of first grade children in schools near Rome, using active case ascertainment, estimated the rate of FAS to be between 4 and 12 per 1,000 children and the rate of FASD to be between 23.1 and 62.6 per 1,000 children.[12] Recently, a high rate of FASD has been reported in a South African population— from 135 to 207 per 1,000 children enrolled in first-grade.[13]

BURDEN OF FETAL ALCOHOL SPECTRUM DISORDERS

The most profound effect of prenatal alcohol exposure is on brain development which results in cognitive and behavioural difficulties.[14] O'Malley provides a description of how this affects the individual; '…the developmental disability of FASD is a complex learning disorder affecting multiple domains of functioning including working memory, attention, impulsivity, learning, interpersonal relatedness, social skills and language development'.[15(p5)] Comorbidity is the rule rather than the exception in people with FASD, beginning with infancy and continuing throughout the lifespan.[15]

The cost of FASD is significant. The estimated lifetime costs for a person with FAS may reach $US2 million.[16] The adjusted annual average cost per child with FAS and Fetal Alcohol Effects (FAE) aged one to 21 years in Canada was $14,342 and the cost of FASD annually to Canada for that age group was $344 million.[17] The estimated costs are based on a prevalence rate of FAS/FAE of approximately 3 in 1,000 people.[17] No cost of illness studies on FASD have been conducted in Australia.

Lifelong Consequence of Prenatal Exposure and Mental Health Problems

A long term follow-up of a cohort of people with FAS and FAE reported a number of adverse outcomes. Inappropriate sexual behaviour, including inappropriate sexual advances, promiscuity, exposing behaviour and voyeuristic behaviour was the most frequent adverse outcome across the lifespan, increasing slightly with each age category—from 39 per cent in children to 48 per cent in adolescents and 52 per cent in adults.[18] Among adolescents and adults, 35 per cent were incarcerated for a crime, 23 per cent hospitalised for a psychiatric problem and 15 per cent had been hospitalised for alcohol and drug treatment. This study reported that one of the strongest correlations of adverse outcomes was the lack of early diagnosis (before 12 years of age). The authors acknowledged that these findings were from a clinical sample, therefore limiting their generalisability.[18]

A prospective Australian study reported that children with FAS are likely to be born preterm (35 per cent), be of low birth weight (65 per cent), have growth deficiency (56 per cent), have microcephaly (53 per cent), have additional birth defects (24 per cent), have speech/language disorder (60 per cent), have sensorineural hearing loss (5 per cent), and have visual impairment (4.3 per cent).[19] A separate study reported that one-third of children diagnosed with FAS had intellectual disability.[20]

Rates of intellectual disability and mental illness, often in the context of comorbid misuse of substances such as alcohol and cannabis, have been found to be significant in certain groups of Aboriginal people. Hunter reported that approximately 40 per cent of Aboriginal people in Cape York who suffered from a psychotic disorder were also affected by intellectual disability.[21] A study in WA reported that maternal alcohol-related diagnosis was the leading known cause of intellectual disability, with no identified genetic origin, and accounted for 3.8 per cent of all intellectual disability in WA.[22] Potentially, 1.3 per cent of intellectual disability in non-Aboriginal children and 15.6 per cent of intellectual disability in Aboriginal children of mothers with an alcohol-related diagnosis could be prevented by eliminating heavy alcohol use by these mothers during pregnancy.[22]

Impact of FASD on Families and Individuals

Despite the documented importance of the quality and stability of the home environment,[18] little is known about families with FASD.[23] Testimonies from birth parents in the United States reported feelings of loss, guilt, shame and blame.[24] A review of a limited body of systematic research findings in this area found that having a child/ren with FASD was associated with financial strain, frustration with the lack of knowledgeable professionals, stress related to the judicial system, and multiple time demands.[23]

A qualitative study of children living with FASD described how they understood the nature of the disability and how it affected their day-to-day life:[25]

> *Sometimes I have trouble concentrating. I am concentrating on one (activity), then I get distracted.*
>
> *Learning is hard. The teachers don't explain things (in a manner that allows her to understand).*

Many expressed difficulty in making and keeping friends:

> *No one likes me. No one plays with me at recess.*

The children described feeling supported by their parents:

> *My mum plays with me and my dad takes me fishing.*

All children talked about how they tried to participate in life despite their disability, but feeling different emerged as an overarching construct.[25]

AUSTRALIAN CONTEXT OF FASD

This section provides a description of some of the action that has been taken to address FASD in Australia. It begins with a description on alcohol and pregnancy; studies reporting the prevalence of FAS; the challenges facing diagnosing FASD in Australia; and includes an example of action taken at a policy level.

Alcohol and Pregnancy

Understanding the pattern and context of alcohol consumption is crucial in preventing FASD. This essential information can be used to inform interventions to address alcohol and pregnancy. An Australian example is provided of how alcohol and pregnancy is being addressed.

Australian studies have reported rates of alcohol consumption in pregnancy ranging from 34 per cent[26] to 59 per cent.[27] A survey of non-Aboriginal women who had given birth between 1995 and 1997 found that 47 per cent had not planned their pregnancy[27] and a national survey of Australian women of child bearing age reported that 24 per cent of women indicated that they would continue to drink alcohol if they became pregnant.[26]

Drinking alcohol in the last pregnancy was a strong predictor of a woman's intention to drink alcohol if she were planning another pregnancy.[28] Women reported that they would be less likely to drink alcohol if their partner encouraged them to stop or cut back (38 per cent) or if their partner stopped drinking alcohol during the pregnancy (30 per cent). Women with high levels of education and women who had given birth previously were more likely to drink alcohol in pregnancy.[28]

In the Aboriginal population, 23 per cent of birth mothers of Aboriginal children reported drinking alcohol in pregnancy.[29] There are no published data on what proportion of Australian Aboriginal women plan their pregnancies, but a qualitative study conducted in a Native American population reported that Native American women were unlikely to plan a pregnancy.[30]

Whilst the rates of reported alcohol consumption in pregnancy are higher for non-Aboriginal women, Aboriginal women are more likely to consume alcohol at harmful levels. A Western Australian (WA) study of women who had given birth over a 10-year period, found that Aboriginal women were 10 times more likely to be diagnosed with an alcohol diagnosis when compared with non-Aboriginal women—23 per cent and 2.3 per cent respectively.[20] Hayes has done extensive qualitative work to describe the complexities around alcohol consumption in pregnancy in Aboriginal communities.[31] Examples of this are provided in the sections 'Adopting a Life Cycle Model' and 'Best Practice Examples of Aboriginal Responses to FASD' further on in this chapter.

Women expect health professionals to ask about, and advise them on, alcohol use during pregnancy[26] but a survey of health professionals reported that most health professionals did not routinely ask pregnant women about their alcohol use or provide them with information about the effects of alcohol on the unborn baby.[32] A qualitative study of health professionals revealed barriers in addressing alcohol use with pregnant women.[33] The authors provided strategies for overcoming the barriers. For example, a barrier included the perception that most women do not drink much alcohol during pregnancy, however Australian research has reported high rates of women drinking alcohol in pregnancy. Rather than assume that pregnant women are not consuming alcohol, a critical strategy in addressing this is to encourage all health professionals to routinely ask all women about their alcohol use.[33]

Resources for Health Professionals in Australia

Health professionals in WA requested resources to support them in addressing alcohol use during pregnancy.[32] Resources were developed in response to this request focusing on enhancing the knowledge, attitudes and practice of health professionals related to alcohol use and pregnancy.[34, 35]

Resources available to Address Alcohol Use and Pregnancy [35]

1. A 38-page booklet containing information on the consequences of drinking alcohol before and during pregnancy, the clinical features of FASD, the role of the health professional, and contact numbers for referrals for women and children. The key message in this booklet is *No Alcohol in Pregnancy is the Safest Choice*;
2. A double-sided laminated fact sheet which summarises information from the booklet;
3. A wallet card for health professionals to give to women, which includes a list of statements to help women say no to alcohol during pregnancy; information about the possible effects of drinking alcohol in pregnancy; contact numbers of alcohol and drug information services; and the message *No Alcohol in Pregnancy is the Safest Choice;*
4. A desktop calendar with month view displaying the message *No Alcohol in Pregnancy is the Safest Choice.*

Prevalence of FASD in Australia

Rates of FAS have been reported at 0.06, 0.18 and 0.68 per 1,000 live births in a national prospective study[19] from the WA birth defects registry[36] and a review of medical records for the Top End of the Northern Territory (NT)[37] respectively.

The above studies have shown that Aboriginal children with FAS are over-represented, with rates of 2.76 per 1,000 live births for Aboriginal children in WA—100 times higher than the reported rate of FAS in other Australian children;[36] 1.8 per 1,000 live births in the NT;[37] and 65 per cent (n = 92) of the children diagnosed with FAS in a national study were Aboriginal.[19] Up to 51 per cent of children with FAS may have a sibling with FAS[19] and some Aboriginal children with FAS may have two siblings with FAS.[37]

Diagnosing FASD

Early diagnosis and intervention may be beneficial to children with FASD.[18] However, the range of expression of dysfunction related to prenatal alcohol exposure makes the diagnoses of FASD, which relies entirely on a clinical assessment and history taking,[37] complex.[7] Guidelines have been developed to assist health professionals in the assessment and diagnosis of FAS[6] and FASD.[7] Some countries have established specialised diagnostic clinics, but these are concentrated in North America (29 of 34 clinics) with none in Australasia.[38] Nearly all of those clinics (97 per cent) had a multidisciplinary team and, for 94 per cent of the clinics, at least one member of the team had specialist training in the assessment of FASD.[38]

Whilst it is recognised that diagnosing FASD is complex, in Australia it is further complicated as health professionals have limited knowledge of the diagnostic criteria for FAS[32,39] when compared with health professionals in Canada.[40] In addition, 52 per cent of health professionals (general practitioners, Aboriginal health workers, allied health, community nurses and obstetricians)[32] and 70 per cent of paediatricians in Australia believed that making a diagnosis of FAS might stigmatise the child or family.[40]

In regards to diagnostic guidelines for Australia, a Delphi survey of health professionals found support for the diagnostic criteria for FAS.[9] Participants indicated a clear preference for the University of Washington criteria.[6] There was, however, no consensus for PFAS or ARND.[9] In addition, a model of care for FASD has been developed in WA.[41]

Policy Context in Australia

The National Indigenous Drug and Alcohol Committee (NIDAC) is the leading voice in Indigenous drug and alcohol policy advice. The action that NIDAC has taken on FASD provides an example of the policy context. NIDAC recognise that FASD is not well known or understood in Australia, with most research in this field undertaken overseas.[42] Their discussion paper provides 15 recommendations under the heading of social marketing, policy and practice guidelines, prevention and service provision, data (national surveys) and recognition of FASD as a disability.[42]

ADOPTING A LIFE CYCLE MODEL

It has been identified that very few studies had been conducted that increased practitioners understanding of the '…psychosocial and milieu into which children with FAS and FAE are born or how this might affect their lives at different stages of development'.[18(p229)] The case studies in Chapter 18 (Parker and colleagues) and Chapter 21 (Milroy) provide greater understanding of the realities experienced by some Aboriginal children.

The reasons why Aboriginal people consume alcohol at harmful levels are complex. Studies conducted by Hayes in both urban and rural Aboriginal communities in Queensland identified a number of issues that impacted on the everyday lives of children, young people and families.[31] Many of these issues were both greatly affected by, and contributed to, the drinking environment in Figure 20.1 (page 365) including:

- family break-down;
- disharmony across the community;
- family and community dysfunction;
- alcohol and drug consumption;
- teenage pregnancy;
- peer pressure;
- unemployment; and
- violence within the home and community.[44]

People described a life cycle in which both alcohol and pregnancy were a normal part of life.[43] Hayes argues that programs aimed at changing individual risky behaviour need to acknowledge the way in which the person is '…inextricably tied to the culture in which he or she exists'. Importantly, this involves considering the social, historical and political background and the cultural aspects of drinking in order to begin to introduce prevention and early intervention strategies to address alcohol use and pregnancy among women.[44]

Stories of Aboriginal Women

Some years ago, with input from Aboriginal community members, Hayes developed a framework which is consistent with Erikson's early life stages to assist in understanding the development of identity and the resulting changes of emotions and physical boundaries across the lifespan.[31] This model proposes an expanded view on the use of alcohol in Aboriginal communities and is informed by stories from Aboriginal people.[31] Some of these stories have been published.[44(p21)] The following story-lines, in addition to those already published, provide examples of interview respondents' views.

Story 1 He got problems now

There was a lot of concern among respondents about women drinking and smoking marijuana while pregnant. Several young women explained:

> *That's another thing besides Fetal Alcohol Syndrome they are smoking marijuana too you know, right up until they have the baby.*

> *There are a lot of women here who use drugs when they are pregnant, I suppose alcohol and drugs can affect the breast milk too.*

> *They drink all through their pregnancy and use yandi (marijuana) too you know, they got no shame.*

Marjorie is a mother who drinks alcohol to try and heal the pain and suffering from domestic violence but recognizes the affect that prenatal exposure to alcohol is having on her children. She explained that her babies were getting smaller and smaller, she drank right up till they were born, spirits, then wine and beers, throughout her pregnancy:

> *My baby he got problems now cause of the grog.*

Story 2 Growin 'emselves up

An older woman spoke of the link between alcohol and the entire life cycle in this way:

> *These kids basically got to raise themselves, the grannies burn out. Some women just keep on having kids, some have seven kids and can't look after them, and they keep the money and dump the kids on other unruly family members. It's really sad, especially if the grannies don't care for them.*

> *Them mothers drink on the river bank, go to bingo, play cards and neglect the kids, the grandmothers have to look after them, the mothers are not being responsible and you end up with kids having kids.*

> *They (mothers) should be encouraged to get off the drugs and grog and be responsible for their kids and stop making excuses for them, these old girls are on their last legs.*

> *There is too much abuse here it's intergenerational, someone's got to do something.*

Story 3 Testing the waters of independence – Fending for themselves

Most respondents agreed that when a child is two to three years old, he or she should be allowed to fend for themselves and to be responsible for themselves. Women in the community said things like:

> *They have to do things for themselves*

> *You see them kids walking all over the community. They know how to cross the road and look after their little friends you know. They think they are all grown up.*

> *They look after their little brothers and sisters and their friends, sometimes they got nobody around to look after them, cause they are all drunk or yarndied up. They are responsible for their own feed, they know what they want, they [the young children] are not safe you know.*

Continued . . . .

Story 3 **Testing the waters of independence – Fending for themselves** *(continued)*

Alternatively, children themselves are taking on the responsibility of their parents at a very young age, helping out their own parents, and caring for siblings. One concerned participant stated that:

> *We see a lot of that, the parents, like they send the little toddlers down into the park here pushing their younger brothers and sisters around.*

> *These kids are three and four year old, with younger babies in the strollers and we've had to help the kids push the prams back up so they can head home, while the mothers are sitting at home playing cards or whatever, doing their own thing. You know you'll see other kids who are in the park well they'll help look after them and each other too; they show responsibility for each other.*

Story 4 **Mimicking adult behaviour – Craving for love and affection**

In a remote Aboriginal community in the study, when a young person reaches the youth stage (11–13 years of age), they are well accomplished at mimicking the behaviour of adults around them. The children in this age group are searching for affection which leads to risky sexual liaisons; however, sadly, their own identity has not yet developed.[42]

A number of concerned respondents believed that:

> *Young people are craving for love and affection, and if the girls say no to the male they get bashed anyway, and the man will go and find someone else and they will be left alone* [meaning they would not have a source of affection].

> *The girls don't care if they get bashed, it's like they need to be with someone only if it's for a short time.*

One distressed informant stressed that:

> *There are children [ten and eleven years-old] placing themselves at risk and being sexually active.*

Other respondents confirmed this:

> *Yes that's right like even younger than the ten year-olds you've got a lot of the eight and nine year-olds following the older siblings and they are getting into the same practice.*

> *There are nine and ten year-olds around here, who drink and smoke yarndi some are sexually active, they walk around at night looking for man.*

GETTING CAUGHT UP IN A LIFE CYCLE OF ALCOHOL AND PREGNANCY

People described a life cycle in which both alcohol and pregnancy were a normal part of life.[42] The relationship between alcohol and pregnancy went deeper and was more complex than the physical effects of either of these issues. People described a set of interconnecting factors that are depicted in the life cycle model which tracks the stages an individual goes through from birth to death, in a community where harmful levels of alcohol are used by some men, women and children. The model shown in Table 20.1 describes various stages across the life course through which an individual progresses.[43]

Table 20.1: Erikson's Psychosocial Stages Summary Chart

Stage	*Basic Conflict*	*Important Events*	*Expected Outcomes*	*Aboriginal Child Experiences in a Drinking Environment*
Infancy (birth to 18 months)	Trust vs. Mistrust	Feeding	Children develop a sense of trust when caregivers provide reliability, care, and affection. A lack of this will lead to mistrust.	If caregivers and parents are consistent in satisfying the child's needs, trust is developed. If the caregiver or parent is inconsistent in satisfying the child's needs, the child is likely to feel mistrust. Nurturing is carried out by the parents but, in addition, a pool of caregivers representing the extended family, including other children, provide nurturing.
Early Childhood (2 to 3 years)	Autonomy vs. Shame and Doubt	Toilet Training	Children need to develop a sense of personal control over physical skills and a sense of independence. Success leads to feelings of autonomy; failure results in feelings of shame and doubt.	The child becomes more responsible for self-learning and independence is evident. This absence of parental expectations eventually places the child in a position where they learn to be irresponsible in terms of their own wellbeing while, paradoxically, they develop caring responsibilities for other children.
Preschool (3 to 5 years)	Initiative vs. Guilt	Exploration	Children need to begin asserting control and power over the environment. Success in this stage leads to a sense of purpose. Children who try to exert too much power experience disapproval, resulting in a sense of guilt.	The need to become independent and to take care of oneself is a priority, as they have been emotionally abandoned by their carers. Beforehand, these children mimic adults unconsciously but at this stage they are quite aware of actively interacting in this role. At three and four years of age, children are expected to take on responsibility for themselves and for other children. This stage flows into the next stage.
School Age (6 to 11 years)	Industry vs. | Inferiority	School	Children need to cope with new social and academic demands. Success leads to a sense of competence, while failure results in feelings of inferiority.	The children appear to have developed a sense of responsibility through the need to care for other siblings which, in turn, will become a catalyst for further pain. It becomes clear that the caring and nurturing process is a way of fulfilling their own needs, especially when they are craving for love and affection, which their own parents or caregivers fail to provide.
Adolescence (12 to 18 years)	Identity vs. Role Confusion	Social Relationships	Teens need to develop a sense of self and personal identity. Success leads to an ability to stay true to yourself, while failure leads to role confusion and a weak sense of self.	The model shows children who are continually exposed to examples of negative adult behaviour develop patterns of behaviour for their later life i.e. children learn to be irresponsible for their own actions as a result of witnessing negative adult behaviour. Paradoxically, children also develop early caring responsibilities for other children, which may eventually lead to damage of the family's abilities and strengths to guide sensible adult behaviours.

Continued . . . .

Table 20.1: Erikson's Psychosocial Stages Summary Chart (continued)

Stage	*Basic Conflict*	*Important Events*	*Expected Outcome*	*Aboriginal Child Experiences in a Drinking Environment*
Young Adulthood (19 to 40 years)	Intimacy vs. Isolation	Relationships	Young adults need to form intimate, loving relationships with other people. Success leads to strong relationships, while failure results in loneliness and isolation.	Responsibility and maturity do not always carry the same expectations for children forced into responsibility at a very early age as it would be the broader population.
Middle Adulthood (40 to 65 years)	Generativity vs. Stagnation	Work and Parenthood	Adults need to create or nurture things that will outlast them, often by having children or creating a positive change that benefits other people. Success leads to feelings of usefulness and accomplishment, while failure results in shallow involvement in the world.	People enter a new stage in their life cycle as they get older. They begin to think more clearly and to recognise their own physical and emotional health needs, guided by the realisation that life experiences have taught them their kind of lifestyle is not sustainable. Flows onto the next stage.
Maturity (65 to death)	Ego Integrity vs. Despair	Reflection on Life	Older adults need to look back on life and feel a sense of fulfillment. Success at this stage leads to feelings of wisdom, while failure results in regret, bitterness, and despair.	They become tired and cannot carry the burden of violence and abuse which they have endured for so long throughout their lives.

Table 20.1 lists each of the development stages identified in Erikson's life cycle model. These stages of the life cycle outlined by Erikson convey typical points of conflict that individuals experience as they grow up. The stages are juxtaposed with the experiences of children and young people described by Hayes in her research with the Aboriginal communities.

Hayes attempts to depict how the cultural world or environment one grows up in 'shapes' the specific manner in which one expresses his or her feelings. The experiences help to illustrate how early social contact by young children with adults serves to teach them the cultural, gender-related and personal rules involved in managing their emotional reactions. This position integrates the roles of nature and culture in individual development. In a strong and functioning family environment these elements are protective. However, when a child is raised in an environment surrounded by dysfunction associated with drinking, these developmental phases are very different. These patterns are reflected in the stories included from Hayes' study.

The case studies and research by Hayes highlights that these areas of 'basic conflict' outlined in Erikson's model are, for Aboriginal children (sometimes with FASD), often far more complex (and potentially negative due to intense exposure to risk factors over protective factors). Further, the stories show that when a child's development is overlayed by the experiences that occur in an environment where drinking occurs at unsafe levels, as part of the child's everyday life throughout their early development—it can often lead inevitably onwards, to a life cycle of addiction and regret (see for example Figure 20.1), as well as continuing that cycle by drinking throughout pregnancy—leading to FASD children.

There are a number of Aboriginal initiatives described in this chapter (page 366) highlighting how Aboriginal communities are working to break this cycle.

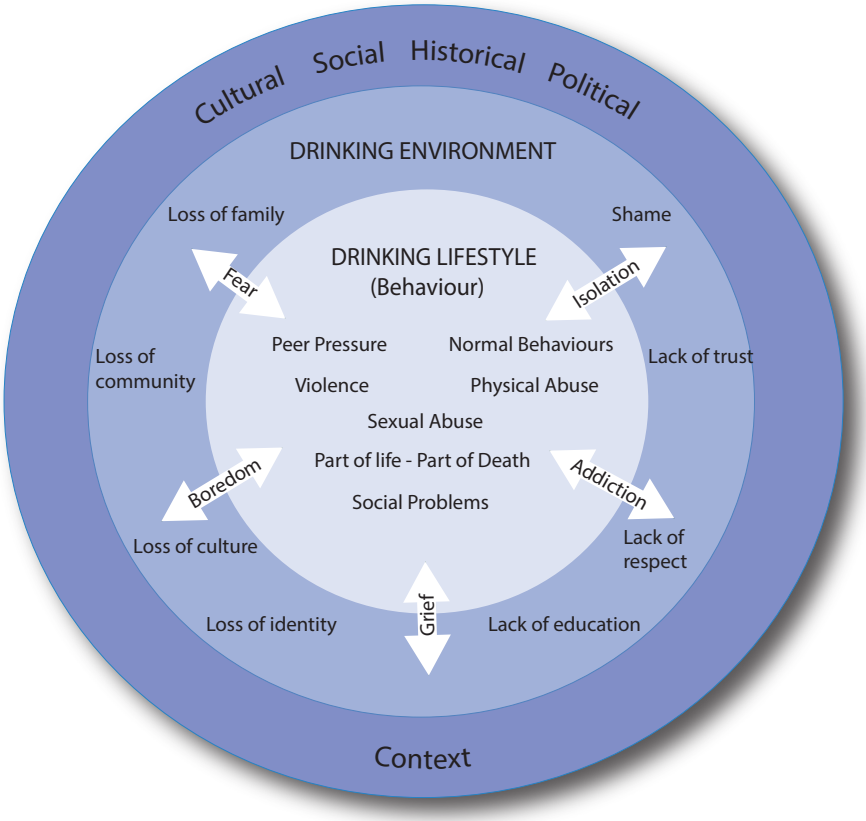
According to Erickson (1998), when an individual is placed in a position where they may begin to reflect back on their lives and are possibly facing the prospects of death, they then come to terms with the meaningfulness of life through overcoming their potential despair.

The older person begins to think clearer and begins to recognise their own physical and emotional health needs, as they realise that life experiences have taught them that their kind of lifestyle is not sustainable. Hence, they become tired and cannot carry the burden of violence, and abuse, which they have endured for so long throughout their lives. Grandmothers don't involve themselves in a materialistic world—they measure their success and strength by being connected to the spiritual world, returning back to culture. Through this process they see the importance of grandchildren, who in turn trigger an awareness of responsibility and nurturing. They realise the children are the lens to the future.

Factors Influencing Community Drinking

Hayes has used this model to identify people that were describing a set of interconnecting factors that are described back to the life cycle model. A whole range of factors feed into the life cycle described previously creating a drinking cycle that leads to alcohol being an accepted way of life and death.[31]

Figure 20.1: Drinking Influences



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Hayes found in her discussions with community people that it was not possible to isolate a set of clinical disorders, such as FAS, from the impact of drinking generally. Nor was it possible to discuss the physical impact of drinking, without giving study participants an opportunity to contextualise drinking within the stories about their whole-of-life experiences. The model highlighted in Figure 20.1 encompasses an approach to drinking that is interactive, holistic and grounded in people's historical, cultural and economic circumstances.

BEST PRACTICE EXAMPLES OF ABORIGINAL RESPONSES TO FASD

Aboriginal people are concerned about the effects of prenatal alcohol exposure in their communities and, in some areas, they have taken measures to address this. The best practice examples below attempt to address many of the complexities described by Hayes that need to be considered in addressing FASD in the Aboriginal population. They include four examples of Aboriginal responses to FASD. The first describes the action taken by the Drug and Alcohol Office (DAO) in WA to develop strategies and resources for women in pregnancy.

Strong Spirit Strong Future

The DAO has developed resources in consultation with Aboriginal people from across WA called *Strong Spirit Strong Future*.[45] These resources use Aboriginal ways to reduce harm from alcohol and other drugs. These resources are only available through participation in a training workshop. The resources include:

1. A booklet 'Promoting Healthy Women and Pregnancies' with information for health professionals and the role of the mother;
2. A double-sided laminated sheet with information on AUDIT–C for healthy women; and
3. Story Telling Cards promoting healthy women and pregnancies.

Also see Chapter 26 (Casey) for further discussion of the concepts and resources underpinning the *Strong Spirit Strong Mind* model and the understanding of working with Aboriginal women in pregnancy from an Aboriginal perspective.

Ord Valley Aboriginal Health Service: 5-Point Plan

The Ord Valley Aboriginal Health Service (OVAHS), an Aboriginal community-controlled health organisation in the East Kimberley, is an example of a primary health care service that is actively addressing alcohol consumption in pregnancy. OVAHS has endeavoured to gain an understanding of the local drinking patterns and the perceived needs of the women and their families. They have implemented a 5-Point Plan which targets five groups to prevent prenatal alcohol exposure.[46] One of the target groups includes all antenatal clients attending OVAHS. Pregnant women are provided with education on FASD, alcohol and other drug assessment and, if needed, one-to-one counselling.[46] These interventions are also provided to the partner, other family members and the community.

A challenge for delivering the program has been the social acceptance of heavy alcohol use in both the Aboriginal and non-Aboriginal population. Evaluation of FASD education reported that over 95 per cent of women indicated that information provided to them and their families was very useful.[46]

Apunipima Cape York Health Council (ACYHC)

In 2002, due to successful community engagement and consultations with two Cape York communities, Kowanyama and Wujal Wujal, a pilot FASD program was delivered using a health literacy approach to provide education and raise the awareness of FASD in Cape York communities.

The aim of the project was to increase preventative health care measures related to excessive alcohol consumption; coordinate preventative health care development in line with Queensland Health's Chronic Disease Strategy; increase awareness of the adverse effects of alcohol misuse during pregnancy and postnatal care; identify barriers and investigate solutions; investigate means of providing 'safety' for those at risk; and complement mother and child care services.[47]

A health literacy model developed by Hayes sought to engage community groups in the development of health promotion materials—while at the same time increasing their literacy levels, problem solving and critical thinking skills—to facilitate and develop a sustainable health education ethic within the community.[47]

The transferring of knowledge and information about the dangers of drinking during pregnancy and the outcome of FASD provided the women, who participated in the groups, with improved literacy skills and raised their level of confidence to educate others in their community about the damage done to the unborn child.[47]

Fitzroy Valley Program – Marulu Strategy

The Fitzroy Valley is a remote area located in the Kimberley region of WA. The Marulu Strategy is an example of a community-driven initiative to address excessive alcohol consumption in their region. In 2007, members of the Aboriginal community were concerned about widespread alcohol use and the relationship to alcohol-related deaths, suicides and violence and crime.[48] They lobbied for alcohol restrictions and, in September 2007, the Director of Liquor Licensing released his decision on restricting the sales of packaged liquor in Fitzroy Crossing.[49] An evaluation of the restrictions demonstrated a reduction of sales of takeaway alcohol from September 2007 to September 2009—8,541 litres to 458 litres respectively at the Crossing Inn.[49] The social benefits that resulted from these restrictions included a reduction in the severity of domestic violence, reduced street drinking and families purchasing more food and clothing.[49]

In 2008, a Women's Bush Meeting identified the need to address FASD. As an outcome of this meeting, Marulu was developed as a strategy that includes diagnosis and prevention of FASD, community education and support for parents and carers of affected children. Marulu is a Bunuba word meaning 'precious, worth nurturing'.[48] Bunuba is one of the five language groups in the Fitzroy Valley. To progress Marulu, two key agencies in Fitzroy Crossing, Nindlingarri Cultural Health Services and Marninwarnitkura Women's Resource Centre, entered a partnership with the University of Sydney Medical School and The George Institute for Global Health.[48] As a result of the partnership, a population-based, active case ascertainment study of the prevalence of FASD is being implemented in the Fitzroy Valley.[50] This study is being conducted in response to the local community initiative and from extensive community consultation. This will be the first study to ascertain FASD prevalence in Australia using a rigorous research design.[50]

CONCLUSION

The prevention of FASD would make an important contribution to improvements in the mental health of children that includes: intellectual disability, cognitive impairment, learning difficulties, speech and language delay, behavioural and emotional problems. This requires supporting women to not consume alcohol during pregnancy. It also requires early detection of FASD to prevent secondary disabilities such as mental health problems and chronic diseases. Steps have been taken in Australia to prevent and address FASD. These are challenging issues that several countries, including Australia, are addressing.

However, understanding issues such as FASD in Aboriginal communities can only result from listening to the Aboriginal perception of health and illness and begin from the beginning as identified by Aboriginal people themselves. Aboriginal people insist that the problem of alcohol in the communities must be viewed from the perspective of a range of social, cultural and historical factors that bridge generations and shape whole lives. Hayes has developed a life cycle model to understand the complexities of alcohol consumption during pregnancy in Aboriginal communities to inform and underpin interventions.

REFLECTIVE EXERCISES

1. Refer back to Story 1 and consider the various factors that may contribute to the developing fetus if a woman drinks alcohol during pregnancy. How does alcohol consumption during pregnancy contribute to small head circumference? What resources could you use as a health practitioner to help you provide a brief intervention? What else could you do?
2. Refer back to Story 4 and consider, as part of a team, what prevention programs you would put into action to prevent risky behaviours in children and youth.
3. What is Fetal Alcohol Spectrum Disorder? Is there a difference between Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder?
4. Consider the ways that your role as a member of an interdisciplinary/multidisciplinary team may contribute to the assessment and management of an Aboriginal child diagnosed with Fetal Alcohol Syndrome.
5. Describe from a perspective of your role, what you would do to ensure that you listen to, and respond to, Aboriginal perceptions of health and social and emotional wellbeing.
    - what do you see as barriers for your role?
    - what do you see as the strengths you could offer in your role?
    - what steps would you implement with the women in the community in your role?

RESOURCES

No Alcohol in Pregnancy is the Safest Choice

For people residing in WA, orders for these resources can be placed through the online order system and they will be supplied at no cost. These resources can be viewed on: http://alcoholpregnancy.childhealthresearch.org.au/alcohol-and-pregnancy-resources.aspx

Strong Spirit Strong Future

The Drug and Alcohol Office (DAO) have developed resources in consultation with Aboriginal people from across WA, called *Strong Spirit Strong Future*.[46] Information on these resources can be found on the Drug and Alcohol Office web site: www.dao.health.wa.gov.au

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