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Closing the gap clearinghouse

Fetal alcohol spectrum disorders: a review of interventions for prevention and management in Indigenous communities

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Summary

What we know

- Fetal alcohol spectrum disorders (FASD) is an umbrella term for the range of physical, cognitive, behavioural and neurodevelopmental abnormalities that result from the exposure of a fetus to maternal alcohol consumption during pregnancy.
- FASD is entirely preventable if alcohol is not consumed during pregnancy.
- The range and severity of FASD-related conditions differ from one person to the next, and the symptoms are apparent to varying degrees throughout life. This makes diagnosis difficult—symptoms can manifest in a variety of ways, and it might not be apparent that a person has FASD.
- Fetal alcohol syndrome (FAS), which represents the severe end of spectrum, is more amenable to diagnosis because it is based on the following specific criteria:
  - growth retardation
  - characteristic facial features (small eye slits, thin upper lip and diminished groove between nose and upper lip)
  - central nervous system anomalies (including abnormal structure and function, such as intellectual impairment).
- Although there are no national data on the prevalence of FASD in Australia, it is known to occur in both the Indigenous and non-Indigenous populations. Studies have found higher rates among Indigenous Australians than non-Indigenous Australians.

What works

- A review of 22 programs in the United States found that pre-natal health screening of all women to identify those who have alcohol-related issues, followed by brief, empathetic interventions by health professionals and motivational interviewing, was effective in causing women to reduce or stop drinking alcohol during pregnancy.
- Strong Spirit Strong Future is a Western Australian Indigenous-specific education campaign to increase awareness of the recommendation of the National Health and Medical Research Council to abstain from drinking alcohol during pregnancy. It has been evaluated and found to be culturally appropriate, but the effects of the campaign on drinking behaviour have not yet been evaluated.
- There is evidence from United States and Canadian studies that the following programs can alleviate some of the effects of FASD:
  - The parenting program Families Moving Forward assisted families and reduced behavioural problems among children aged 3–13 with FASD.
  - Children's Friendship Training, neurocognitive habilitation therapy, and sustained attention training improved the skills of primary-school-aged children with FASD.
  - Stimulants and antipsychotic medications were effective in reducing hyperactivity among children with FASD.
- The following strategies have been shown to reduce alcohol-related harm in Australian Indigenous communities. These strategies have the potential to reduce FASD rates by decreasing overall drinking levels, including the number of women drinking alcohol during pregnancy, and how much they drink:
  - supply-reduction strategies such as increasing the price of alcohol, restricting trading hours, decreasing the number of outlets selling alcohol, dry community declarations, and culturally sensitive enforcement of existing laws
  - demand-reduction strategies such as early intervention, providing alternative activities to drinking alcohol, and providing treatment and ongoing care to reduce relapse rates
  - harm-reduction strategies such as community patrols and sobering-up shelters.

What doesn't work

- Targeting or shaming women for drinking alcohol while they are pregnant is not effective in causing them to reduce their alcohol intake.

What we don't know

- The prevalence of FASD in the total Australian and Indigenous populations.
- Whether the Western Australian education campaign Strong Spirit Strong Future is changing the attitudes of Indigenous communities, pregnant women and their partners to alcohol use during pregnancy and their drinking behaviours.
- Whether the United States-based parenting program Families Moving Forward would be effective in assisting families and reducing behavioural problems among Australian Indigenous children with FASD.
- Whether training programs such as Children's Friendship Training, neurocognitive habilitation therapy and sustained attention training would be effective in assisting Australian Indigenous children with FASD.
- Whether stimulants or antipsychotic medications are effective in addressing the behavioural problems experienced by Australian Indigenous children with FASD.

Introduction

This resource sheet defines FASD and provides currently available estimates of their prevalence in the overall Australian population and in the Indigenous population. The current recommendation of the National Health and Medical Research Council (NHMRC) on the consumption of alcohol during pregnancy is also provided. Where appropriate, comparisons are made with other countries.

The resource sheet reviews the Australian and international literature published since 1990 on the effectiveness of programs that aim to prevent FASD or to alleviate its effects. Evidence on the effectiveness of Australian and Indigenous specific programs is also assessed, including those programs that have been developed and implemented in partnership with Indigenous Australians.

Background

Alcohol can readily pass through the placenta and enter the blood stream of the fetus, where it can adversely affect its development (Hepper 2014). FASD is an umbrella term for the range of physical, cognitive, behavioural and neurodevelopmental disabilities that result from exposure of the fetus to alcohol. FASD can include: abnormalities in the formation of the face, intellectual and learning disabilities, deficits in executive functioning, memory problems, speech and language delays, inattention, hyperactivity, internalising and externalising behavioural problems, and social impairments (The Parliament of the Commonwealth of Australia 2012).

The range and severity of FASD symptoms differ from one person to the next, and the symptoms remain apparent to varying degrees throughout life. Intellectual impairment is commonly associated with FASD, but some children with FASD have average or even above-average intelligence (Streissguth et al. 2004). Although babies who are more severely affected could be diagnosed in infancy, it is also common for developmental and learning delays and behavioural problems to be referred and diagnosed only once children are at school. Delays in diagnosis can mean that crucial opportunities for actions that might reduce the effects of FASD can be lost.

NHMRC guidelines on reducing the health risks associated with alcohol recommend that not drinking alcohol during pregnancy is the safest option. Nevertheless, the risk of harm to the fetus is likely to be low if a woman has consumed only a small amount of alcohol before she knew she was pregnant or during her pregnancy (NHMRC 2009). Regular heavy drinking (4 or more standard drinks in one sitting at least once weekly) or binge drinking (more than 5 drinks in one sitting), particularly in the first trimester of pregnancy, is strongly associated with FASD-related characteristics (Elliott et al. 2008).

Although a higher proportion of Indigenous than non-Indigenous women abstain from alcohol, a higher proportion of Indigenous women drink at high-risk levels. Just over 1 in 3 (35%) Indigenous females aged 18 and over reported that they had not consumed alcohol in the previous 12 months, compared with 20% of non-Indigenous females. On the other hand, 40% of Indigenous women reported that they had consumed alcohol at high-risk levels in the previous 12 months (compared with 31% of non-Indigenous women). Fourteen per cent of Indigenous women reported that they drank at high-risk levels at least once a week, compared with 5% of non-Indigenous women (AIHW 2013).

Prevalence of FASD

FASD is not a diagnostic term, rather it is an umbrella term for the following diagnosable conditions: FAS, partial Fetal Alcohol Syndrome, alcohol-related neuro-developmental disorder, and alcohol-related birth defects (The Parliament of the Commonwealth of Australia 2012).

A diagnosis of FAS (which represents the severe end of the spectrum) is based on the following criteria:

- growth retardation
- characteristic facial features, including small eye slits, thin upper lip and diminished groove between nose and upper lip
- central nervous system anomalies including abnormal structure and function, such as intellectual impairment (The Parliament of the Commonwealth of Australia 2012).

Early detection of FASD-related conditions in babies and young children is crucial to allow for early intervention to improve long-term outcomes. An Australian diagnostic instrument has been developed and will be clinically trialled in 2015 (Telethon Kids Institute 2014).

International researchers have used 3 main approaches to estimate the prevalence of FASD-related conditions:

- Record review: this involves researchers reviewing birth certificates, birth defects registers and medical records. Because the diagnosis of FASD-related conditions is complex and records are generally of variable quality and completeness, record reviews tend to underestimate the prevalence of FASD-related conditions (May et al. 2009).
- Clinic-based studies: these can be used to estimate the prevalence of FASD-related conditions for the treated population (that is, those who use these clinics), but they do not necessarily provide accurate population-based estimates for the broader population. Despite this limitation, rigorous research studies using comparison groups in prenatal clinics have included the examination of infants and young children. Clinic-based studies tend to underestimate the prevalence of FASD-related conditions because only the most severe cases are diagnosable throughout the infancy period to about 3 years of age (May et al. 2009).
- Active-case ascertainment: this involves systematically searching for children with FASD in select populations and providing clinical diagnoses for those with FASD-related conditions. Active-case ascertainment often includes an in-school component. Although the same diagnostic criteria are used in active-case ascertainment as in clinic-based studies, some children with FASD do not attend clinics, and others are not seen by clinic staff at an age at which a diagnosis of an FASD-related condition can be made. Active-case ascertainment tends to provide higher prevalence rates of FASD-related conditions than record reviews or clinic-based studies (May et al. 2009).

May et al. (2009) compared the prevalence estimates for FASD-related conditions obtained using the 3 approaches outlined above and concluded that active-case ascertainment yields the most accurate prevalence estimates.

Based on the results from active-case ascertainment studies in the United States, the prevalence of FAS in typically mixed racial and socio-economic populations has been estimated to be between 2 and 7 cases per 1,000 live births (0.2% to 0.7%). The prevalence of the disorders associated with FASD among younger school-aged children has been estimated to be up to 2% in the United States, and up to 5% in Italy (May et al. 2009).

Australian estimates

Australian estimates of the prevalence of FAS have been based on analyses of data held in birth defects registers and reviews of case notes and clinic records. These studies are likely to underestimate the true prevalence of FAS. The Lililwan Project: Prevalence of Fetal Alcohol Spectrum Disorders in the Fitzroy Valley (Western Australia) is an active-case ascertainment study of all Fitzroy Valley children born in 2002 and 2003; a key component of that study is to more accurately estimate the prevalence of FASD. The results of this study are not yet available.

A summary of the findings of Australian studies on the prevalence of FASD-related conditions is provided below:

- The Western Australian Birth Defects Registry was analysed for data relating to births between 1980 and 1997. The study estimated FAS prevalence to be 0.02 per 1,000 births for non-Indigenous children and 2.76 per 1,000 for Indigenous children (Bower et al. 2000). In contrast, the Victorian Births Defects Register recorded just 3 cases (all non-Indigenous) of FAS for births from 1983 to 1998 (Pyett et al. 2008).
- In a 10-year retrospective study in the Northern Territory, all case notes were reviewed for FAS. All 43 of the identified or possible FAS cases were found to be for Indigenous Australians. This gives a rate of between 1.87 per 1,000 births for identified FAS, and 4.7 cases per 1,000 live births for possible FAS (Harris & Bucens 2003).
- The Paediatric Outreach Service of a major hospital in Far North Queensland analysed the records of 3,562 children seen by the service from June 2001 to February 2006. The average age of the children was 7.6 years, with an age range of 0–18 years. More than 2 in 5 (44%) of the children were from Aboriginal communities, 18% from Torres Strait Islander communities, and 38% from non-Indigenous predominant communities (such as regional towns). The data were used to estimate the prevalence of a number of diseases, including FASD. The prevalence of FASD-related conditions among the children from Aboriginal communities was found to be 15 per 1,000 children and 2 per 1,000 for children from Torres Strait Islander communities (Rothstein et al. 2007). The proportion of non-Indigenous children that the Paediatric Outreach Service diagnosed with FASD was similar to that of Torres Strait Islander children overall (less than 1%), but the non-Indigenous prevalence rate was not reported.
- Using data held by the Australian Paediatric Surveillance Unit, 1,154 practising Australian paediatricians were contacted and asked to report monthly on any cases of FAS they had diagnosed in a child aged under 15 between January 2001 and December 2004. Almost all (96%) requests for information were answered (55,392 replies were received). There were 92 confirmed cases of FAS identified nationally, of these, 65% were for Indigenous children (Elliott et al. 2008).

In summary, there are no national estimates of the prevalence of FASD-related conditions in Australia, but studies have found higher rates among Indigenous Australians than non-Indigenous Australians. Active-case ascertainment is considered to provide the most accurate prevalence estimates, but it is time intensive. The results of an active-case ascertainment study in the Fitzroy Valley of Western Australia are not yet available.

The effects of FASD

There is not a lot of information or data about the effects of FASD-related conditions in Australia. A United States study of people with FAS (the more extreme end of FASD) aged 6–51 reported the following:

- nearly two-thirds (60%) of those aged 12 and over had experienced disrupted schooling
- nearly all (90%) had mental health problems
- about one-third of those aged 12 and over (30%) had alcohol and other drug use issues
- half of those aged 12 and over exhibited inappropriate sexual behaviour (Streissguth et al. 2004).

An Australian study of 4,714 children born to non-Indigenous mothers in Western Australia between 1995 and 1997 successfully linked the birth and educational records of 80% of these children at ages 8–9. The study found that children were twice as likely not to achieve the benchmark for either (a) reading after heavy prenatal alcohol exposure during the first trimester, or (b) writing after prenatal exposure to occasional binge drinking in late pregnancy. Low-to-moderate prenatal alcohol exposure was not found to be associated with academic underachievement (O'Leary et al. 2013).

The cost of FASD

The lifetime cost of care for a person with FAS in 2002 in the United States has been estimated to be $2 million, resulting in a total annual cost for FAS in the United States of more than $4 billion (Lupton et al. 2004). Estimates are not available for the costs associated with the other FASD-related conditions (partial FAS, alcohol-related neuro-developmental disorder, and alcohol-related birth defects).

Given the uncertainty of prevalence estimates for FASD in Australia, and the lack of data on the level of services required to care for a person with FASD, comparable costs are not available for Australia (Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders 2009).

Government policies

The National Drug Strategy 2010–2015 provides the current policy framework for action on alcohol and other drugs. The Strategy takes a harm minimisation approach and specifies objectives under 3 pillars: demand, supply, and harm reduction. Under the harm-reduction pillar, the Strategy recommends that consideration be given to the introduction of pregnancy health warnings on alcohol products as well as the development of 'co-ordinated measures to prevent, diagnose and manage foetal alcohol spectrum disorders and make available appropriate supports to affected children and families' (MCDS 2011:29). An evaluation of a 2-year voluntary labelling initiative to place pregnancy health warnings on alcohol products found that just over one-third (38.2%) of all alcohol products had a pregnancy health warning, with less than a quarter (23.1%) of ready-to-drink products being labelled (Siggins Miller 2014). At the June 2014 meeting of the Legislative and Governance Forum on Food Regulation, Ministers agreed to continue the voluntary labelling scheme and to review it again after 2 years (Legislative and Governance Forum on Food Regulation 2014).

The Strategy committed to the development of a National Aboriginal and Torres Strait Islander Peoples Drug Strategy in recognition of the unique needs of Indigenous people who are affected directly or indirectly by harmful alcohol and other drug use (MCDS 2011). It is currently being finalised.

The National Drug Strategy is supported by the Commonwealth Action Plan: Responding to the Impact of Fetal Alcohol Spectrum Disorders in Australia. The Plan details actions aimed at reducing the prevalence of FASD and improving outcomes for FASD-affected children. It provides ongoing support for a number of programs in Indigenous communities (DoH 2014).

A number of states and territories have programs in place to address FASD. For example, the Western Australian Government has developed a model of care for FASD that prioritises prevention strategies that are embedded in a broader alcohol harm reduction framework. The model of care recommends the universal screening of women of child-bearing age for alcohol use and the provision of information to them about the risk of FASD (Department of Health 2010). A detailed implementation plan for the model of care has been developed and is currently being implemented (Department of Health 2013).

Review of Australian and international programs

Comprehensive international reviews of interventions targeting FASD consistently found fewer than 20 interventions that have been rigorously evaluated and hence can provide a reliable evidence base for the management of FASD (Chandrasena et al. 2009; Davis et al. 2011; Gray et al. 2000; Gray & Wilkes 2010; Henderson et al. 2007a, 2007b; May et al. 2009; Paley & O'Connor 2009; Peadon et al. 2009; Pyett et al. 2007). This resource sheet draws heavily on the findings of these reviews.

In 2012, the Australian Parliament held an inquiry into FASD. It concluded that, although awareness of FASD in Australia is increasing, further work to prevent, identify and manage FASD still needs to be done. The inquiry made recommendations for educating the community, health professionals, parents and carers, teachers, youth workers, police, court officials, and prison officers. It also recommended mandating health warnings on alcoholic beverages (The Parliament of the Commonwealth of Australia 2012).

Prevention programs

Australian studies

The Closing the Gap Clearinghouse resource sheet *Reducing alcohol and other drug related harm* (Gray & Wilkes 2010) identifies the following 3 broad types of interventions as being effective in reducing alcohol-related harm:

- supply-reduction strategies such as increasing the price of alcohol, restricting trading hours, decreasing the number of outlets selling alcohol, dry-community declarations, and culturally sensitive enforcement of existing laws
- demand-reduction strategies such as early intervention, providing alternative activities to drinking alcohol, treatment, and ongoing care to reduce relapse rates
- harm-reduction strategies such as community patrols and sobering-up shelters.

The above strategies have been shown to reduce alcohol-related harm in Indigenous communities, such as alcohol-related hospitalisations, and therefore they are expected to help in reducing FASD by decreasing overall drinking levels in the population (and therefore decreasing the risk of women drinking alcohol during pregnancy). They have not been specifically evaluated in relation to their effect on FASD.

Heavy drinkers have been known to avoid health professionals or others who could relay unwelcome messages about the effects of heavy drinking on their babies. A fear of interference from government, such as the removal of children, has also been reported. Identifying women who have given birth to a child with FASD previously can also be difficult because of under-diagnosis and late diagnosis of FASD-related conditions (Pyett et al. 2008).

Pregnant women are more likely to resist help if the intervention causes them to feel targeted, so it is important to build empathy with them. Routine use of screening questionnaires in clinical practices might be effective at identifying at-risk women without stigmatising them (Pyett et al. 2008).

Strong Spirit Strong Future, a key component of the Western Australian FASD model of care implementation plan, is an Indigenous-specific education campaign that started in 2010. It aims to increase awareness of the NHMRC guidelines about drinking alcohol during pregnancy. The Telethon Kids Institute has evaluated the processes within the campaign and found that they are culturally secure, competent and well managed (Drug and Alcohol Office 2014). The effects of the campaign on drinking behaviour has not been evaluated.

Phase 3 of the Lililwan Project: Prevalence of Fetal Alcohol Spectrum Disorders in Fitzroy Valley (Western Australia) is investigating the effect of alcohol restrictions that were introduced in 2007 on FASD prevalence (Elliott et al. 2012a, 2012b; Fitzpatrick et al. 2012). The project has estimated the baseline prevalence of FASD among children born in 2002 and 2003 and is using these data to examine the relationship between prenatal alcohol exposure and FASD characteristics, and to inform the drafting of health, education and family support plans for children with FASD (Fitzpatrick et al. 2012).

Because Australian diagnostic guidelines for FASD had not been developed when the Lililwan project started, Canadian guidelines with some normative race-based standards for facial characteristics for FASD taken from African-American standards were used. A diagnostic questionnaire that took into account local culture and languages was developed for interviews with parents and carers. The questionnaire is being used to determine the demographics, antenatal exposures, birth outcomes, education and psychosocial status of more than 100 children, with the Fitzroy Valley communities participating directly in its design and implementation (Fitzpatrick et al. 2012). Results from the study are yet to be published.

The Healthy Pregnancies, Healthy Babies for Koori Communities project in Victoria was also initiated out of concern about FASD in Indigenous communities. This project developed training resources such as a flipchart for Indigenous health workers, and was delivered through 6 workshops to Indigenous-controlled community health

services. The training resources emphasised not only the need to drink less alcohol, but also to eat healthier food, and to smoke less. The messages were delivered in a holistic and culturally appropriate framework (Pyett et al. 2007). This project has not been evaluated.

International studies

Handmaker and Wilbourne (2001) evaluated 22 interventions based in pre-natal clinics in the United States. They found that prenatal health screening of all women to identify those who have alcohol-related issues, followed by brief, empathetic interventions by health professionals and motivational interviewing, when implemented using a stepped-care approach, is effective in causing women to reduce or stop drinking alcohol during pregnancy.

Stepped care involves the following:

- an initial screening at a prenatal clinic
- for those women who report drinking during pregnancy or having alcohol-related problems in the past year, a more thorough assessment interview conducted in an empathetic style, combined with advice
- for high-risk drinkers, a motivational intervention by a health care professional, during which a plan for change is negotiated (Handmaker & Wilbourne 2001).

Calabria et al. (2012) conducted a systematic review of family-based interventions that had the potential to reduce alcohol-related harm in Indigenous communities. They found 142 intervention studies, of which 19 were family-based, but none was Australian. The studies were from the United States (11); the United Kingdom (3); Sweden and Holland (3); Mexico (1); and India (1). Of these, only 1 United States study targeted an Indigenous community, but the authors of the review considered it to be methodologically weak. They found less-than-optimal evidence for the effectiveness of family-based interventions.

Programs aimed at alleviating the effects of FASD

A range of strategies has been implemented in other countries to assist children and young people affected by FASD, but the evidence base is limited (Chandrasena et al. 2009). The more promising strategies are outlined below. There were no evaluations found of Australian programs aimed at alleviating the effects of FASD.

Programs to assist children with FASD

Parenting program

Families Moving Forward (FMF) is a positive parenting program developed by researchers at Washington State University to help families raising children aged 3–13 who have FASD (FMF 2014).

An evaluation of FMF was based on a sample of 52 children with FASD and their families. The children (aged 5–11) had challenging behaviours. Half of the children were randomly assigned to the FMF program and the other half (the control group) received the community standard of care available in Washington State. Each family in the FMF group received 16 fortnightly sessions with mental health staff. These were conducted over 9 to 11 months. They also received medication, consulted a psychologist or occupational therapist, and received other community services as required (Bertrand 2009).

The evaluation found that caregivers in the FMF group showed significant improvement in their sense of parenting efficacy, with more perceiving that their family needs were met, compared to caregivers in the control group. Caregivers in the FMF group also reported significantly fewer child behavioural problems (Bertrand 2009).

Training programs

Children's Friendship Training (CFT) is a parent-assisted social skills program for primary school-aged children. It was developed at the University of California, Los Angeles (UCLA 2014). The efficacy of CFT was assessed for 100 children aged 6–12 with FASD. There were 51 children and their families randomly allocated to the CFT group, and trained over a 12-week period. Their social skills were assessed at baseline, after completion of the training, and after a further 3 months. The remaining 49 children and their families constituted the control group, and they received training after the CFT group. The children in the control group were assessed at baseline, after the children in the treatment group had finished their training, and after they had completed training (O'Connor et al. 2006).

Children in the CFT group increased their knowledge of appropriate social behaviours, and according to parent reports, they improved their social skills and had fewer problem behaviours than those in the control group. These improvements were maintained at the 3-month follow-up. After receiving the training, the control group showed similar improvements to the CFT group. Interestingly teachers did not report improvements in social skills in the classroom after training. The reason for this difference between parent and teacher assessments was thought to be because teachers may focus less on children's social skills than on their behaviour in the classroom. Because CFT is not designed to address behaviours related to successful classroom functioning, teachers might not have observed the improvements that were identified by parents (O'Connor et al. 2006).

A randomised controlled trial of neurocognitive habilitation therapy for children with FASD and their foster and adoptive caregivers found that the program significantly improved the executive functioning and problem-solving skills of children in the treatment group. Although the trial was relatively small, with 40 children in the treatment group and 38 in the control group, it indicates that neurocognitive habilitation is a promising intervention for children with FASD who are in foster care (Wells et al. 2012).

A randomised controlled trial of sustained attention training involving 20 Canadian Inuit children aged 6–12 with FASD found that the training significantly improved the children's non-verbal reasoning ability. Each of the children received 12 half-hour daily sessions: 10 of the children (the treatment group) were provided with sustained attention training, and the other 10 children (the control group) did art activities and games (Vernescu 2007). Although this trial was a pilot, it indicates that sustained attention training could be an effective intervention for Indigenous children with FASD.

In a United States study, Kable et al. (2007) evaluated a program to improve behaviour and maths functioning for 61 children aged 3–10 with FASD. The intervention group of 28 children received 6 individualised mathematics instruction sessions and an assessment and educational plan that had also been given to a control group of 26 children. The carers and parents of children in the intervention group were also trained to help their children acquire maths skills. The behaviour of both groups was assessed at the beginning and end of the program, and both demonstrated improvements. At the end of the program, the intervention group was found to have significantly higher mathematics scores than the control group. These mathematical skills were maintained at a follow-up session 6 months after the program finished (Coles et al. 2009).

Medication

Drug treatment for school-aged children with FASD has focused on the potential of drugs that are also used for attention deficit hyperactivity disorder (ADHD), given some of the behavioural symptoms these conditions share. Generally, these studies find improvements in hyperactivity but not in their inattention. Their sample sizes were often very small, and these studies have been criticised for a lack of information about their randomisation processes and potential for selection bias (Chandrasena et al. 2009).

In a pilot study conducted at a Native American residential school, the short-term effectiveness and side effects of the stimulant methylphenidate (trade names Concerta, Methylin, Ritalin, Equasym XL) was investigated in relation to 4 children aged 5–12 with FASD. The children were given methylphenidate, a lactose placebo, or a vitamin C placebo for 5 weekdays during 3 successive weeks. The trial was double blinded so neither the researchers, teachers, nurses, the children or their parents knew who was taking the active agent and who was

taking the placebos. To minimise carryover effects, the children received no medications during weekends. Methylphenidate was found to significantly reduce hyperactivity and impulsivity compared to the placebo controls, but did not improve inattention scores. Some children receiving methylphenidate experienced decreased appetite, mild stomach aches, and headaches (Oesterheld et al. 1998).

Snyder et al. (1997) tested stimulant medication (methylphenidate, pemoline or Dexedrine) against a placebo on 12 Canadian children aged 6–16 with FASD and ADHD. The children were randomly allocated to either treatment. Again, those children who received stimulants showed significant improvements in relation to their hyperactivity but not their inattention.

Doig et al. (2008) investigated the effects of medication on symptoms of ADHD among children with FASD. The medication trials did not use control groups and involved 27 Canadian children with FASD and ADHD. The trials used stimulants or combinations of psycho-stimulants together with other medications and showed significant improvements on standard rating tests for ADHD, although more so for hyperactivity and defiance than for inattention. The authors recommended a larger, placebo-controlled trial to confirm or refute their findings.

Frankel et al. (2006) combined medications with Children's Friendship Training (CFT), an approach that was discussed earlier in this paper. Twelve sessions of 90 minutes' length were given over a period of 12 weeks to 77 children aged 6–11 with FASD, with parents also given training about FASD and social skills. The children were divided into 4 treatment groups and given either (1) anti-psychotic medication, (2) stimulant medication, (3) both types of medication, or (4) no medication. Children who were given antipsychotic medication (either by itself or in combination with stimulant medication) showed significantly greater improvements in self control, behaviour, and assertion than those who were not given antipsychotic medication.

Nutritional supplements

There is evidence from animal trials that supplementing the diet with antioxidants during pregnancy can reduce the severity of many FASD characteristics. The antioxidants investigated included flavonoids, vitamins C and E, folic acid and betacarotine (Cohen-Kerem & Koren 2003). The use of choline as a nutritional supplement prenatally and shortly after birth in animal trials has resulted in improved cognition and memory (Chandrasena et al. 2009). These programs have not yet proceeded to human trials.

Programs to assist young people and adults with FASD

A high proportion of young people and adults with FASD come into contact with the criminal justice system. Memory difficulties, inability to plan, and failure to recognise the consequences of their actions mean that fines might not be paid and probation orders and good behaviour bonds breached (The Parliament of the Commonwealth of Australia 2012). Many of those charged are neither diagnosed nor diverted into treatment. Without a formal medical diagnosis of FASD, it is difficult for magistrates to use impaired functioning as a mitigating factor in sentencing.

The Supreme Court of Western Australia has included FASD in its *Equality Before the Law Bench Book*, which provides legal practitioners with information on identifying disadvantages that need to be addressed to ensure equal treatment for those with FASD (The Parliament of the Commonwealth of Australia 2012).

For young people and adults with FASD, the priority for support services has been to address secondary disabilities and reduce the risks that these adults could be exposed to. Grant et al. (2004) trialled a 12-month program in the United States for 19 women (with an average age of 22), who were suspected of having FASD and co-morbid substance abuse. Each participant was assigned a case manager who was trained in FASD interventions. The case manager supported the participant to access inpatient and outpatient treatment, establish a network of service providers, and secure stable housing. Participants were assessed during intake and after the 12-month program. At the end of the program, 84% (16 women) were living in stable housing compared

to 47% (9 women) at the start of the program. Fourteen of the women sustained long periods of not using drugs or alcohol, compared to only 3 women prior to the intervention. Although the intervention did not use a control group, and there were relatively few participants, it does suggest that individualised management of adults with FASD can be effective.

Conclusion

FASD is an umbrella term for the physical, cognitive, behavioural and neurodevelopmental disabilities that result from exposure of the fetus to alcohol. It is entirely preventable if alcohol is not consumed during pregnancy.

The effects of FASD on individuals, families and communities can be severe. There are no national data on the prevalence of FASD or even its most severe manifestation (fetal alcohol syndrome) in Australia, but a number of smaller studies have found higher rates of FASD among the Indigenous population than the non-Indigenous population.

Early detection of FASD-related conditions in babies and young children is crucial to allow for early intervention to improve long-term outcomes. An Australian diagnostic instrument for FASD has been developed and will be clinically trialed in 2015 and then disseminated across Australia (Telethon Kids Institute 2014).

A review of 22 programs in the United States found that pre-natal health screening of all women to identify those who have alcohol-related issues, followed by brief, empathetic interventions by health professionals and motivational interviewing was effective in causing women to reduce or stop drinking alcohol during pregnancy. Research in the United States and Canada found that the following are effective in alleviating some of the effects of FASD: the parenting program Families Moving Forward; training programs including neurocognitive habilitation therapy, sustained attention training and Children's Friendship Training; and medication.

Strong Spirit Strong Future, a Western Australian Indigenous-specific education campaign to increase awareness of the recommendation of the NHMRC to abstain from drinking alcohol during pregnancy, has been found to be culturally appropriate. However, the impact of the campaign on attitudes towards drinking and drinking behaviour has not yet been evaluated. In Australia, programs and activities to address the effects of FASD have been implemented, but none has been evaluated. The Lililwan project in the Fitzroy Valley shows promise.

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Abbreviations

ADHD	attention deficit hyperactivity disorder
CFT	Children's Friendship Training

FAS	fetal alcohol syndrome
FASD	fetal alcohol spectrum disorders
FMF	Families Moving Forward
NHMRC	National Health and Medical Research Council

Terminology

Indigenous: Aboriginal and Torres Strait Islander and Indigenous are used interchangeably to refer to Australian Aboriginal and Torres Strait Islander people. The Closing the Gap Clearinghouse uses the term 'Indigenous Australians' to refer to Australia's first people. This term includes 'Aboriginal Australians' and 'Torres Strait Islander people'.

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