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Improving services to families affected by FASD

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We are sincerely indebted to the parents and carers that participated in this research. We remain in awe of their enduring efforts in caring and advocating for their children, often in the face of an uneducated and discriminatory system. For many it has become their life's endeavour and they have spoken to us with candour of the great joys their children have brought them, but also the strains and challenges they have endured with great dignity and persistence. This report is dedicated to them and their children.

Executive summary

Parenting any child is not easy and parenting a child with Fetal Alcohol Spectrum Disorder (FASD) is very much harder; women who give birth to children with FASD are not “bad mothers”. Higher Fetal Alcohol Syndrome (FAS) and FASD prevalence has been reported in groups where disadvantage is common and heavy alcohol use is the norm (May, Brooke et al. 2000; Urban, Cherisch et al. 2008). It is also known that women who have given birth to a child affected by FAS are at increased risk of subsequent affected pregnancies (Burd, Cotsonas-Hassler et al. 2003). In this context these women are likely to have an alcohol use disorder and for these women to be able to make changes to their alcohol consumption they need to have culturally and socially appropriate treatments accessible to them. Unfortunately, this area has been neglected; alcohol use disorders are chronic relapsing disorders and prevention will not occur without effective treatment.

Alcohol is a teratogen but definitive cut-offs with respect to harms have not yet been established. In this context of uncertainty, views on the use of alcohol in pregnancy are polarised and often contentious. Some stakeholders point to the need for clear universal messages that abstinence be the sole message delivered. Others argue that universal messages should focus on what is clearly known; that binge drinking and high level of alcohol consumption have been found to be significantly associated with a range of harms, and that we know less about the impact of minimal amounts of alcohol in pregnancy.

The current National Health and Medical Research Council’s *Australian Guidelines to Reduce Health Risks from Drinking Alcohol* state that for women who are pregnant or planning a pregnancy, not drinking is the safest option. Despite this, some women continue to drink and therefore women should have access to detailed information about how to reduce alcohol-related harms, be encouraged to avoid alcohol throughout their pregnancy, and if they choose to drink should be strongly encouraged to do so at minimal levels. For those women who are unable to stop or reduce their alcohol consumption (i.e. have an alcohol use disorder) supportive and effective treatment options are required through specialist services.

The key to reducing FASD must be multifaceted and occur through prevention, early intervention and tertiary approaches. Prevention efforts may encompass supply reduction through initiatives such as labelling and pricing; early intervention efforts through targeting at risk groups and tertiary efforts through access to appropriate and effective treatments.

The current study focuses on some of the ongoing consequences of alcohol exposure in utero. The health, education and social issues for the people exposed to alcohol in utero and the challenges they and their carers face were investigated. This is the first study to examine some of the issues around caring for children living with FASD in Australia. We examined information provided by carers of children/adults with FASD to determine the issues involved in raising these individuals and their recommendations on how best to optimise life outcomes for them. As would be expected, this group have strong views on a range of issues. In particular, they were united in their views that there is a need for greater awareness regarding FASD, the government should provide more support for the children in their care and the risks of alcohol use in pregnancy should be more effectively disseminated.

Recommended approach to prevention, treatment and management of FASD

Prevention

- Prevention strategies should be put in place to reduce alcohol-related harm at the population level.
- Consistent standardised messages should be given to women about the effects of alcohol use in pregnancy. This should take a “no blame” approach; both biological mothers and non-biological carers need to be supported.
- Women who misuse alcohol should be targeted using secondary and tertiary approaches.
- It should be recognised that alcohol use disorders are chronic relapsing disorders and biological mothers of children diagnosed with FASD are likely to require specialised support. Without the provision of effective and culturally appropriate treatment approaches for these women, prevention of FASD will be difficult.

FASD should be identified as a disability

- FASD was described by carers as an ‘invisible’ or ‘silent’ disability, with little recognition of the burden associated with the disorders.
- FASD should be classified and funded as a disability.
- Classification of FASD as a disability will increase awareness about the disorder in the general community and improve understanding and support for people affected.

‘This isn’t like any other disability in Australia. If it is a common disability, then there are services and support; if it is a rare disability, there is compassion and support; with FASD there are no services, no compassion and no support.’ Carer of adult living with FAS

Need for greater understanding and increased knowledge about the effects of FASD

- Carers proposed that there needs to be increased knowledge of FASD in the general community.
- Education of professionals with respect to FASD should be undertaken to increase knowledge and expertise in the health, education and justice systems.
- Carers noted that there are a lack of diagnostic services and health professionals with expertise in FASD.
- Carers of non-biological children should be provided, where possible, with adequate information about the biological mother’s alcohol use and potential effects on children in their care.
- All carers of children affected by FASD should be provided with information about the nature of the disorder and effective strategies on how to deal with the behaviour and health of these children.

Effective interventions for the management of FASD should be identified and disseminated

- There is a need for further work on effective interventions to improve the health and potential of people with FASD.
- Implement environmental accommodations in schools to meet the needs of students living with a FASD (eg. reduce classroom stimuli, increase one-to-one learning opportunities).
- Resources containing effective strategies need to be provided to parents and carers.

Carers should be supported

- Carers need support. FASD is a lifelong and often severe disability for which carers carry the burden (lovingly), in most cases without adequate support or assistance. Carers should be supported and assisted in the management of these individuals.
- Recognise and respect the expertise and experience of carers who can value add to the knowledge and skill base around FASD.
- Ensure placements of children in out of home care are supported and sustained.
- Alcohol is the problem, not the parent who drinks. Parents who use alcohol in pregnancy need support to reduce future fetal exposure.

*'We have to prevent it, absolutely 100 per cent we have to prevent it but we also have to accept that it happens and it's happened and there should be no shame and blame for anybody. What needs to happen is that those people who have acquired it **need to get the best support and assistance that they can.**' Carer of child living with FASD*

Areas for future research

- Implement and evaluate a pilot program of known effective interventions for families caring for children affected by FASD.
- Identify, pilot and evaluate interventions to reduce alcohol exposed pregnancies among women that have already had an affected child.

Introduction

Alcohol is widely used in Australia and is an integral part of the social and cultural aspects of Australian life. The majority of Australians consume alcohol at levels that pose a low risk to their health; however, substantial proportions of Australians have been recorded drinking at risky and high risk levels. Approximately one-third of adult women report drinking at least weekly and this pattern is most frequently reported by women of childbearing age. Eleven percent drink at risky levels for alcohol-related harm over a lifetime, 30 percent drink at risky level for risk of injury on a single occasion and 5 percent of women report drinking daily (AIHW 2011). A minority will experience problems such as alcohol misuse or dependence.

Although the majority of women abstain or reduce their alcohol intake following pregnancy awareness, a proportion will continue to drink during pregnancy, and some at high risk levels (O'Callaghan, O'Callaghan et al. 2003; Colvin, Payne et al. 2007; Powers, Loxton et al. 2010; Peadon, Payne et al. 2011). Given that approximately half of all pregnancies are reported to be unplanned (Naimi, Lipscomb et al. 2003), it is likely that some women inadvertently expose their unborn child to alcohol before they are aware they are pregnant.

Alcohol is a teratogen and alcohol use during pregnancy has been associated with a number of adverse pregnancy outcomes including miscarriage, premature birth, stillbirth and low birth weight (Olegard, Sabel et al. 1979; Burns, Mattick et al. 2006; O'Leary, Nassar et al. 2009; Patra, Bakker et al. 2011). Fetal Alcohol Spectrum Disorders (FASD) is the umbrella term for a range of abnormalities in the unborn child caused by alcohol exposure in utero. These include, at the more visible end of the spectrum, Fetal Alcohol Syndrome (FAS), as well as Alcohol Related Birth Defects (ARBD) and Alcohol Related Neurodevelopmental Disorders (ARND). A diagnosis of FAS relies on the occurrence of distinct facial characteristics in conjunction with impaired growth and structural or functional abnormalities of the central nervous system (Stratton, Howe et al. 1996). FAS is often regarded as a measure of the complete spectrum of adverse fetal outcomes known as FASDs however this obscures the more prevalent neurobehavioural conditions (Malbin 2004). The characteristic facial features of FAS can dissipate as the child ages (Streissguth 1997) and in the absence of physical indicators/markers there is a tendency to make invisible the majority of individuals living with FASDs (Chudley, Conry et al. 2005; Thomas, Warren et al. 2010).

Adverse effects from fetal alcohol exposure may persist over time and result in significant challenges throughout childhood and into adulthood. International prospective longitudinal studies have reported a range of adverse outcomes including disrupted education, social difficulties and persistent behavioural and mental health problems (Streissguth, Bookstein et al. 2004; Sayal 2007; Spohr, Willms et al. 2007; Sayal, Heron et al. 2009; O'Leary, Nassar et al. 2010; Robinson, Oddy et al. 2010). Individuals with FASD are at increased risk of problems into adulthood classified as 'secondary disabilities' including; increased risk of mental health disorders (anxiety and depression), educational and employment difficulties, increased risk of substance use disorders, increased risk of criminal justice involvement and incarceration and inappropriate sexual behaviour (Streissguth and O'Malley 1997; Clark, Lutke et al. 2004; Streissguth, Bookstein et al. 2004). Risk factors for secondary disabilities include disrupted family life and exposure to violence, while living with a stable caregiver is

a significant protective factor (Clark et al. 2004). Due to the secondary disabilities associated with FASD, caregivers often have extensive responsibilities over a long period of time.

There is limited information on how many children and adults are affected by a FASD in Australia. As previously noted, research is much clearer with respect to FAS. Although State and Territory-based studies have reported birth prevalence rates of FAS of between 0.01 and 0.68 per 1,000 live births (Bower, Silva et al. 2000; Harris and Bucens 2003; Allen, Riley et al. 2007; Bower, Rudy et al. 2007; Elliott, Payne et al. 2008; Van Essen, Gibson et al. 2008), the prevalence of the other disorders in the FASD spectrum has not been estimated in Australia. The available prevalence figures are likely to underestimate the true prevalence of FAS due to issues of data collection and the methods of ascertaining cases (Elliott et al. 2008). It is therefore not known how many families are caring for children or adults affected by FASD in Australia. In addition, there is very little information available regarding the issues involved in caring for individuals affected by FASD in Australia.

There is evidence to suggest that parents and other caregivers of children with emotional and behavioural problems experience a variety of stressors, including; financial, disruption of family relationships and social life, interruptions at work, limits on personal time, fatigue, sadness, guilt, parenting stress and guilt, as a result of their care giving responsibilities (Brannan and Heflinger 1997; Yatchmenoff, Koren et al. 1998; Hauser-Cram, Warfield et al. 2001; Early, Gregoire et al. 2002). A recent Canadian study of caregivers of youth aged 13-19 with FASD reported higher levels of strain than found in clinical samples (Periera 2010). There is some evidence to suggest that those under more strain use more services (Brannan and Heflinger 2006) and this impacts on planning and policies for service provision.

This project aimed to provide information on ways to improve services to families affected by FASD. This was achieved by conducting interviews with parents and carers of children affected by FASD on their experiences in raising children with FASD, the services they have used, and their recommendations for methods to improve service delivery to themselves and their children.

Methods

The project received ethics approval through the UNSW Human Research Ethics Committee (HREC Ref 11314).

Potential participants were recruited through contact lists of the National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) and the Russell Family Fetal Alcohol Disorders Association (RFFADA) via email. Both these organisations include individuals and organisations that care for children, or who provide services to children affected by FASD (eg. foster care organisations and disability services). Potential participants received an information sheet with the researcher's contact details. People interested in participating contacted the researcher for more information or to schedule an interview time. Verbal consent was obtained and all interviews were conducted over the telephone by a trained researcher. Interviews were recorded and transcribed. With their permission, participants were put in a draw to win an iPad.

The interview schedule was semi-structured. It included: demographic information; questions on the carer's family situation; information on the pregnancy of the child in their care; information on the child's diagnoses; health issues for the child and the carer; the services used; and experiences with health, education and criminal justice systems. The interview also included standardised questionnaires; The Kessler 10 (K10) (Kessler, Andrews et al. 2002), The Personal Behaviors Checklist (PBCL) (Streissguth, Bookstein et al. 1998), The Caregivers Strain Questionnaire (CGSQ), and the Multidimensional Scale of Perceived Social Support. The latter three questionnaires were also used in a small exploratory Canadian study of caregivers of youth affected by FASD (Periera 2010).

The Personal Behaviors Checklist (PBCL-36) (also known as the Fetal Alcohol Behaviors Scale or FABS) is a 36 item checklist that was developed to describe the behavioural nature of an individual with FAS. Clinically, individuals identified with FASD share a similar behavioural profile. The scale has adequate test-retest reliability and is uncorrelated with age, sex, race IQ and alcohol-related diagnosis (Streissguth et al. 1998). It was designed to be self-completed by the caregiver of the child. In this study the researcher administered the 36 item instrument to the caregiver over the phone as part of the interview.

The Kessler Psychological Distress Scale (K10) was used to measure psychological distress of the carer in the previous four weeks. The K10 is a 10-item self-report measure designed to screen for clinically significant psychological distress in general population samples (Kessler et al. 2002). It has been widely used in Australia and elsewhere and has established reliability and validity across diverse settings (Slade, Grove et al. 2011).

The Caregivers Strain Questionnaire (CGSQ), a 21 item self-report instrument, was used to assess caregiver strain (Brannan and Heflinger 1997) as there is evidence to suggest that parents and other caregivers of children with emotional and behavioural problems experience a variety of strains as a result of their caregiving responsibilities. The CGSQ has been used widely in clinical and research settings to measure the objective strain and subjective strain of caregivers of children with learning difficulties, behavioural and emotional problems (Kenny and McGilloway 2007; Schoeder and Remer 2007). The CGSQ has demonstrated internal (Brannan and Heflinger 2006) and external validity (Brannan and Heflinger 1997).

A recent Canadian study that examined strain among caregivers of youth affected by FASD (Periera 2010) reported higher levels of global strain (i.e. the overall strain of caring as determined by the three subscales described below) when compared to other clinical samples including carers of youth with learning disabilities (Kenny and McGilloway 2007), serious emotional and behavioural (Taylor-Richardson, Heflinger et al. 2006), and mental health (Brannan and Heflinger 2006) problems. The carers of youth with FASD also scored higher on each of the three subscales (Periera 2010). The subscales include; objective strain (OS), subjective externalised strain (SES) and subjective internalised strain (SIS). The objective strain subscale includes events that are the direct result of caregiving (e.g. interruption of work, personal time or financial strain). The subjective scales incorporate the emotional or psychological strain of caregiving and can be externalised, i.e. outwardly expressed for example as resentment or anger, and internalised i.e. inwardly expressed for example worry or guilt.

Social support has been shown to decrease the burden on carers. The Multidimensional Scale of Perceived Social Support, a 12 item questionnaire was used to measure the carer's perceived social support (Zimet, Dahlem et al. 1988). A global score and three subscales reflecting the source of support, i.e. family, friends, and significant other support, were calculated. The MSPSS has been validated for construct validity and reliability (Zimet, Powell et al. 1990) and used in studies of caregivers of children with behavioural problems.

Quantitative data were analysed in SPSS and the qualitative data were analysed for themes using NVivo software. Results are presented in three sections: demographics of participants, issues around diagnosis, and issues around caring for people affected by FASD.

Results

Twenty nine semi-structured telephone interviews were conducted between October 2011 and March 2012. They ranged in duration from 47 minutes to an hour and twenty minutes, with an average time of one hour. In families caring for more than one child affected by FASD, respondents were asked to focus on 'the most challenging child' but to provide information when relevant about other affected or at-risk children in their care.

Demographics of participants

General demographics

People from all states and territories except the ACT were interviewed. Ten were from major cities, eight from outer regional areas, five from inner regional areas and six from remote or very remote areas. Twenty-six females and four males participated in the interviews. One interview involved both parents. Participants ranged in age from 34 years to 68 years with a median of 50 years. The majority (90 per cent) were born in Australia with 93 per cent only speaking English at home. Two thirds (66 per cent) had post school qualifications, 17 per cent completed year 12 and 14 per cent completed year 10. The majority (72 per cent) were married or in de facto relationships. Four participants (14 per cent) were divorced and four (14 per cent) were never married.

Twenty-one participants reported on caring for children under the age of 18 (ranging from 3-16 years, mean/median 10 years). Eight participants discussed caring for adults aged 18 to 32 (median 20 years) reflecting the ongoing caring needs for people affected by these disorders. One participant did not currently have a child in their care but had recently cared for a child for 8 years and reported on their experiences during that time.

Relationship of the child to the carer

Participants reported caring for one (n=10, 34 per cent) to five children (mean 2.4, SD 1.4, median 2). There were compositional differences among participating families. Thirteen participants were foster parents, three were biological parents, four were adopted parents, five were relative carers and four guardians participated in the interviews. Throughout the report the term 'carer' will be used to incorporate all types of carer relationships unless specified otherwise. In addition to the children in their care, 22 participants (76 per cent) had children that were not living with them, all but one participant reported that the children not living with them were their adult children (mainly biological). There were families with a combination of biological and adopted or foster children, families with foster children only and carers looking after children and/or grandchildren, nieces and nephews.

Length of time caring for child with FASD

Participants had cared for the child or children in their care for 1.5 to 31.5 years, reflecting the age of child. Fifteen of the carers had the child from the age of six months or less, seven were under the age of five, five were between five and eight years old and one was 13 years old when they came into care. Participants were asked how many children they had cared for that had FASD or they suspected had FASD. Eleven carers reported they had cared for one child and 12 carers reported caring for two children with FASD. The remaining carers had cared for three, four, 16, 25, 30 and 33 children that either had a FASD or they suspected were affected by FASD.

'I've had 41 children through my house. I'd probably say - oh, 25 of them would've been affected'. Carer of a child with FAS

'We cared for 14 children altogether and looking back I can pick up a couple that may have had some prenatal exposure to alcohol, but ...they were never diagnosed. We had a lot of special needs kids, and I think alcohol was probably a factor for a few of them.' Carer of a child with FAS

Diagnosis

Participants were asked about whether the children in their care had received a diagnosis of FASD. Four key themes emerged:

- Comorbid diagnosis
- Difficulty in obtaining a diagnosis
- Carers labelled and stigmatised as bad parents
- The need to have funding attached to diagnoses

Personal Behaviour Checklist scores

The Personal Behaviour Checklist (PBCL) contains 36 items describing behaviours commonly seen in people affected by FASD. Research from a normative study showed that about 80 per cent of the reference sample scored below 12, while about 80 per cent of those from a FAS sample scored greater than 12. The study found that having a father with alcohol problems did not affect the scores although having a mother with alcohol problems raised the scores indicating that the checklist reflects fetal alcohol exposure as opposed to living in an 'alcoholic' household (Streissguth et al. 1998).

In the present study, all carers reported behaviours from the children in their care that resulted in scores of more than 12 on the PBCL -36. The scores ranged from 16 to 34 with a mean score of 26.2 (SD 5.0). Twenty of the children had been diagnosed with FASD (see Table 1); an additional four had health professionals suspect FASD (one of whom was currently going through the diagnostic process) and four had not been diagnosed with a FASD but their parent or carer suspected they had FASD. Of those diagnosed, FAS was the most common diagnosis (n=12). Three of the children were diagnosed at birth, four were under two years old when they received a diagnosis, five were between the ages of four and six, four between the ages of 8-12 years and four were diagnosed as teenagers. Just over

half of the children were diagnosed by a paediatrician (n=11), other specialist (n=2), GP (n=2), psychologist or neuropsychologist (n=2), geneticist (n=2), and one carer did not know who diagnosed the child.

Co-morbid disorders

Children were given a range of diagnoses in addition to the FASD diagnosis, most commonly Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD).

'The more labels that get hung on a child, the less the practitioner knows what to do, in my experience.' Carer of a child with FAS.

Table 1: Types of diagnoses of children of carers that participated in interviews

FASD Diagnosis	n
Fetal Alcohol Syndrome (FAS)	12
Fetal Alcohol Spectrum Disorders (FASD) – not specified	6
Alcohol Related Neurodevelopmental Disorder (ARND)	1
Partial FAS	1
Other conditions diagnosed¹	n
Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)	15
Learning disorder/intellectual disability/ global delay	7
Anxiety disorder	6
Autism	4
Aspergers syndrome	2
Sensory processing or integration disorder	3
Reactive attachment disorder	3
Post traumatic or chronic stress	2
Oppositional Defiant Disorder (ODD)	2
Obsessive Compulsive Disorder (OCD)	1
Conduct disorder	1

¹the majority of children were diagnosed with more than one condition/disorder

Difficulty in obtaining a diagnosis

Difficulty in obtaining a diagnosis of FASD was an issue that many carers discussed. The process was often lengthy and unclear, particularly for children born without the characteristic facial features of FAS and not diagnosed at birth. This proved frustrating for many who cited the following factors as problematic: lack of awareness of the condition amongst professionals and services with the professional capacity to make a diagnosis, and some professionals unwilling to make a diagnosis for fear of 'labelling' the child.

'one of the huge frustrations is not being able to get him diagnosed just because he doesn't have any facial pathology - before he left hospital ... thepaediatrician there was concerned that he may suffer from FAS because his mother was alcohol dependent but because he didn't have any of the features .. they didn't believe he had a problem.' Carer of child with suspected FASD.

'he was born with very obvious signs of FASD, looking back, but the paediatrician was reluctant to hang that label on him because he thought it would make the child less able to find foster parents and, as he said to me, it's not a nice label, you don't want that label.' Carer of child with FAS.

'it's a long, unclear process.....the first paediatrician that we went to said, if I diagnose something like this, you're just giving a kid a label. No you're not, I said. You're actually giving a diagnosis. I said, what the kid has without a diagnosis is a label. They'll be labelled as a naughty kid with hypochondriac parents.'

I said, probably in high school it's going to matter the most. I've worked in high schools. I know what teachers think. I've sat in the meetings when they were talking about kids with difficult behaviours and all this kind of thing. ...I know what they say about the parents.'

I said, if I have a diagnosis and I'm going to say to the teachers, X has a real diagnosisthe majority of teachers will say, you've got a real diagnosis here; a parent who is supportive and is doing the best they can and working with the school, teachers, to help this kid get through....I'd been pursuing a diagnosis since he was a baby. I'd been to a couple of early intervention programs and assessments and psychological assessments. They would sometimes do things. They would do an assessment on his speech. They would do an IQ assessment. They would do different things like that. But no one was ever able to come up with any real diagnosis that would explain to teachers and explain to people that he was spending time with in any way what it was that was affecting him.' Carer of a child with suspected FASD.

Carers labelled and stigmatised as bad parents

Carers reported that not knowing what the problem was with their child was incredibly frustrating and sometimes their parenting skills were called into question, this was both hurtful and counterproductive.

'We didn't know what was wrong with him. He was about four. I was hitting my head on a brick wall. Everybody kept saying, it's parenting..... Once the diagnosis came in, you knew what to focus on and that helps so much having a diagnosis.' Carer of a child with FAS.

'I struggle with trying to get the paediatricians to recognise that he might have a disability of some sort. That's across the board, because I have difficulty with his behaviour at home and they have just put it down to just me and he's just naughty. It's been a huge struggle for me to try and get across that some of these behaviours just don't seem normal to me and I haven't seen them before with other children; because I'm a childcare worker so I have some knowledge of behaviour.' Carer of a child with suspected FASD.

'Because our kids are more likely to have a normal IQ and less likely to have insight into their own needs - when I tried to access services they believed it was my parenting that was the problem and suggested I get some training. The last thing we need is mainstream parenting training.' Carer of an adult with FAS.

Obtaining a diagnosis and understanding what the potential issues was thought to be invaluable in helping carers to deal with their own expectations and knowing what they can do to assist their child.

'When I finally found out (when she was 17) what was wrong, as much as it was a really difficult thing to deal with in the beginning, I could finally breathe. I knew what the problem was. I knew I had re-adjust my expectations.' Carer of an adult with FASD.

'I think we would do some things differently if we had had the knowledge that it was severe FAS in the beginning, we would have approached things differently and we wouldn't have made so many mistakes.' Carer of child with FAS.

'It was good to have a diagnosis because then you know and you can work with what you've got but up till then it was a real constant struggle.' Carer of child with suspected FASD.

One carer noted how important the diagnostic report is to them and how it can be useful in helping to explain to others their child's particular deficits and needs. As some carers reported, their child was often considered to be difficult or naughty but having a diagnosis was empowering for parents to challenge the perceived views about their child.

'what I would like to see is that anyone who suspects their child has been fetal alcohol affected to be able to go to somewhere and get a neuropsychological assessment as I did with X. What it gave us was confirmation that this was a fetal alcohol spectrum disorder. But also it gave us some clues as to what his deficits were. The report that I got at that time, which is now four years old, has been like gold for me. I occasionally get it out just to read over it so that I can go back to say a teacher and say, what you have to understand about X is that his memory is impaired in this way and his executive functioning is impaired in this way and this is all brain damage. It's not just him being difficult'. Carer of a child with FASD.

'the challenge is trying to make people see that there's something worthwhile; that she's just not a naughty little girl.' Carer of child with suspected FAS.

'I think the big one is understanding that a diagnosis is actually not a label. FASD is not listed as a disability but I think it's going to be. People only see sometimes the benefits of a diagnosis if it's attached to money, this can help get respite care. That's not necessarily the case. It validates parents, what they're going through. .. just the fact that you're able to go to the school and say, I've got a diagnosis here - that is helpful. There are lots of valid reasons to get a diagnosis that have got nothing to do with whether there are finances or

whether the person gets a carer payment. Getting a diagnosis is bigger than all those things.' Carer of child with suspected FASD.

The need to have funding attached to diagnoses

A number of carers noted there was no funding for FASD and because of this some health professionals gave other diagnoses (including autism and anxiety) to enable the child to access to funding for education support or disability services.

'She understood that he was fetal alcohol affected, but because there was no way of getting funding for that specifically, she looked at the characteristics that he had and thought he would actually slip in under a diagnosis of autism. So we did an assessment and he ended up with that diagnosis. I guess you could say purely for the purpose of gaining funding. So he could have a teacher aide in the classroom.' Carer of a child with FASD.

'we needed to fudge things and emphasise his intellectual needs- he didn't really have an intellectual disability, he was right on the cusp, but we had to sort of not lie, but emphasise his cognitive deficits in order for him to be enrolled there.' Carer of a child with FAS.

'he wasn't eligible or he went through a lot of those services when he was little trying to get a diagnosis. But because he didn't have a diagnosis until he was 15 and until the last fortnight on disability services, a lot of the services, he wasn't eligible to get.' Carer of an adult with FASD.

Some carers had other children with a recognised disability (eg. Autism or Downs Syndrome) and noted the inequity with respect to the support provided to these children in comparison to their child/children with FASD.

'Huge. Makes all the difference. You get access to so much more services and support across the board really. The only reason we get anything at all for X is because we kick and scream constantly and say she needs to have help.' Carer of child with FAS.

Caring for people affected by FASD

Positives

Carers reported the many positive attributes their children had and expressed the unique joys of parenting children affected by FASD. Two main themes emerged:

- Loving and caring
- Creative and humorous

Loving and caring

A number of respondents noted their children to be extremely loving and caring. They showed great determination and were full of energy.

'..very delightful and engaging little boy, very active, very affectionate and very likeable. He's thoughtful, he's great with little kids and he's gentle around animals and those sorts of things. He's given us a great deal of joy over the time which is good because sometimes that helps to make up for the challenges that we've had with him.' Carer of child with FASD.

'They're great people. They're great human beings. They deserve the best. You can't do that if you're not going to acknowledge it. That's the problem.' Carer of child with FAS.

'she's very loving, she's very caring, she's very thoughtful.' Carer of adult with suspected FASD.

'He is a really loving boy, as well. People always comment to me that he is really lovely. He's polite outside the house..... He's oblivious to a lot of it, sometimes. He is really endearing in that way, and funny.' Carer of child with suspected FASD.

Creative and humorous

Carers reported their child to be particularly creative, loved music and displayed great musical and artistic talent.

'He's got a good sense of humour. He is quite creative.' Carer of child with FAS.

'He's got a wicked sense of humour and he really can be quite funny at times, but he can also be the most annoying. People love him because he is funny and he's interesting.' Carer of child with suspected FASD.

'He's got quite a unique sense of humour and that can at times be funny or misplaced'. Carer of child with FAS.

'She's great. I mean she's a [laughs] very funny, delightful, full of life, enquiring. She loves doing stuff. She's energetic. She's great fun to be around and she's a really delightful person so long as she's coping and she's focused and directed and she's not overly hyper and overly anxious.She's very talented. She sings beautifully. She's got the most amazing voice. She's very musical. She writes beautiful poetry.' Carer of child with FASD.

Sometimes these characteristics 'mask' the challenges individuals living with FASD face each day. One carer noted that her child *'had charm to burn'* and *'he presented as being a lot more competent than he actually was because of his verbal skills. Despite his speech not being clear, his written verbal skills were really quite excellent and he was quite creative, you know, he used to write stories, he had good computer literacy from an early age and music.'* Carer of child with FAS.

Some carers described their children as eager to do well despite things being difficult for them.

'she can be really loving and she really wants to do well. she's a beautiful person.' Carer of adult with FASD.

'they are eager to learn, eager to do experience new things. They both try really hard when it's something difficult, even when it's obvious that they're not getting it, they still try really hard.' Carer of children with FASD.

Carers said that seeing their child develop and achieve was wonderful and this gave them great happiness, especially when they had been told previously that they may not attain certain milestones.

'to be able to see her achieving things, and she wants to achieve things, and to be able to congratulate her for her achievements.... she is such a kind, caring, loving child, to see her blossoming like that is just magnificent.....being able to see such wonderful results for our persistence, for our love of the child, is great for a parent to experience that.' Carer of child with FAS.

'she's come along in leaps and bounds in all ways; academically and socially comparatively - compared to the way she was before. She's healthy, she's happy, she's a terrific asset. She's just a nice little kid, really.' Carer of child with suspected FASD.

'the positive would be seeing her develop every day, doing things that they said she never would..... it's rewarding seeing the outcome and knowing they told me that X was at the point where they didn't know whether she would live or die Then to see her come back to life and to smile, it's amazing. I wouldn't swap her for the world, I really wouldn't. I just wish her mum would see her. She has no contact with her. I wish she would so she could see that she's okay.' Carer of child with FAS.

Challenges

Carers were asked ‘Overall, compared to children about the same age, do you think your child is...easier than average, about average or more difficult? All but one of the carers reported that the child in their care was ‘more difficult’. One carer reported their child was about average. Carers reported three particular challenges they experienced in caring for their children:

- Persistence and exhaustion
- Impulsivity and poor understanding of consequences
- Managing aggression

Persistence and exhaustion

The constant and ongoing care needs of their charges were identified as challenging with carers noting that ‘every day is a challenge’ and caring is ‘hard yakka’.

‘it's just been one huge, huge, huge mountain. We still haven't reached the top. We haven't got over the hump yet.’ Carer of adult with FASD.

‘High maintenance constantly. She was never a naughty child, she was always a beautiful child but just high maintenance. Always had to be watching her and doing things for her because she couldn't do them.’ Carer of adult with FASD.

‘it just starts to feel like you're pushing uphill all the time. It's a tiring thing bringing him up.’ Carer of child with FASD.

‘in dealing with a child with these sorts of disabilities, it is the persistence thing. You've got to be going over things again and again and again and you've got to keep on track, so that the child learns that you're not going to give up on them and learns that there are positive outcomes to these things. So, the child...becomes less and less resistant the more that you put the structures in place and persist with them. If we were to give up on these things, X would give up on them. But, it's bloody hard work.’ Carer of child with FAS.

‘The difficulties are around her inability at times just to deal with the everyday stimulation of life and to manage that and to keep her behaviour under control.’ Carer of child with FAS.

Impulsivity and poor understanding of consequences

The frustration of having to teach and reteach their child was evident and the lack of understanding of consequences of their behaviour was discussed by a number of respondents.

‘you're hitting your head on a brick wall sometimes - to just get messages through.’ Carer of child with FAS.

‘every day was a brand new day. Every day, the rules had to be put in place. Every day, that repetition of “we're doing this again”. It was like everything else was wiped clean..... the repetitiveness of it, the fact that he doesn't learn, or doesn't remember impacts on day to

day life. So, we do have to go over things more often, go over rules more often, early in the day, and that kind of thing.' Carer of teenager with suspected FASD.

'most of the challenges that we've had raising him have been about education, about teaching him. Either teaching him stuff at home - right from the start I just found him much more difficult than other children I'd had to teach the basics of just numeracy and reading and things like that. He seemed to need a lot more work to learn a lot less than every other child I'd ever worked with. I was a.... school teacher before too, so I had that experience as well.' Carer of teenager with FASD.

'he struggles with consequences and can be very irrational and do silly things, not comprehending that there is a consequence to what we do.' Carer of child with FAS.

Managing aggression

Many carers raised the problem of managing aggression as a challenging issue that they found to be difficult to cope with. A number of carers had been physically hurt by their children with one carer hospitalised. Carers reported their children experience *'unbelievable meltdowns'* (Carer of child with FASD) and uncontrolled tempers:

'the most horrific temper is triggered by anything and that can calm as quickly as it starts. It's quite an amazing spontaneous temper which is frightening if it can't be settled in the next 10 years.' Carer of child with FAS.

'he can get very upset and very angry and at times it's been a bit physical, like kicking and - and also himself too, self-harm like hitting his head.' Carer of child with suspected FASD.

'he has an aggressive side, which is very difficult to manage and I have found it hard to cope with.' Carer of child with suspected FASD.

'The difficult things have been really managing the temper. For me, she brings out my darker spots, you know, when she starts going off. I find myself being my less best self. She drags me to the edge of my patience and tolerance.' Carer of an adult with FASD.

'Just not listening, constant arguing and fighting and the violence.' Carer of adult with FASD.

Carers reported the child in their care being destructive; damaging toys, household objects and furniture. This was described by carers of children at a variety of ages. Often carers reported their children would snap quickly or over seemingly small incidents. Their rage could resolve just as quickly with no understanding by the child as to why others were confused or shocked.

'He's very destructive. He's pulled the keys off the computer. Smashed the glass of the bathroom shower recess. He gets angry, he destroys. He might throw things.' Carer of child with FAS.

'very aggressive - and a lot of the time he snaps very quickly, like can go from being totally fine to absolutely diabolical in one second. Very destructive, causes so much damage in my house - his belongings, other's belongings. holes dug in walls, fan broken, holes smashed in doors, drawing all over the walls. He has broken beds, pulled beds apart, smashed apart wooden drawers,... he doesn't think of the consequences of his actions before... You know, he can actually get a huge shock at what happens.' Carer of child with FAS.

Health issues for the child

Carers were asked about health issues faced by their children. Carers addressed:

- Physical conditions
- Mental health conditions

Physical conditions

Carers were asked about the current health of the child in their care with most reporting their current health as good to excellent, although many acknowledged it had not always been that way. Often carers reported that their child had been physically unwell when they had first come into their care and that they had accessed many services in that time. A few carers noted that the child was considered lucky to have survived given their significant health issues in addition to severe neglect.

'It's good at present but we have to work hard. We have to make sure that he has a great diet, he gets enough sleep. If he loses a few hours, couple of late nights in a row I can guarantee, someone's got a sore throat, he'll have bronchitis.' Carer of child with suspected FASD.

Table 2: Current health of the child

Health status	n	Percentage %
Excellent	7	24.1
Very good	10	34.5
Good	8	27.6
Fair	1	3.4
Poor	2	6.9

*One child no longer in care and therefore carer not aware of current health

Participants' noted that their children had a range of specific health issues, a few had been born prematurely, some had significant heart, kidney or stomach problems and a few had facial abnormalities. Some of the health issues were ongoing and some had outgrown them or they had been resolved with surgery (one reportedly had 18 surgeries, another 20) or other interventions.

'He had lots of medical issues when he was younger.' Carer of child with suspected FASD.

Hearing, vision and speech problems were commonly reported ailments. The majority of carers mentioned sleep problems (22/29) with a few taking medications for sleep disorders. Other health issues reported, included; global developmental delay, low muscle tone, bladder control, vitamin deficiencies, reflux and other digestive issues. Carers often reported their child was small for their chronological age and lost weight easily; they had low immunity and were prone to illness.

'we had terrible health issues with her because she was really sick constantly.' Carer of child with FAS.

'When X got a cold, everything totally devastated his body. A cold would knock him out for weeks and weeks. He was so little and so - what's the word, fragile. He was chronically fragile and things would upset his system for so long that it took him ages and ages to recover from just a cold.' Carer of child with FAS.

'Throughout the first two years of his life he had one chest infection after another. He was on antibiotics for five months straight. I just could not get him off. Physio every second hour, during the night holding him upright so he could breathe. It was full-on.' Carer of child with suspected FASD.

'when they first came to me, I felt their immune systems were not quite up to par and it probably took me two years before those things settled in both of them.' Carer of child with suspected FASD.

Mental health conditions

Almost half of the children had been diagnosed with ADHD. Many were currently on medication for ADHD and a few had been on medication in the past but were no longer being medicated as the child or the carer (or both) did not want to continue.

Carers were also asked about any other mental health issues. Anxiety was commonly reported for children of all ages. Carers of older children or adults often reported mental health problems, including self-harm and suicide attempts. A few children had experienced significant trauma in their early life and were dealing with residual issues. As carers reported these children often had significant ongoing health issues which meant that accessing services and consistent care was very important.

'with ongoing health issues we need consistency and the availability of things for this child'
Carer of a child with FAS.

Health services accessed

With respect to health services accessed, four main themes emerged:

- Multiple practitioners
- Poor communication between practitioners
- **Practitioner views and lack of knowledge about FASD**
- **Increasing education and training of health professionals**

Multiple practitioners

Participants reported attending a variety of health professionals in the last year including General Practitioners (GPs), paediatricians, occupational therapists, physiotherapists, psychiatrists, counsellors, social workers, and hearing, vision and speech specialists. Carers reported both positive and negative experiences, finding some health professionals helpful and others not. Carers reported some professionals being helpful in securing referrals or for prescribing medication, but lacking expertise in dealing with FASD specifically.

'Helpful for the medical conditions but not the associated conditions.' Carer of an adult with FAS.

It was also recognised that the nature of the work was not conducive to consistency as retaining staff was problematic.

'Very high burn out and in fact the more caring they are, the more invested they are the less time they seem to spend in the system, unfortunately. So we've learnt never to count on anybody.' Carer of child with FAS.

'Social workers in our life all the time but no continuity - some of them were more supportive or helpful than others, some of them listened better than others but in general they didn't stick around. The system isn't conducive to consistency and longevity.' Carer of child with FAS.

Poor communication between practitioners

The complexity of the care that some of the children required was an issue that often came up. Care was supplied by multiple practitioners and often lacked co-ordination and follow-up.

'At any given time this child had five or six doctors and several other allied health professionals in his life so they were just like ships that passed in the night. Most of them didn't have ongoing contact with him and that's really what he needed. It was too hard; he was passed around like a hot potato.' Carer of child with FAS.

'Yes, but was out of his depth.... they didn't know about - there were so many complications with it, they just kept referring me on.' Carer of a child with suspected FASD.

Some participants noted that doctors often suggested the issue was with the carer and not the child and advised carers to change parenting practices or see someone about their parenting skills. The issue of the mother drinking during pregnancy was dismissed.

'I had it dismissed by a lot of doctors. They dismissed the alcohol.' Carer of a child with suspected FASD.

'They called me an over reactive mother and I was projecting my own issues onto the poor child No one listens to you when you're a mother.' Carer of a child with FAS.

Carers reported that it was helpful when they had the same GP or paediatrician over many years who understood FASD and the child.

'(my GP) out of all of them she was the only one who had a handle on things. She realised that somebody needed to coordinate this child's issues and was willing to do that. Unfortunately other practitioners were not willing to cooperate with her, so she wasn't able to do terribly much, but she was certainly more willing than most.' Carer of child with FAS.

A few acknowledged that their own persistence assisted the services that their child received.

'Because of my nature. I would ask a lot of questions. I've got a friend who is fostering and she's come away from the speech therapist and she said he's absolutely useless but I'm thinking but did you ask her these questions. She said no. I'm thinking well - it's more that if the carer asks questions and that that they ... people will want to ... the information but I suppose some people don't know what questions to ask.' Carer of child with suspected FAS.

Practitioner views and lack of knowledge about FASD

The most common issue raised by carers regarding health services was that health professionals were lacking knowledge of FASD. Some expressed frustration or concern regarding the lack of knowledge.

'Do you know what? I'm sick of educating the service providers.' Carer of an adult with FASD.

'I'm the one who alerts people to the fact that the child seems to have characteristics of FAS or FASD and I don't like being the one who knows the most when I feel like I know so little.' Carer of a child with FASD.

One carer of an adult with FASD notes that there have been improvements regarding health professionals' awareness but there are still no appropriate services.

'whenever the issue of FAS came out we raised it and there was always the feeling that the person then went off to research it. That was fairly isolating.' Carer of an adult with FAS.

'Or sometimes the professionals would look at you blankly like 'what are you talking about?'there's greater awareness but still that hasn't translated to any appropriate services or the awareness of what will help the FAS individual.' Carer of an adult with FAS.

In comparison to other disabilities participants felt there was a real lack of expertise regarding FASD.

'comparison with Down syndrome because there's so much information there and there are so many people who are expertsand have lots of experience and knowledge. There's lots of stuff out there that you can draw on and use which is not the case with FAS. The people that you tend to access don't have the experience.....nobody ever really knows quite what to do.... you can't draw on expertise in quite the same way.' Carer of a child with FAS.

Some carers reported on the difficulties of having to deal with health professionals who did not seem to agree that FASD was a real disorder.

'We have a bit of a problem with our paediatrician because we have the same paediatrician for both the girls and he doesn't believe in FAS.' Carer of child with FAS.

Or that they would not give a diagnosis of FASD because of the negative connotations,

'He didn't have a positive attitude, he didn't really believe that the FAS diagnosis appropriate. He said to me that it wasn't a nice diagnosis and I shouldn't be asking for it. He said that I was a bad mother for wanting a psych evaluation.' Carer of child with FAS.

Increasing education and training of health professionals

As physical, neurobehavioural, developmental and mental health issues were often complex, continued and consistent care was reported as necessary with improved referrals to appropriately trained professionals. Carers often reported that professionals were not adequately informed about FASD.

'Well for starters, I think there probably needs to be more education for the medical professionals. I don't think it's well known. The same would go for teaching.' Carer of an adult with FAS.

'a better referral system. Knowledge, education about FASD really needs to be out there.' Carer of a child with suspected FASD.

Proper assessments for the child and listening to the carer were also commonly identified as areas for improvement.

'When we have seen a psychiatrist or psychologist mainly, they mainly only talk to me and they've had very little to do with him. I know I've really struggled with that. I really want someone to be able to watch him and observe him on a regular basis, either at home or at school, because people were just blaming me for - that I'm not doing things consistently and whatever. So yes it's mainly been me and then I have been judged and haven't really gotten anywhere. I find seeing the psychiatrist or psychologist a waste of time in the end because it's not me I want them to see. They need to see a bit of me but he has just not ever been closely observed.' Carer of child with suspected FASD.

Educational issues

Children attended public, private and religious schools, including both mainstream and special schools. Many carers had tried multiple and different types of schools for their children. A couple of carers had tried or were currently home schooling their children after not being satisfied with the amount of support they were getting at school or after the child had been asked to leave. A few children had been excluded from day care due to behavioural issues), while some of the children had been suspended or expelled, some numerous times. (eg. 'twice', 'about 5 times', 'many times', 'Never expelled by suspend, oh hundreds of times').

With respect to educational issues the key themes that emerged were:

- Stigma and lack of awareness
- Carer advocacy
- Lack of funding for additional support

Stigma and lack of awareness

The issue of lack of awareness about FASD within the educational system and the stigma associated with the condition came up repeatedly.

'The whole issue of FASD is an issue of taboo within the public school system. Nobody wants to talk about it; nobody wants to deal with it. Nobody wants to trust parents with telling the school what sort of methods they should be using.' Carer of a child with FAS.

Carer advocacy

Carers consistently advocated for their children and provided educators with information about FASD themselves.

'I did a lot of getting to know the teacher in the lead-up before he started, providing her with heaps of information, lots of resources, so that by the time he started she probably knew as much about X as I did without having ever lived with him. So she was looking forward to the challenge, actually, and she's done a marvellous job. It was just about I had to break the ice. I gave her lots of things and lots of tools to work with him. We work with similar tools like picture cards. I gave her a set of everything that I had at home and I said this is how I do it and this is what I work. She said okay, we'll do the same thing. So she's been very willing to change the way she does things so that it's a lot easier for him.' Carer of a child with FASD.

Carers reported they often initiated any support children received and often it was quite a process or battle to obtain (and retain) any funding. Carers reported having to continue to reapply each year.

'We had to fight for her.we have to fight for every little tiny bit that we can get. We're constantly told she's not eligible. She's not eligible for anything. She's not eligible.' Carer of a child with FAS.

'It's ridiculous that they have to go through the whole process every year when, you know - fair enough, maybe once every three years because people can change over years, but every year? There's not going to be that much change in a year. the diagnoses aren't going to change.' Carer of a child with FAS.

Lack of funding for additional support

Carers reported there was a lack of funding for additional support within the education system. Carers noted that if their child had autism or a recognised or more well-known disability they would get support as funding is available.

'if X was diagnosed with autism it would be easier in a school environment because people would say, we know he's got something.' Carer of a child with suspected FASD.

'the big thing is it's the funding on how they give them to these kids. Like, he doesn't fit the normal guidelines for disability services and everything comes through there, whether they need funding or whether they don't need funding and it's just because he was one point over the IQ doesn't mean that he didn't need help.' Carer of an adult with FASD.

Another carer, who in addition to her child with FASD has a child that could obtain support due to a different disability, reported that support *'should be based on needs, not on labels.'* Carer of a child with FAS. This carer reports that for her children, the child that is eligible for support does not need it as much as the child that is ineligible.

Again carers reported that you needed a particular diagnosis to get funding. Carers noted that the cuts offs used for the purpose of obtaining funding were not helpful as FASD children were often borderline.

'he hasn't been diagnosed with any of those and that makes it hard for him to get much extra help.' Carer of child with suspected FASD.

Some teachers or schools have shared funding from other children to support the child but sometimes this is tenuous.

'he didn't actually get the funding for full time. He got funding 0.7 but the school were absolutely brilliant and they topped it up themselves to full time, which I'm very grateful for because that has enabled him to have a successful year.' Carer of a child with FAS.

'he got put in the special education unit for this two hours a day but we've been told that if another child comes along to that unit and they can't have them all - they have limited spaces - X will be taken out because he doesn't have a diagnosis.' Carer of a child with FAS.

Accessing the appropriate professionals to obtain reports for funding was problematic for some carers.

'They have to reapply each year, which is silly because it's not like they're going to suddenly get better, so we need to reapply. He's supposed to have a psychiatrist's report but we couldn't get him into any psychiatrists because there aren't many that take in kids and the ones that do, most of them refuse to take kids who are under the care of the Department, obviously because they're sick of the slowness in paying or something. I don't know. But in ringing around, they're like, no. As soon as they heard he was under the Department, no, we don't take Department children. So we couldn't get him into a psychiatrist so we're hoping

that the psychologist's report is enough and he'll get the same funding. We're a bit worried it's going to be reduced but I won't know that until he starts back at school.' Carer of child with FAS.

Carers reported that within the education system there was not enough support for the level of teaching required (even in special schools) and expectations were often too high.

'X requires lots of repetition and -.....building upon knowledge with very small steps, but very clear, repetitive steps. That sort of thing works with X, but they simply do not have the ability to do that at the school that she's at, because they've got not enough teachers in the class. They simply can't structure things rigorously enough for that to work with X.' Carer of a child with FAS.

There is a lack of information available for FASD specific programs.

'we've got very much beefed up legislation about what rights children have within the education system, but we don't have the sorts of diagnostic studies to support the warranting of a special program for kids was FASD, like you have for kids with autism, for example.' Carer of a child with FAS.

A carer acknowledges that it is not the educators role to diagnose the child and that diagnosis is a sensitive issue and some carers (for example some biological parents) may not be pursuing a diagnoses but if their children are affected they will still need strategies put in place to support the child.

'Because then you have biological parents who maybe have - there might be a FASD kid in the schoolif the parent is not pursuing a diagnosis or wanting to know about it, which is often the case with FASD - that's why it's easier to diagnose ADD and ADHD - but the kid will still need support. The teacher and school psyches will still need to work together to work out some strategies. you keep putting strategies forward until you find the one that works best.....Your role is to educate the child; not to make sure every child gets a diagnosis, because that's a family matter and you've got to be very sensitive about those things.' Carer of a child with suspected FASD.

In this study the majority of participants were non-biological parents. Obtaining a diagnosis was clearly an issue for the majority of carers interviewed including the few biological mothers interviewed. The sensitivity of the diagnosis needs to be considered as there is substantial stigma associated with alcohol and drug problems generally, and FASD specifically, and a diagnosis for a biological mother may be confronting as it is not only the child labelled. It is not the educators' role to diagnose FASD but they need to be aware of the condition to provide the required support when FASD is suspected.

Suggestions for improving educational support

Carers were asked 'How do you think educational support could be improved for children with FASD?' Three main areas were repeatedly discussed:

- Improving education and training of teachers
- Allocation of funds for educational assistance
- Educational environment

Improving education and training of teachers

Education and training for teachers and increasing knowledge about FASD was commonly recognised as an area that requires critical improvement within the education system. It was acknowledged that teachers needed to learn appropriate strategies to assist the children.

'Awareness. .. all the teachers, the teacher's assistants, awareness of what FASD presents, the way it presents, within their education. There have to be other strategies for them to be able to learn. Often, things that worked with my own children, helping them with their reading, doesn't work with these children, because of poor working memory. Essentially a lot of awareness about what the effects are because the children, for the most part, look for want of a better word, 'normal'. They haven't got an obvious disability or a disability that would be obvious to most people.' Carer of a child with FASD.

'Especially for teachers. Our teachers actually are blessed in our school. They've actually had training by a guidance officer with a passion for this particular disorder. So they're more aware than the average but the reality is, most teachers - like, I had spoken to a teacher who graduated I think about five years ago. He had never heard of fetal alcohol. He actually works in an Aboriginal school, where the vast majority of children do have it. He hasn't had any formal training in how to manage them. So it's the blind leading the blind.' Carer of a child with FAS.

Providing support based on the needs of the child, as opposed to the diagnosis, would be ideal.

'I mean in an ideal world, these kids would have an assessment done that showed where they were strong and where they were weak and the teacher will take that on board. The teacher would only have a few kids in the class. She'd have a teacher aide to help her.' Carer of a child with FASD.

Allocation of funds for educational assistance

Most carers reported that diagnosing the condition and the allocation of funding was an area that requires improvement. Generally there was a sense that services and support were lacking and that acknowledging the problem, recognising the disability and improving the level of awareness about FASD within the education system was necessary.

One carer states:

‘.we need to call it what it is so that the individual schools can gather resources to deal with it. That’s the first thing. Then there needs to be education put in to support the teachers, whether it be in a mainstream setting or a special school setting. Once we call it what it is, we need to have specific training for these people who are working with it, We know how to deal with it but we have to pretend it’s something else. It’s stupid, the way it is and as a parent you’re reliant on a school having knowledge and experience but not calling it that. It’s pathetic and it’s not fair on the teaching staff either. the sooner we nationally acknowledge that FASD exists, and that it’s real and that it requires a standardised diagnostic system, and that’s the first step and the second step is to put training in to not just teachers but also doctors, nursing staff, anyone who’s a frontline professional having dealings with these kids and adults, now.’ Carer of a child with FAS.

The assessment process, including consideration of the cut-off criteria used for funding purposes requires improvements. One carer suggested a more holistic approach for assessing the needs of the child, which would include consideration of behavioural issues, and whether the teacher required assistance in addition to IQ scores.

‘You had to be below 75 to get anything like that; which was a frustrating process, because they take the kid - any student - out of the classroom; put them in a nice solitude place; one-on-one testing. They go, you’re good. They put him in the optimum learning environment and they go, no, you’re fine. Put them in the least optimum learning environment...’ Carer of a child with suspected FASD.

‘The whole testing process needs to be overhauled.you can still do IQ tests, but I think that should only account for so many points, for example. If a child has a diagnosis, that obviously affects learning or behaviour, that earns you some points. Is the teacher saying she needs help? That’s got to add up to something. Let’s have a look at the IQ test. Okay, he’s a pretty bright kid, but he has these behavioural issues, so we’re going to have a teacher’s aide come in here for two days a week not five days a week. But at the moment everything hinges on the IQ; that’s all it hinges on. Other factors, like us getting a diagnosis or that the teachers actually ask for help none of those factors get brought into it.’ Carer of a child with suspected FASD.

Educational environment

Participants noted that decreasing class size, more one-on-one support and a less distracted environment (reduce noise and distraction) would improve the educational experience for children affected by FASD.

‘for most kids having colour in the classroom, having lots of bright, different things and having a variety of things - switching from that activity to that activity is good and helpful. But X needs routine, routine, routine, routine; one-on-one is good; with no distractions. That’s his optimum learning environment. They take him out of that distractive classroom, test him on a one-to-one, in the best learning environment, and then expect him to perform outside that environment. That’s one of the issues I have with the education system and the way they test these things.’ Carer of a child with suspected FASD.

'More one-on-one for sure. Small group lessons as opposed to aid in a classroom.' Carer of a child with suspected FASD.

Carers suggested the need to have specific programs designed for children with FASD and there is a lack of information regarding effective programs. There is a need to study affected children in Australia and determine if different teaching approaches are effective to ensure funding.

*'a program needs to be devised by someone. **There is no specific program in the education system to address the needs of children with FASD;** that is quite clear. Nobody is game enough to make a start on it, because the numbers do not warrant, in their opinion, the finances to do that.'* Carer of a child with FAS.

A few participants suggested that life skills programs would be helpful for older children (eg. how to catch public transport, buy things at shops, cooking, managing money etc)

'He's not going to be able to cope with the school work so what are we going to do educationally to get him ready and equipped for work? I mean I'm sure there's something there but I just haven't got there yet.' Carer of a child with suspected FASD.

Employment

Some of the older children and adults had experience obtaining employment. They had worked in both part-time and full-time positions and had worked for employers that were aware they had FASD and others that were not. A number of themes were raised in discussion around employment. These were:

- Enjoyment of the workforce
- Disclosure of diagnosis to employers
- The type of work

Enjoyment of the workforce

Carers noted that their children were often capable of working and enjoyed being employed and all the benefits this brings.

'She is capable of holding a job. She's very capable of holding a job, but it has to be the right job.' Carer of an adult with FAS.

'X actually enjoys the structure of work and she enjoys the human contact but a number of times, as a mother, my heart's gone out to her because it's like an expectation were beyond what she's capable of but because she presents so well, it's like an invisible disability.' Carer of an adult with FAS.

Carers of younger children express concern for the future regarding obtaining employment and are hopeful that services are available to assist them when they reach that stage.

'that's one of our biggest concerns is to try and get her into a job that she will feel fulfilled in and that she will bring to the fore all the strengths that she has and develop fully as a fully-functioning adult.' Carer of child with FAS.

'guess I believe and I haven't really explored these yet, but I hope to through the school, that there are agencies that employ intellectual disabilities. Even though X's cognitive ability or his IQ is above 70 although not very much so, I think that in actual fact his other cognitive deficits, the attention span, the memory, his inability to learn things very quickly and easily are going to be bigger problems for him in the working environment. I'm wondering whether an agency that does employ people with intellectual disability might have employers who would understand and who would be willing to take on a person like X, with conditions attached. The fact that he may never work full time, but he might be able to work a small shift...I do worry that anybody but me and his immediate family will just think that he's being lazy and thoughtless and careless and all those sort of things.' Carer of child with FAS.

Disclosure of diagnosis to their employer

The majority of carers recognised the importance for employers to be aware of FASD as this would assist in finding work and ensuring the work given to the person was appropriate.

'more understanding of FAS is needed in job support services'. Carer of an adult with FAS.

'to have somebody that will work alongside them and just teach them by the elbow If they have somebody that they see is not a threat.' Carer of an adult with suspected FASD.

Some respondents noted that employers should listen more carefully to carers or support services and adjust their expectations for the individual in light of this information.

'They need to listen to what we are telling them that what they can do otherwise they are putting them up for failure all the time and this is the sad part you know you got people saying all the time yes you are doing great, oh she's so beautiful – and she is, she's all these things they are saying but when she's in a situation that she can't deal with she goes for sensory overload and it all collapses around her, so they need to listen you do this, you do that and she'll be fine. Because the reality is she is not going to be fine and it's only going to put more pressure on her to achieve what they told her she can achieve cause she wants to do it.they didn't really believe that they thought like most people do, that she could do more things than she knew she was able to do and she just couldn't handle the expectations. Carer of an adult with FAS.

'you'd have to find employers who are prepared to understand that they need - they can achieve their job, but they just need that extra - they need routine - they have to be routine-type jobs. Don't expect - and give them a chance to make the errors, and they would be trying their hardest to do it. It's just that it takes them a bit longer.' Carer of an adult with FAS.

A number of respondents noted that whilst carers recognise their child's strengths, that employers do not understand how FASD affects the type of work a person could engage in. This could set a person up for failure and have a negative impact on self-esteem.

'her organisational skills, as you can imagine, are none at all. They expect her to be normal and they expect her to do all those tasks that they set her. Then when she takes like three hours, then they get really upset with her..... They don't understand that she's not quite normal.' Carer of an adult with FAS.

Whilst many respondents agreed that receiving a diagnosis was the cornerstone of appropriate management for their children, once the child entered the workforce, it was felt that "diagnosis" could move to "label/stigma". This could affect the self-esteem of the individual and may also lead to discrimination. A carer noted how a child often just wants to 'fit in' and did not want to advertise their disability.

'they don't think that he's got a problem. They ..don't like the fact that they've got a disability. They ..don't go around saying, I've got a disability. Give me a go.' Carer of an adult with FAS.

The need to 'fit in' also translated into a desire for independence from their caregivers. Whilst understandable as a developmental milestone, it was felt this discontinuity was particularly problematic as taking on employment was an additional stressor for a person with FASD that required strong carer support.

'once they get to this age they don't want parental involvement. If we had been involved I think we probably could've - the job could have been maintained longer. But once they get to this age they are regarded as able to look after themselves and employers don't want to talk to parents.' Carer of an adult with FAS.

The type of work

With respect to the nature of work, it was felt employers need to have an understanding of FASD characteristics including their individual strengths. For example, people with FASD often need concrete language, and clear concise tasks with constant reminders

'she could have a job if it's all routine - the same thing every day. She will do it, but she wouldn't look outside that box and see, oh, that might need to be done; I'll do that. She would think, oh, well, they didn't ask me to do that, so I won't do that. She would need a boss that would be understanding enough to say, okay, this is your job, and expect that from her, and she would do it - exactly what they asked her - but she wouldn't do anything else. Wouldn't have any insight.' Carer of an adult with FAS.

A diagnostic assessment outlining the strengths and limitations of each individual was identified as a helpful tool in addition to having a support person to inform the employer.

'they do an assessment, they can give me a list of her strengths and her weaknesses. If I go back to the employer and say these are her weaknesses, this is what she has difficulty with, this is what you need to do. I suppose if there was a middle person that could do that like they do with children with disabilities, when they do the workplace placements, if they had ... an idea there was something wrong I think they would be treating her completely differently than what they are. So if we had diagnoses and we had support from those sorts of people then they would see that okay, we need to support this person.' Carer of an adult with FAS.

'aside from telling her to go to the Disability Employment network, there's really no employers that have the patience that's needed to deal with them. She needs someone to constantly remind her to remember things because she's always forgetting things. ...she might do something one day and forget how to do it the next, so just that tolerance and understanding and patience to reiterate things to her over and over and over again.' Carer of an adult with FAS.

Carers acknowledge the success with employment through support services and the patience required while also acknowledging the ongoing day to day challenges.

'He's worked through a support agency. It's an employment agency for people with disabilities.... he loves it once he gets there but getting him up, he's got no idea of consequences. You know, we tell him that he may lose the job if he doesn't turn up for work and be switched on and be awake or whatever but you know, he doesn't comprehend that.....But the people he works with are very, very patient and they've done a great job to be able to keep him on for as long as they have. So they're learning as well. They're just great people that he works with and for.' Carer of an adult with FAS.

Carers suggested that disability programs within larger firms would be useful particularly if they had staff members that were skilled in dealing with individuals living with disabilities. Again carers acknowledged their children were employable but more understanding of FASD is needed.

'Maybe some of the big firms could have a liaison officer ..., yes, we will employ people with disabilities, and we need to look at them and see them and assess them and see what jobs they could do within our business. Then you wouldn't be just going and dealing with just

some Human Resource Officer, who doesn't know anything about people with disabilities. and find out what they can actually do.... It's just dealing with that disability, and ... would be the best thing - people to have on their job, because they'd be so conscientious and she would just want to do the right thing...they'd be great people to employ, but you've just got to get someone to make sure that they know - they understand ...coming into it and being a bit more understanding.' Carer of an adult with FAS.

Criminal justice involvement

Carers were asked if the child in their care had any involvement with the criminal justice system and if they thought aspects of FASD made children more vulnerable to come into contact with criminal justice. Three key themes emerged:

- Custody/access issue
- Vulnerability
- Violence

Custody/ access issues

A few participants had past contact with the justice system due to issues with biological family (eg. custody or access issues).

'we had to ring the police when they came back from access where he'd been belted so badly that he was black with bruises.' Carer of child with FAS.

Vulnerability

A few of the carers with older children had contact (for mostly minor incidents) with criminal justice. Many participants reported their child had not had contact with the justice system but that they were still young. There was also a sense that carers were aware that their children were vulnerable and/or even a sense that contact with the criminal justice system was almost inevitable. eg. *'give him another year or two'*.

'Not yet, but there's still time. It will come somewhere along the line, and that's what we're trying to protect him from.' Carer of child with FAS.

'What's going to happen in ten more years or even five more years; six more years? you don't have to have a disability to ... come under the influence of the wrong crowds. How much harder it will be to steer away from those things?' Carer of child with suspected FASD.

Carers reported that they thought that having FASD made their children particularly vulnerable as they were often trusting and easily led.

'she's not involved with it, a lot of her friends are and she doesn't see the danger in it'....'she was oblivious to it all.' Carer with an adult with FASD.

'he's young of mind, He's drawn to them and they're drawn to him. I can take him into a crowded room with 100 people. He can talk to nobody and he can walk out of that room and pick up every bad habit of everybody that was in there.' Carer of an adult with FAS.

'she's got very poor judgement. She seems to have extremely poor judgement about what is safe behaviour and what is not safe behaviour.' Carer of child with suspected FASD.

Violence

Impulsivity and aggression were cited as issues by a number of respondents. Carers had called the police when they had been threatened by their child.

'he's had a couple of other minor incidents where we've used the police but that's usually because of his attacks on me.' Carer of an adult with FAS.

'rang the police one day, getting them to come around here and have a talk to him about his violence and things towards us.' Carer of a child with FAS.

'I have called the police on her a couple of times. The screaming had one of the neighbours call the police one time. ... she'd stolen money out of my purse, gone berko, broke a window.' Carer of an adult with FASD.

One carer reported that in a recent incident with police the officers were not aware of FASD but it was encouraging that they requested information.

'I know they didn't understand...they actually asked me to give information because they didn't know what it was it was good to see that they request it that's a step in the right direction, it means they are listening and they are realising that these kids need different handling and I can only speak highly enough in them dealing with X the other day' Carer of an adult with FAS.

Improvements to criminal justice

Participants were asked how they thought improvements could be made to the criminal justice system. Increasing the awareness of FASD and identifying specific strategies for dealing with people with FASD were raised by carers as areas for improvement.

'more tolerance and probably more an understanding I guess and knowledge so that they know how to deal with these kids.' Carer of an adult with FAS.

'to try and get them to acknowledge FASD and tailor the diversionary programs to suit kids with those specific learning needs.' Carer of a child with FAS.

The extent of the problem for the criminal justice system was raised by some carers.

'I think we're looking at a sleeping giant there. I think many of the kids - and being a foster carer .., I've seen these kids go through the system and be labelled as bad. By the time they get to high school they're labelled as bad or incorrigible or ADHD or whatever conduct disorder label they want to put on it, and they're destined for the juvenile justice system and I believe, personally, that if we had proper screening tools, a large proportion for these kids would be shown to have organic deficits related to FASD. So the behaviour is not voluntary and it needs to be managed in a way that they're not doing it. I mean, ordinary behaviour management strategies do not work with these kids and I think it would explain a large degree of the recidivism that we see in the juvenile population.' Carer of a child with FAS.

'Everybody's temper is frayed. The person with the FAS has often got an alcoholic parent or surrounded with other alcoholics. They all just lose their lolly. My heart goes out to the criminal justice system for trying to find ways around it. It's just a nightmare that just keeps getting bigger.' Carer of an adult with FASD.

Carers and their health

Four general themes emerged with respect to carer health:

- Strain
- Too busy to care for self
- Uncertainty of the future
- Caring for other people's children

Strain

The CGSQ was used to indicate the levels of strain experienced by carers. Carers were asked to focus on the past six months and to remember how things had been in their household. The CGSQ produces a global score (range 3-15) and three subscale scores (range 1-5). Higher scores indicate higher levels of strain. The subscales include; objective strain (OS), subjective externalised strain (SES) and subjective internalised strain (SIS). The objective strain subscale includes events that are the direct result of caregiving (eg. interruption of work, personal time or financial strain). The subjective scales incorporate the emotional or psychological strain of caregiving and can be externalized, i.e. outwardly expressed for example as resentment or anger, and internalized i.e. inwardly expressed for example worry or guilt.

The mean scores for each subscale across for all carers are presented in Table 4.

Table 4: Mean global and subscale scores for the Care Giver Strain Questionnaire (n=29)

	Mean	SD	Range
Global score	8.81	2.04	4.11 - 12.73
Objective strain	2.99	0.81	1.36 - 4.82
Subjective externalised strain	2.39	0.76	1.00 - 3.75
Subjective internalised strain	3.43	0.82	1.50 - 5.00

The mean global score of 8.81 indicates significant strain in the sample.

The mean subscale scores were similar, although slightly lower than those reported by Periera (2010) who examined caregivers of youth with FAS in Canada. The current study was similar to the Canadian study, although the carers in that study were caring for youth aged 13-19 and reported higher scores than found in other samples.

The objective score of 2.99 in this sample was higher than studies of carers with severe emotional disturbance 2.03 (Heflinger & Taylor- Richardson, 2004) but lower than in the study of carers of youth affected by FASD (3.28)(Periera 2010).

The mean subjective scores were again similar to the Canadian study (2.50 for SES and 3.78 for SIS) (Periera 2010) and higher than other studies (eg. SIS 1.98 Taylor-Richardson et al. (2006), 2.7 (Bussing et al., 2003); 2.93 kinship and 3.21 parental caregivers; Heflinger & Taylor-Richardson, 2004).

Too busy to care for self

The carers also reported on their own health and were asked about their health in the past year and during the most stressful year caring for their child. Some acknowledged that caring had taken a toll on their health although often they reported being so busy caring for their child/children that they neglected their own health as it was not a priority.

'I was busy, I was being a mum.' Carer of child with FAS.

'were so busy focusing on the health of the children that our health didn't really come into it.' Carer of a child with suspected FASD.

'I've just aged quicker than normal.' Carer of adult with FASD

'it was all consuming with him. I didn't have the energy to think of anything but him.' Carer of adult with FAS.

Some of the carers either currently worked or had worked in the health or education sectors and felt that they had some knowledge of how things worked and therefore used their knowledge to advocate for their child but this also meant that they were left to manage without support.

'I am considered to be so self-sufficient, I suppose, that I was just left to sort of manage really, I suppose.' Carer of an adult with FASD.

'I haven't found any that are not helpful. They're all overstretched, of course, and I tend to try and do as much as I can without having to always be on their door.' Carer of a child with FASD.

Uncertain future

The ongoing nature of the caring role and uncertainty for the future was noted as being difficult. *'23.5 hours of the day caring, there is not a lot left. It is the hardest part of caring.'*

'Simply because with each year that's passed since then, his problems seem to have just become greater and affecting him more and we've felt less able to help him and to assist him along the way so to speak.' Carer of child with FASD.

'There was a lot going on and I just didn't realise that I was just going at a hundred miles an hour and there was just so many - I've been pulled from 20,000 different directions.' Carer of a child with FASD.

Caring for others children

Many of the carers had adult children and were now raising a second generation of children, sometimes their grandchildren. Although often rewarding, some found being older parents challenging.

'raising kids the second time around sucks, it really does, for people that don't, that can't get the support and when there is a mental problem its even double. It's really hard, it really is a hard road.' Carer of a child with FAS.

In addition there are emotional issues of caring for someone else's children, including children of a relative. One carer highlighted the lack of support for carers and also for the biological parents of the child, although recognising the biological parents may not be in a position to care for the child, they have lost a great deal and there is a lack of support for these parents.

'One thing I have found difficult all these years, the fact that there is middle generation in all this. There's the parents of these children and everything swirls around that, the emotions they feel, the lives they lead and what they've lost and the fact that until something is done, kinship carers will never get any government support because we won't speak out. There is no way that I could ever put my son and the mother of these children out in public because their shame is already too great. For whatever the reason there is still that generation of people that have lost out in this I have the children, I have the problems, I have everything else, but I am also very aware that there's a man and a woman in this world that hate me and resent me because I have their children. And I don't know how we can help them, I honestly don't but I do feel that they are the people that for whatever the mistakes they made they are the ones that we tend to forget.' Carer of child with suspected FASD

Carers mental health

The carers completed the K10 which asks questions about how they had been feeling in the past 30 days. The K10 measures global non-specific psychological distress with higher scores indicating greater distress.

Studies suggest that people scoring less than 20 on the K10 are likely to be well. One-third of the people scoring 20-24 and two-thirds of the people scoring 25-29 are likely to meet criteria for a current mental disorder and when they do, be mildly or moderately disabled. Four out of five people scoring 30 and above will meet criteria for a mental disorder and are likely to be severely disabled (Andrews and Slade 2001; Kessler, Barker et al. 2003).

Almost two-thirds of the carer sample reported scores less than 20 indicating they are currently likely to be well. Approximately a third of the carer sample (n=9) reported scores between 20 and 29 indicating that they may be experiencing mental health symptoms consistent with a mental disorder with mild to moderate disability. Two of the carers interviewed scored above 30 which may indicate severe levels of distress consistent with a diagnosis of a severe depression and/or anxiety disorder.

Table 5: Mental health of carers – K10 scores (n=29)

Score	n	Percentage %
Low score <20	18	62.1
Mild 20-24	8	27.6
Moderate 25-29	1	3.4
High 30+	2	6.9

Two key themes emerged with respect to treatment of the carers' mental health:

- Professional help
- Support networks

Professional help

Carers reported seeing mental health professionals at various times. A few acknowledged that the caring was stressful or had that pointed out by professionals

'it was one psychologist that really brought my attention to the fact that I do get anxiety and the anxiety comes directly from the children.....In terms of my management, because the children are being medicated, I'm coping better.' Carer of a child with FAS.

A handful of carers reported they were currently on medication for anxiety or depression or stress related illness although some discounted that it was due to caring for the FASD affected child.

'I am on medication for a stress disorder, which was diagnosed a number of years ago. It isn't relevant to the care of X, really. So, I'm on medication for that, but that works quite

well. I'm much more even-tempered now than I used to be I've been on that medication for - well, it did coincide with starting to look after X.....'. Carer of a child with FAS.

There was the perception that many carers were on medication to cope.

'All the parents who are dealing with this, ... foster carers and whatever who are dealing with kids with FAS, seem to all be on medication for their own benefit, for their own sanity.' Carer of a child with suspected FASD.

Support networks

'You know at the end of the day, my life is easier if my daughter has the support she needs. I don't need the support. I do now because she doesn't have any. She has the support then I don't need them.' Carer of adult with FASD.

The levels of perceived social support were assessed in the sample using the Multidimensional Scale of Perceived Social Support. The scale included a global score of caregiver perception of social support and three subscale scores relating to the source of support; family (Fam), significant other (SO), and friend support (Fri). Higher scores indicate greater perceived support.

Table 6: Multidimensional perceived social support scores among carers (n=29)

	Mean	SD	Range
Global score	5.26	0.83	3.5 - 6.25
Family support	5.08	1.31	1 - 6.5
Significant other support	5.53	0.94	2.25 – 6.75
Friend support	5.17	1.05	2 - 6

The mean scores above five in the carer sample indicate relatively high levels of perceived social support (Zimet et al. 1990). The perceived social support among our sample was higher than in the study of caregivers in Canada (Periera 2010). In addition to the standardised measure of perceived social support, carers volunteered information about the support they received or needed. Some carers reported that they received adequate support from family and friends.

'My support was from my friends. When I was falling over..... At that falling over point one of my girlfriendsjust put it all in place. She found the people that were needed..... I'd be lost without them.' Carer of adult with FASD.

Some carers reported feeling isolated as a result of their caring responsibilities even when they have very supportive friends, while others reported being isolated from friends due to their caring responsibilities.

'My beautiful friends I know they love me and I know they support me but for me it's every day hard slog it goes on and on and on but within their lives it doesn't impact their lives. For the first years there was support but they get on with their lives it doesn't have the same impact.' Carer of child with suspected FASD.

'You lose your friends because you don't go anywhere, you don't make friends.' Carer of adult with FASD.

Again the issue of having support from parents in similar situations was raised.

'They are kids that are really tough to help and the support we can get or probably just as much is knowing that other people out there are finding these children quite challenging as well is enough to give you that kind of support. We need to support each other.' Carer of child with FAS.

'don't know how you can set up a government organised service to know - that people would take up the use of because at the falling over times it's most likely the middle of the evening. It's an inappropriate time to call on anybody else at 2 o'clock in the morning or something when it is only family, friends and neighbours that can hold you together.' Carer of adult with FASD.

Carers suggested that they would like online support parent networks and a few of the carers that were involved in online forums found them to be very helpful.

'where parents, carers, people who've adopted children with FASD can actually go online and talk in a closed, safe environment. We can talk about my child's doing this, has anyone else had this experience and how did you get over that. I find that really quite helpful because it's spontaneous. It's like you want a question, you ask it. We even have parents who are FASD affected themselves who have worked through that whole process and are now functioning in a way that they are part of a community.' Carer of child with FASD.

One carer noted that they had not accessed services for themselves but the support from the professionals that were helping their children was welcomed.

'Because we're also the hidden victims because we're the ones putting up with all this constant getting up .., sleep deprivation, how do you cope during the day. It was really good to sit back and go yeah, you know what, we do do a bloody good job because we are bloody getting up early and going to bed late and dealing with these two children all day that are a little bit different.' Carer of a child with FASD.

'have a really good support team around me, the people in disability services I find - and the psychs that deal with X. I often - I'm always venting with them. So in terms of my own wellbeing I vent a lot of the stuff all the time, do you know what I mean?' Carer of a child with FASD.

Others used other techniques like meditation to cope. *'I went to learn how to meditate. So I relieve stress by meditating.'* Carer of child with FASD.

Biological mothers' drinking and other relevant information

- Complex comorbid issues
- Lack of identification and treatment for problematic alcohol use in pregnancy
- Prevention

Complex co-morbid issues

Carers of non-biological children were also asked about their knowledge of the biological mothers drinking. Many reported that they had been provided with information or had had some contact with the mother and that alcohol and/or drug abuse was common. Carers mentioned that biological mothers were often dealing with complex personal issues including drug use, mental health issues, and domestic violence. Unplanned pregnancies were commonly reported.

'She was intoxicated - prior to pregnancy, during pregnancy with both children; and a very heavy drug user.' Carer of a child with suspected FASD.

'She was in a domestic violent relationship.' Carer of a child with suspected FASD.

Lack of identification and treatment for problematic alcohol use in pregnancy

Some carers cared for more than one child from the same family that had FASD or they were aware of siblings that were also affected. A couple of carers knew or suspected the biological mother may have had FASD herself.

'We are researching and what we've come up with I would suspect that she may be first generation FAS and X second. Her partner was a violent alcoholic but what information we got about her and her siblings, it read very much that it looked like that she may have been a first generation FAS herself.' Carer of an adult with FASD.

'She had Hep B - multiple partners, so we don't know who his father was..... She's had five or six children all up andthey all seem to have these kinds of problems and he's the last one in the line.' Carer of a child with FAS.

Some carers were not aware of the biological mother's history and this indicates there is a need for better communication between foster organisations and carers.

'They didn't tell me that she was addicted to anything or what FASD was. So when we first got her, every day she'd have spasms and her whole body would stiffen up, but we didn't know what it was. She'd just scream and scream for ages. We'd just walk the floor. At one stage we thought she was having some sort of seizure, we just didn't know what it was. Then one of the case workers, I was at a meeting and they said, so how's she going with her addiction? I said, what? He said, didn't they tell you she was addicted when we got her? I was like, no. So that would have been the most stressful because we couldn't help her.' Carer of a child with FAS.

Biological mothers who participated (n=3) were asked about their personal experiences during pregnancy, including their alcohol use. Two mothers were young and had unplanned pregnancies, with one unaware for the first two months.

They were asked if health professionals had asked them if they had been drinking during pregnancy or if they had been asked when accessing services for their children.

'No one asked. I brought it up myself.' Carer of adult with FASD

'No one told me, no one ever asked me if I drank alcohol..... I don't present as an alcoholic. No one ever asked the question and ... foryears it was exhausting, it was absolutely exhausting because I kept going back to people asking what's wrong, what am I doing wrong, how do I fix this? I spent \$10,000 in one year just on doing things to try to help her because I didn't know what was wrong. The doctor's said she'll be fine, she'll grow out of it and not knowing, not having that knowledge.' Carer of adult with FASD.

All three women reduced or ceased their drinking after they became aware of the pregnancy. They reported they were reassured by health professionals not to worry.

'But after that time no, I never had anything else to drink.....I had stopped drinking as soon as I decided to continue the pregnancy.' Carer of adult with suspected FASD.

'I think she said to me look, there's a lot of women who do drink before they realise they're pregnant and there's no bad outcomes from pregnancy..... So I did voice some concerns initially but got reassured that everything would be fine.' Carer of adult with suspected FASD.

'Not to the same extent that I was. I didn't get rotten drunk but I did continue drinking. I do recall watching advertisements back then. They had an advertisement from a television saying that it was okay to drink alcohol when you were pregnant - in moderation of course..... So because of that I thought well, this is obviously coming from the Health Department and obviously it's okay to drink alcohol when you're pregnant and I didn't think twice about it. I didn't drink to the same extent though.' Carer of adult with FASD.

Women were also asked about their antenatal care and treatment for alcohol use. None of the women had received formal treatment for alcohol use as none of them believed they had a problem.

'I didn't believe that I had a problem and I'm not an alcoholic. ...I mean even now I don't drink at all. I'm just more of a social drinker and because of that I didn't think it was a problem.' Carer of adult with FASD.

No one brought it up mentioned it. At that time I didn't think it was a problem. I didn't think I was an alcoholic then. I never asked anyone. No one asked me, so there wasn't an opportunity.' Carer of adult with FAS.

Prevention

Carers acknowledged that prevention is essential but that it is a population problem as alcohol consumption is integral in Australian life.

*'Honestly I believe a lot of this has got to do with a lack of knowledge about what FASD is. Because it's so - every second child up here - that's an exaggeration but the majority of children suffer from some form of disability that that's been caused as a result of whilst they're - prior to birth, in uterine. So out they pop and you've just got to go along the path - the trail to find out what's wrong with these kids. But I think a lot of it - **a lot of this whole - the problem is a lack of understanding about what FASD is and how is it caused.**How can we prevent this? **it has to start before the child's born, that whole education thing - too late after they've been born. So I think there's just got to be a greater awareness.** I don't know how that happens because that's a whole - a global problem.*

That's a whole of Australia problem so who can do that and who will grab it by the horns and run with something like that? Because it's really a silent disability. No one knows about it and no one wants to know because it's got to do with drinking so we'll just put it under the carpet. We'll just hide that. Because it can be preventable, it is a preventable disorder, that's the saddest part. These children didn't have to be born like this.' Carer of child with suspected FASD.

Carers suggested that there is a need for consistent messages regarding alcohol use in pregnancy and increasing knowledge about FASD.

'Even doctors are still saying pregnant women can drink. Doctors in Australia are still saying that. It's just beyond a joke.'

'I said, what are you doing drinking? She said, the doctor said if I stop drinking now it's going to affect the baby. I said, for God sake, what doctor are you going to because this is pathetic. Another thing, I think it's not just educational awareness, I think it's overall, it's an awareness.' Carer of a child with FASD.

'My biggest help would be to stop it, stop people drinking when they're pregnant. I don't know how you do that. It's just such a - to insist that a child comes into the world not being able to tap into their best brain because of the reactions of parents - I think the tackling needs to start there. I mean, I think girls in school need to know about having a rod in their arm and to prevent pregnancies if they're going to be drinking. I think once the chicken's out of the egg there is no easy answer. It's just very difficult.' Carer of an adult with FASD.

Discussion

This is the first study to examine some of the issues around caring for children living with FASD in Australia. These qualitative interviews with carers of individuals of a variety of ages provide a rich, first-hand account of some of the issues involved for families affected by FASD.

Increasing awareness and knowledge about FASD was one of the main themes encountered in the interviews. Carers reported that the awareness about FASD in the general community needed to be improved. Increasing knowledge among health professionals and educators was also highlighted by the vast majority of carers. Training and education of people providing health care for and educating children is required. Carers often reported frustration at the lack of service provider expertise to deal with their children's problems. Many health professionals and educators reportedly lacked the knowledge and skills to deal with children affected by FASD. Carers reported that they had to research the condition and educate health professionals and educators themselves. Carers also reported a need for programs designed specifically for people affected by FASD and changes to the education system to accommodate affected students. Students needed additional support and as they often did not function well in a busy, stimulating classroom environment more one-on-one or smaller group support would improve the educational experience.

The lack of facilities or professionals willing and able to diagnose individuals was problematic for many carers, with many reporting it a frustratingly long process to get a diagnosis. The fact that a FASD diagnosis was not recognised by services to obtain funding for educational assistance was one of the major hurdles for many of the carers. Carers reported that the children were often borderline for disability criteria and this impacted on ability to obtain funding. The testing of affected individuals was also raised as an issue to be considered as testing was often done one-on-one which may artificially inflate their ability as opposed to testing being conducted in the normal classroom environment where affected children may struggle.

Involvement with criminal justice was reported by a handful of carers however the low reporting of criminal involvement was to be expected with many (n=14) of the children in care under 12 years old. Carers recognised that FASD made their children more vulnerable as they were often described as young for their age, easily led and with no awareness of consequences of their behaviour.

Consistent messages from health professionals' regarding alcohol use in pregnancy would be beneficial. Despite the most recent 2009 National Health and Medical Research Council's *Australian Guidelines to Reduce Health Risks from Drinking Alcohol* stating that no alcohol is the safest option during pregnancy, participants reported pregnant women being told by health professionals that it was 'ok to drink alcohol during pregnancy'. In addition, although most of the non-biological carers were provided with some information about the biological mothers alcohol use during pregnancy, some were not provided with any information and this suggests a need for better communication between placement agencies and carers.

The stigma of FASD was an issue raised by carers and carers suggested that increased awareness could improve the issue of the stigma. It is important to embrace a 'no blame' approach. Alcohol is the cause of FASD; it is not bad parenting and blaming parents and/or

carers is not beneficial. Parents and carers, biological or otherwise, need to be supported. In particular, biological mothers, who may have an alcohol use disorder, need to be offered community support or clinical treatment options. Professionals that come into contact with pregnant women need to be skilled in responding to alcohol misuse and have the patience to work with women rather than take a punitive or an avoidant stance. Women that have one child with FAS are at increased risk of having a second child affected (Burd et al. 2003) and it is therefore an important prevention strategy to support and treat these women. In this sample carers often reported that the child in their care also had siblings that were affected. There is a need for improvements in accessing treatment and suitable treatments need to be available for pre-conceptual or pregnant women.

Caring for individuals with FASD is ongoing and the strain of caring was evident. Carers reported significant physical symptoms and mental health issues. A minority of carers reported significant levels of distress psychological consistent with a diagnosis of clinical depression or anxiety. Carers also reported the benefits of social support and suggested that contact with other parents in similar situations was desirable and helpful. Due to the complexities and challenges of caring for an individual with FASD, carers need to be adequately supported.

International research has identified protective factors that reduce the risk of developing secondary disabilities associated with FASD including; living in a stable and nurturing home; not having frequent changes of household; not being a victim of violence; having received developmental disabilities services; and having been diagnosed before six years of age (Streissguth et al. 2004). These protective factors reveal practical opportunities for intervention and prevention. Supporting the carers of these children/adults living with FASD is essential, ensuring stable and continued care and access to disability services where appropriate. Interventions that reduce domestic violence need continued support. They have a twofold benefit in that they can identify women who may be in critical need of specialised support and identify children living in families where alcohol misuse means their safety is compromised. In addition, the issue of availability of trained health professionals and services to provide diagnosis needs to be addressed in Australia; about half of those diagnosed in the sample were diagnosed after the age of six.

It not known how many families are caring for children or adults who are affected by FASD in Australia but this study provides some information on the experience of some foster carers, guardians, relative carers and a few biological parents on their personal experience and provides suggestions on how services could be improved. Greater understanding of FASD in the general community and increased knowledge and expertise of professionals would significantly assist families caring for individuals with FASD.

Conclusion

The interviews highlighted the need for much greater awareness of FASD in the community and in services that have contact with affected individuals. Carers reported that when they accessed help the people that they went to for help had no (or very limited) knowledge regarding FASD and that they had to continually educate teachers, health and other professionals about FASD. The initial step to improve services would be increase the awareness and expertise regarding FASD. This could be achieved through public health campaigns about FASD to increase the awareness in the general community including some of the challenges affected individuals face. Formally recognising FASD as a disability and making funding available may also increase awareness.

In addition to increasing community awareness, improvements in the education and training of health professionals and educators is necessary. Information on FASD should be included in the curriculum of university and other courses that involve training professionals in health, education and the justice sectors. Ongoing education within these sectors regarding FASD and appropriate strategies to assist affected individuals is also required. The interviews highlighted the lack of expertise among health professionals to diagnose individuals causing frustration among the carers. National agreement is required on the diagnostic criteria for FASD and a protocol for assessment to be used in Australia. The establishment of diagnostic services and appropriate training of professionals may improve service provision. Multi-disciplinary clinical teams could be trained in specially convened workshops by national or international experts and then could have the responsibility for training other health professionals. On-line training could also be investigated as an alternative to workshops (Burns, Elliott et al. 2009).

There is increasing international knowledge regarding useful strategies for improving the lives of people affected by FASD and there is a need to review available evidence and implement appropriate programs (Kalberg and Buckley 2007; Bertrand 2009; Blackburn, Carpenter et al. 2010). Research from the US has identified effective interventions (Bertrand 2009) and these interventions could be piloted and evaluated for their effectiveness in the Australian context. A systematic review could be conducted to identify other programs that could also be piloted and evaluated.

As well as evaluating interventions for individuals and families to assist them in caring for children, there is also a need for interventions to prevent alcohol affected pregnancies as treatments for women of child bearing age are lacking. As the evidence suggests women that have had one child affected by FASD are at greater risk of having another child with FASD, a targeted intervention with these women has merit. There are significant issues in identifying these women. Generally these women have a range of confounding issues that contribute to the condition and it is very difficult to tease out the role of alcohol, especially when physical features of FAS are not present. The biological mother of any child diagnosed with FASD should be provided with information on alcohol consumption in pregnancy, additional support and access to treatment. Finally, there is a lack of interventions for biological parents who are coping with the loss of the children from their care. Interventions or programs that address this loss may help prevent further affected pregnancies. There is a need for effective interventions to be identified, piloted and evaluated in the Australian context.

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