



Foundation for Alcohol
Research & Education



Evaluation of Information and Support for Parents and Carers of Children with a Fetal Alcohol Spectrum Disorder

Lead Investigator: Dr Amanda Wilkins

Investigators: Heather Jones, Dr Rochelle Watkins,
Dr Raewyn Mutch, Winthrop Research Professor Carol Bower
Telethon Institute for Child Health Research

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Executive Summary

Nearly half of all Australian children in out-of-home care are living with foster carers. International research reports that the majority of children with a Fetal Alcohol Spectrum Disorder (FASD) were in foster or adoptive care. Awareness of the importance of information and resources specific to FASD and appropriate support for foster carers was the catalyst for applying for funding from the Foundation for Alcohol Research and Education. A Reference Group comprising representatives from foster care and FASD organisations together with two project researchers was formed to guide the project.

The Project

The aims of the project were threefold; firstly to identify what FASD information and resources foster carers had accessed, secondly to evaluate current Australian FASD information and resources, and thirdly to investigate the specific needs of foster carers with respect to information and resources to support them raising a child living with FASD.

The project sought to identify and evaluate the information and resources through the following sources:

1. Focus groups with a total of 26 foster carers held in the metropolitan area and a regional centre
2. A face to face interview with one foster carer in the metropolitan area
3. A paper-based survey of foster carers to evaluate the information and resources they had accessed with input from 10 foster carers
4. A review of accessible paper-based , audiovisual and electronic resources specific to Australia

Key findings

The following key findings were identified from the focus groups and interview.

General information

The majority of carers gained information on FASD through contact with other carers and attendance at meetings organised by foster care services.

The majority of carers accessed information and resources via the internet rather than print materials.

Information specific to a child

Health professionals were identified as the main source of specific information.

The barriers in finding specific information related both to gaining access to health professionals and in the quality of information provided by health professionals and Department for Child Protection case workers.

Carers encountered reluctance by health professionals to discuss FASD as a possible diagnosis because they didn't know enough about the pregnancy and birth history and often had insufficient knowledge and expertise in FASD.



Carers reported barriers in gaining support related to the knowledge and attitudes of child protection workers, and issues within the care system including departmental 'red tape' and lack of communication with health professionals.

They also reported barriers to obtaining support related to the knowledge and attitudes of health care providers, the lack of recognition of FASD as a disability, the association of social stigma with a FASD diagnosis and the lack of specific FASD services.

Some carers reported positive experiences in their relationships with health professionals and praise for the support given by school staff, child protection case workers and disability services, however, positive experiences were much less common than negative ones.

Overall the carers in the focus groups demonstrated a high level of commitment to the children in their care, but felt that support for their role as carers and for the complex needs of the children were inadequate and this lack of support contributes significantly to carer stress and fatigue.

Information and resources identified by foster carers in paper-based survey

- National Organisation for Fetal Alcohol Syndrome and Related Disorders website and specifically the spokesperson
- Key people within foster care organisations
- Training courses initiated by foster care organisations
- Conferences and seminars
- Training session conducted by the Department for Child Protection
- Let's Talk FASD website
- Grog babies

Australian FASD information and resources identified and evaluated by project team

Within the terms of this project the search was directed at Australian FASD information and resources that may be relevant to foster carers and parents. Specific alcohol and pregnancy primary prevention posters, booklets, brochures, DVDs, websites and advertising campaigns were excluded from the search. The evaluation was conducted using the following parameters: (i) type of information, (ii) date of publication, (iii) cost, (iv) accessibility, (v) target audience, (vi) content, (vii) language and (viii) cultural sensitivity.

Support Organisations:

- National Organisation for Fetal Alcohol Syndrome and Related Disorders
- Russell Family Fetal Alcohol Disorders Association

Websites:

- National Organisation for Fetal Alcohol Syndrome and Related Disorders
- Russell Family Fetal Alcohol Disorders Association
- Telethon Institute for Child Health Research: Alcohol, Pregnancy and FASD
- Government of South Australia, Women's and Children's Health Network
- Physical as anything



Booklets and brochures:

- Fetal Alcohol Spectrum Disorders (FASD) The Preventable Disability
- Foetal Alcohol Spectrum Disorder (FASD) Information for People Working with Children and Families
- Living with Fetal Alcohol Spectrum Disorder: A Guide for Parents and Caregivers
- Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorders: A Resource for Health Professionals
- Government of Queensland, Care Plan for FASD
- Fostering Services Fact Sheet: Foetal Alcohol Spectrum Disorder

DVDs:

- Drinking for Two
- Tristan: Hopes, dreams and challenges of a young boy living with a FASD

Training Courses:

- National Organisation for Fetal Alcohol Syndrome and Related Disorders
- Russell Family Fetal Alcohol Disorders Association
- National Indigenous Australian Foetal Alcohol Syndrome Education Network
- Rural Health Education Foundation

Churchill Fellowship Reports:

- Education of Students with Fetal Alcohol Spectrum Disorder
- Models of Care for children with Foetal Alcohol Syndrome
- Prenatal alcohol exposure and the impact on parenting affected children especially in Aboriginal communities in Canada and the United States of America

Workshops

In response to the identified carer needs for general information in a face-to-face setting, two interactive workshops were held in the metropolitan area and regional centre with 17 foster carers attending. Carers' response to the workshops was overwhelmingly positive with participants commenting in the evaluation that it was great to listen to real life stories and gain practical strategies for managing children living with FASD. Two additional workshops were held with staff from the Department for Child Protection, with 97% indicating that it was useful and practical, and relevant to their work with children and families.

Conclusions

The highest priority for focus group participants was someone to listen to them and somewhere to take their children for diagnosis of FASD. Carers were hopeful that the diagnosis would enable a plan to be put in place for the child with respect to services required, school support and interventions to prevent secondary disabilities. Validating the carer's concerns was seen as a key benefit of diagnosis.

The carers indicated that their needs for general information about FASD would best be met by face-to-face workshops, testimonials and information on effective interventions based on real life experiences.



They expressed a preference for audio-visual resources, rather than printed materials and for resources containing Australian content.

Further research is indicated to identify the information needs of Aboriginal carers in both metropolitan and regional centres and to evaluate targeted resources.

Further research is also required to investigate the knowledge and attitudes towards FASD of child protection workers and to develop and evaluate specific interventions or processes to improve communication between the welfare sector and health professionals.



Glossary of Terms and Abbreviations

Acronym	Full Text
AIHW	Australian Institute of Health and welfare
DCP	Department for Child Protection
FaHCSIA	Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs
FARE	Foundation for Alcohol Research and Education
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorder
NHMRC	National Health and Medical Research Council
NOFASARD	National Organisation for Fetal Alcohol Syndrome and Related Disorders
rffada	Russell Family Fetal Alcohol Disorders Association
UK	United Kingdom
USA	United States of America
VON	Victorian Order of Nurses (Canada)
WA	Western Australia

Fetus/Foetus and Fetal/Foetal

The word 'fetus' is from Latin origins and meant offspring, bringing forth or hatching of young. Fetus is now the Standard English spelling throughout the world in medical journals. Where the alternate spelling of foetus is used in a published report, resource, website or journal article the spelling has not been changed. This also applies to the use of fetal or foetal.



Background

In Australia there are three types of out-of-home care: foster care, kinship care and residential care. Kinship care is care by a family member or a person with a pre-existing relationship with the child. Foster care is offered in the private home of a substitute family who receives payment to cover the child's living expenses. The third type of out-of-home care is residential care where placement is in a purpose built facility and care is provided by paid staff. A statement by Alan Curren, who in 2001 was the Deputy Director of Child Care at Barnados [1] reflects on the significance of foster care and the importance society should place on the needs of the child and the carers.

“A safe family-like placement in which children can grow up is a corner stone both of family support, and work with those children who are not able to grow up with their families of origin. To put a child with a ‘new’ family is a massive intervention in his or her life, and one which will have profound consequences for the child, the placement family and the family of origin.”

The Australian Institute of Health and Welfare (AIHW) 2011 data show that 37,648 children were living in out-of-home care on 30 June 2011, with 45% in foster care [2]. In a survey of foster carers by the Australian Foster Care Association in 2000 [1] the majority of carers were in the 35-54 year old range, and 20% were over the age of 54 years. The report to the Department of Family and Community Services *Supporting strong parenting in the Australian foster care sector* [1] described the socioeconomic profile of foster families. The main income earner in 20% of foster families was professional, 15% were managers or administrators and 22% were plant or machinery operation, or tradespersons. A further 20% indicated that the main bread winner was unemployed. In addition data from the report indicates that foster carers' educational qualifications appeared to be marginally higher than the general population. Single people, couples and families enter into their role as foster carers with the belief and objective of providing a safe and nurturing home for a child.

Children in care represent a vulnerable population of children, who are at risk of developmental delay, learning difficulties and mental health disorders [3-7]. As many as 75% of children in foster care have a family history of mental illness or drug and alcohol abuse [8]. Because of the association of maternal substance abuse, including alcohol abuse, with child abuse and neglect, these children are also at risk of Fetal Alcohol Syndrome (FAS) and related disorders [8-10]. Fetal Alcohol Spectrum Disorders (FASD) is a broad term including diagnoses for which the common factor is exposure to alcohol in-utero [11]. Alcohol is known to harm the developing fetus and in particular to cause irreversible damage to the brain, resulting in impairments in learning, attention, memory, sensory perception and processing, language, social judgment, emotional regulation and motor coordination [12-15]. If the fetus is exposed to alcohol during the first eight weeks of pregnancy, the effects may include the characteristic facial features of FAS and congenital birth defects. However, children with FAS represent only a proportion of children who suffer adverse effects due to their exposure to alcohol before birth. If the fetus is exposed to moderate to high dose alcohol after the first trimester, there is little or no measureable change to the facial features, but there is measureable change to brain function, such as learning abilities, cognitive function, emotion and impulsivity [14, 16, 17].



Data from the FAS Diagnostic and Prevention Network Clinic in Washington State reports a prevalence of FAS in the foster care population 10-15 times greater than in the general population and that 81% of children diagnosed were in foster or adoptive care [8, 18, 19]. Other international studies also report that up to 80% of children with a FASD are not raised by the biological mother and in many cases the child is subject to multiple out-of-home placements [19]. An Australian prospective national surveillance study reported that only 40.2% of children with FAS were living with their biological parent(s); 21% lived with another relative and 38% lived with adoptive or foster parents [20]. In a recently published United Kingdom (UK) retrospective FAS case series [21], 74% of children were either subject to a care order at the time of referral or attended with adoptive parents, and a further 11% were accompanied by social workers to the referral appointments. In one study 35% of mothers of children diagnosed with FAS were also identified as having a FASD [22].

The prevalence of FAS and FASD has been estimated in many countries using an array of epidemiological methods. The most recent analysis of FAS in the United States of America (USA) in mixed-racial and socioeconomic populations gave a prevalence of at least 2 to 7 per 1,000. The prevalence within the broader spectrum of FASD in populations of younger school children in the US and some Western European countries is estimated at 2-5% [23]. Within Western Australia reports of FAS to the Birth Defects Registry in 2000 found a rate of 0.02 per 1,000 births within the general population and 2.76 per 1,000 for Aboriginal births [24]. A national surveillance study of cases of FAS reported by Australian paediatricians between January 2001 and December 2004 reported a birth prevalence of 0.06 per 1,000 live births [20]. It is generally conceded that FAS is under diagnosed and under reported in both the Aboriginal and non-Aboriginal populations in Australia. In addition to the lack of knowledge by many health professionals [25-27], Payne *et al* reported that 67% of surveyed health professionals who cared for pregnant women were concerned about stigmatising the child and their family with a diagnosis of FAS and few felt prepared to deal with FAS [28].

Malbin [29] and Streissguth [30] note that the primary disability of FASD is compounded by under diagnosis which leads to the high rate of secondary characteristics, including trouble in the home, at school and with the law. Overall, research findings indicate increased stress amongst parents of children with behavioural or emotional difficulties than parents of typically developing children [31, 32]. This highlights the importance of appropriate support and interventions for children with living with a FASD and effective strategies and practical resources for parents and families raising children with a FASD.

Objectives

With a high proportion of children with a FASD in Australia likely to be placed in foster care it is important that foster carers are provided with information, resources and support. This project sought to identify what information and resources are available to carers of children living with a FASD in Australia, to evaluate these resources and to investigate the specific information needs of foster carers.



Outputs

In planning the project, the project team at the Telethon Institute for Child Health Research (Telethon Institute) identified the following outputs:

1. Formation of a Reference Group
2. Periodic reports to the Foundation for Alcohol Research and Education (FARE)
3. Conduct of a minimum of two focus groups with foster carers
4. Analysis of Australian FASD resources for foster carers and parents
5. Provision of a final report to FARE

Outcomes

Identifying what information, resources and services exist, and what the barriers and enablers are to accessing this information will:

1. Enable the targeting of future resources for carers and parents
2. Improve foster carers access to general information about FASD through the provision of interactive workshops and links to Australian and international resources
3. Improve the knowledge of child protection workers with respect to FASD through interactive workshops
4. Raise the profile of the National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) and the Telethon Institute's role in advocacy, research and training
5. Provide future direction for advocacy on behalf of NOFASARD, the Telethon Institute and FARE
6. Promote a better working relationship between carers and child protection agencies to achieve the best outcomes for children in care

Ethics

Ethics approval for this project was granted by the University of Western Australia Human Research Ethics Committee.

Process

The project was conducted between March 2011 and July 2012. To ensure the requirements of the FARE contract were achieved a management plan and timeline were developed. An initial application was made to the University of Western Australia Human Research Ethics Committee in April 2011. With subsequent amendments and resubmissions final approval was received in August 2011. Correspondence to relevant organisations seeking representatives for the Reference Group and further consultation on involvement in the project began in September 2011. The first meeting of the Reference Group was held in November 2011. For reasons identified by the Reference Group and outlined in the next section of the report, focus groups were held in February 2012. The process involved listening to the experiences of foster carers, analysing the data, identifying how this resonated with the research, feeding back to the focus group participants, conducting workshops for foster carers and community service provider staff and preparing the final report. Figure 1 highlights the key components of the project.



Figure 1: FASD resources project flow chart



Reference Group

To align with the objectives of National Health and Medical Research Council (NHMRC) and the Consumers' Health Forum of Australia's *Statement on Consumer and Community Participation in Health and Medical Research* that consumers and researchers will collaborate and draw on each other's knowledge to build on and strengthen the quality of health and medical research in Australia, the project team identified organisations that are directly involved in foster care and/or FASD in Western Australia. The Reference Group was one aspect of meaningful and inclusive consumer and community participation.

Representatives from the Foster Care Association of Western Australia, Foster Families South West, NOFASARD, Child and Adolescent Community Health Aboriginal Health Team and Wanslea (a non-government agency providing services to children and families) were invited to join the Reference Group. In addition, Dr Amanda Wilkins a consultant paediatrician and specialist in child development and community paediatrics took a lead role on the Reference Group. A project manager was appointed to assist with the research and take responsibility for the practical aspects of the project and the outputs required. The project manager was also a member of the Reference Group.

Role of Reference Group

The role of the Reference Group was to guide the project by:

- Working with the project team to develop the survey questions
- Assisting in the planning for the focus groups, developing the questions and using their networks to invite people to participate in the focus groups
- Reviewing reports and providing input into publications arising from the research project

The Reference Group offered significant real life experience, expertise and commitment to the care and support of children and their families.

The Reference Group primarily conducted its business by email and teleconference, with face to face meetings convened on two occasions during the project.



Focus Groups

The purpose of the focus groups was to evaluate currently available resources and identify what parents and carers of children with FASD see as the key elements for new resources and support services. In the original development and planning for the project there was an intention to include both Aboriginal and non-Aboriginal birth parents, foster carers and kinship carers of children with a FASD. In considering the recommendation from the Ethics Committee, the Reference Group discussed whether it was realistic to have both birth mothers and carers in the same focus group. The Reference Group suggested that the project manager further discuss this issue with spokespeople from the national office of NOFASARD and the Russell Family Fetal Alcohol Disorders Association (rffada). Having received advice from both birth mothers and foster carers it was agreed that in line with the Ethics Committee recommendation separate focus groups should be offered for birth mothers and foster carers.

The Reference Group also discussed the concerns that it would be culturally more appropriate to offer separate focus groups for Aboriginal and non-Aboriginal foster and kinship carers. The Reference Group endorsed this view and recommended that Dr Wilkins and the project manager contact Yorganop Association Incorporated (Yorganop) to discuss holding focus groups or yarning circles with their registered carers. Yorganop works alongside Aboriginal families and community members to enhance the well-being of Aboriginal children and young people in care.

Members were of the view that there was insufficient time to advertise and allow foster carers to discuss the purpose of the focus groups prior to the commencement of school holidays in December 2011. The Reference Group also discussed the conduct of focus groups in Perth and a regional centre, and day and evening options to cater for a wider range of foster carer needs. It was agreed that the focus groups should be held in the metropolitan area and a regional centre after children returned to school in February 2012.

Methods

Recruitment

The Reference Group was unable to identify birth mothers to recruit for a focus group in either the metropolitan area or the regional centre. The project team met with a representative from Yorganop to discuss the project and possibility of holding focus groups with foster carers registered with the organisation. At the meeting a high level of interest in the project was expressed with suggestions that a focus group could be held with the north and south metropolitan carers' groups during their regular meeting times. Further information on the project was provided via email, followed by further contact, however these consultations did not reach a conclusion within the project timeline.

Potential participants for the foster carer focus groups were obtained through the Foster Care Association of Western Australia and Foster Families South West. Following consultation with each organisation a day time and evening date were identified. Each organisation was asked to circulate information about the focus groups to their membership. The information included focus group dates and times, project details, registration form, consent form and a reply paid envelope (Appendix 1). The project covered the mailing costs for each organisation. Interested foster carers were asked to complete the registration and consent forms and return them to the Telethon Institute in the



enclosed envelope. The Foster Care Association of Western Australia targeted specific families with the information while Foster Families South West mailed the information to all carers on their database. The information provided to carers clearly identified that the purpose of the focus group was to discuss resources and information on FASD available to foster carers.

The registration form asked participants to provide their name, postal address, email address and phone number. This information was used to provide confirmation of the event, send a thank you letter after the focus group and an invitation to attend the feedback sessions and workshops. No other descriptive information such as age, ethnicity, educational attainment, number of years as a foster carer or number of children was requested of participants. The consent form made specific reference to the focus group being recorded to assist in transcribing the information for the project. If a consent form was not provided to the project manager by the due date, a form was provided on the day with all participants signing before the commencement of the focus group.

Prior to the focus groups being held, an issue of confidentiality of 'what is raised and said at the focus group' was identified by several participants. This matter was discussed between the person raising the issue on behalf of other foster carers, the focus group facilitators, the lead researcher and project manager. It was agreed that the facilitators would send a letter via email or mail where no email address was provided, to all confirmed focus group participants. This letter (Appendix 2) introduced the facilitators and reassured participants that their contributions would be treated with respect and confidentiality, there would not be any request for personal information about them or the children in their care, and that their unique experiences and perspectives were invaluable to this project.

Facilitators

The need for independent facilitators to optimise the collection of qualitative data was identified and two researchers within the Collaboration for Applied Research and Evaluation at the Telethon Institute were approached to discuss the project. The facilitators are researchers in the area of maternal and child health and experienced in leading and evaluating focus groups. Based on availability it was agreed that one person would facilitate the regional focus groups and the other would facilitate the metropolitan focus groups.

Question Development

In consultation with the Reference Group an initial set of eight questions were identified for the focus groups. Following discussions with the facilitators these were condensed to four key questions with associated prompt questions:

- How did you find out about FASD?
- Who/where did you turn for help?
- What information and resources are available?
- What information and resources would you like to be available?



Conduct of Focus Groups

Participants in the focus groups were foster carers of children diagnosed with a FASD or suspected of having a FASD. Although participants were identified through the Foster Care Association of Western Australia or South West Foster Families they were not representing the organisation. To allow maximum opportunity for discussion it was proposed that each focus group include 8-10 participants. There was sufficient interest to conduct one focus group during the day in the metropolitan area and one face-to-face interview, and two focus groups in the regional centre, one in the evening and one in the day. The focus groups were held in a comfortable and welcoming environment with refreshments provided. The lead investigator and project manager acted as note takers at all three focus groups. In addition to the written information provided prior to the focus group, the facilitator provided an introduction on the purpose of the group, the intended use of the findings and the ground rules for the focus group. The facilitators acted with respect, were unbiased and able to listen to the women.

In line with the Telethon Institute consumer and community participation policy [33], participants were given an honorarium to contribute towards out of pocket expenses such as parking, petrol or child minding. Participants were requested to sign the focus group attendance sheet to receive the payment. All participants were provided with an information pack on alcohol and pregnancy and FASD, and contact details for support organisations (Appendix 3).

Interview

One foster carer was unable to attend the metropolitan area focus group and was invited to participate in a face-to-face interview with the focus group facilitator. The interview was conducted using the same introduction to the project and questions used at the focus group. The foster carer was provided with the honorarium and invited to attend the feedback session and workshop.

Focus group and interview evaluation

All participants were requested to complete an evaluation form (Appendix 4). A total of 10 questions were included in the evaluation. These included a Likert statement, 'yes or no' and open-ended questions. Participants were asked to evaluate the importance of this issue, if the purpose of the focus group was clear, were they encouraged to participate and if there was an opportunity to contribute their point of view. Foster carers were also asked to identify things that they learned from the discussion, what other issues they would have liked to discuss and if they would be interested in receiving further information.

Feedback sessions on focus group and interview findings

At the conclusion of each focus group participants were thanked by the facilitator and given an overview of the next steps for the project. Carers were invited to attend a feedback session to discuss the findings and seek confirmation that they accurately reflected their comments. Carers would be informed via email and mail of the scheduled date and venue for each group.



Analysis process

After each focus group and interview the audiotapes were transcribed verbatim. Non-verbal vocalisations such as laughter and sighs were also documented. Each transcript was read in its entirety and checked for accuracy. Hand written notes taken by the lead investigator and project manager were also used to check the transcripts for accuracy. Field notes from the focus groups and interviews were also provided to researchers by the facilitators for incorporation into analysis. From the transcripts 973 statements or phrases were detected. These statements were edited and statements with similar meanings were used to categorise responses. Consistent with the objective of this study, meaning units were extracted by identifying key words or phrases for the following key areas of investigation: sources of information, sources of help, type of information and resource preferred. Inductive coding of the complete transcripts was also performed to identify underlying themes of the focus groups and interview.

One facilitator commented that discussions at times became ‘freewheeling’ as this enabled the participants to voice their frustrations and share common experiences about caring for foster children who had disabilities or complex physical, emotional and psychological conditions. While sometimes outside the scope of the questions, the facilitator thought this was an important ‘ethical’ aspect to the research.

Results

Twenty six foster carers participated in three focus groups, comprising 10 carers in the metropolitan area and 16 in the regional centre. In addition an individual interview was conducted and included in the analysis. All carers were female. Table 1 provides a breakdown of participants at each focus group. The focus groups included a mixture of experienced and newer foster carers with one or more foster children currently in their care.

Table 1: Summary of participation by venue and interview type

Venue	Interview type	Number of participants
Metropolitan area	Focus Group	10
Metropolitan area	Interview	1
Regional centre	Focus Group	7
Regional centre	Focus Group	9
		27

Q1. How did you find out about FASD?

In analysing the data from this question it was apparent that some carers responded to this question by identifying how they found general information about FASD while other carers responded with specific information about the child in their care. Therefore we report responses about sources of information according to the two categories of ‘sources of general information on FASD’ and ‘information specific to a child’.



General information

The majority of carers gained their general information through direct contact with other foster carers and attendance at meetings organised by foster care services. Some carers obtained information from the internet; however, no one reported obtaining information via hard copy resources. Table 2 summarises who and where foster carers accessed general information about FASD. The use of the internet was contingent on computer access. Some carers stated that not everyone has a computer while others commented that they would like to know that the information available on the internet was accurate as *“a lot of what you get is opinion”*.

This carer’s statement encapsulated the views of the more internet savvy carers.

“If you sit back, you don’t have the information, no-one is going to come to you.”

Table 2: Sources of general information on FASD

Who	Where
<ul style="list-style-type: none"> • Another foster carer • Leader within foster care organisation • NOFASARD – spokesperson • Adoptive parents in New Zealand • Word of mouth • Life experience 	<ul style="list-style-type: none"> • Meetings with presentations by NOFASARD, Wanslea, Ngala, Parkerville Childrens Services • Conferences • Foster carer meeting • Foster carer training sessions • Teaching assistant training • Internet including NOFASARD, Russell Family facebook site, support groups from USA and Australia, UK DVD on FASD available from internet

Foster carers identified a number of barriers to obtaining information about FASD. Several participants commented that there seems to be a great deal of mystery about FASD within the community and a high level of resistance within the Department for Child Protection (DCP) to discuss or provide information to foster carers. One carer noted that she had been a nurse for a long time and had never heard about FASD until she started fostering. Most carers ‘ferret’ out their own information from international websites.

The financial cost of attending meetings and conferences was highlighted as a barrier.

Misinformation was also identified by some participants with one carer reporting that she had been told that FASD was a problem only within Aboriginal communities. Some carers were concerned that information they had found was difficult to understand and was not Australian. Table 3 summarises the barriers to obtaining general information about FASD.



Table 3: Barriers to finding general FASD information

Barriers
<ul style="list-style-type: none"> • Haven't pursued it as too busy coping and trying to manage • Not everyone has access to a computer and the internet • Cost of attending seminars and conferences • Lack of knowledge by health professionals • Some of the information beyond the capabilities of foster carers to understand • Department for Child Protection don't provide anything • Lot of mystery around FASD and concern whether opinion or fact • Have to work it out yourself

Specific information

Health professionals were identified as the main source of information specific to the child in care in relation to FASD. Table 4 summarises where foster carers accessed information specific to a child and who provided this information.

Table 4: Information specific to a child

Who	Where
<ul style="list-style-type: none"> • Paediatrician • Psychiatrist • Other specialist • Psychologist • Aboriginal health worker • Overseas doctor • Personal contact with birth parent 	<ul style="list-style-type: none"> • Child's medical record • Child's DCP case notes • Aboriginal Health Service • Medical service in Australia • FASD clinic overseas

Foster carers reported significant difficulties in accessing specific information related to possible FASD for the child in their care (Table 5). Often the history of prenatal alcohol exposure was unknown to the foster carer. The group reported their perception that the prenatal history and information about the birth mother was withheld from foster carers by DCP and they hypothesised that this could be because of confidentiality issues or because a fear of offending or stigmatising the birth mother. Foster carers also reported poor communication of information to health professionals by DCP. Some carers reported initial consultations with health professionals during which the possibility of a FASD was raised, but this was not pursued.

Table 5: Barriers to obtaining specific information about a child

Barriers to obtaining specific information
No information available 25 years ago
Lost medical records
Unknown pregnancy history/ alcohol exposure
Information about pregnancy history/ alcohol exposure withheld from foster carer
Information about pregnancy history/ alcohol exposure not communicated to health professional
Lack of knowledge and experience of health professional
Difficult to know where to look or go
Health professional not willing to pursue diagnosis
Too sensitive to ask birth mother directly about alcohol use
Suspected diagnosis not communicated by health professional to foster carer
Birth parent declined genetic consultation

Q2. Where did you go and who did you turn to for help?

As indicated in Table 6 foster carers identified more barriers in obtaining help and services compared to enablers. Barriers related to difficulties in ‘navigating’ the health and welfare system, the slow response of the system and the need to follow departmental protocols. Some carers reported feeling disempowered and unable to pursue health assessments on their own initiative.

“You are very limited in what you can do/ they won’t let me take the child to where I want.”

Several carers spoke about their long journey and *“endless rounds of appointments”*.

Carer fatigue was identified as a barrier to pursuing FASD services. Time restraints for the carer were also mentioned e.g. one carer reported needing to use her sick leave to attend medical appointments, whilst another carer reported:

“being too overwhelmed and busy coping, day by day”.



Table 6: Barriers and enablers to obtaining services and support

Barriers to obtaining services/ support	Enablers in obtaining services/ support
DCP protocol, 'red tape'	Supportive case worker
Public system is so slow	
Diagnostic 'labelling' viewed negatively	Diagnosis of specific disorder facilitated support
Foster carers lack of parental rights	
Lack of acknowledgement of child's problems	Allied health/Aboriginal health workers facilitated referral for diagnosis
Lack of knowledge and experience of health professionals	Health professional with FASD knowledge and experience
Misdiagnosis or only co-occurring diagnoses treated	
FASD less easy to recognise than other disabilities	
Lack of recognition of FASD as a disability	Recognition of FASD as a disability/access to disability services
Support services tied to specific diagnoses other than a FASD	Education support/supportive school environment
Foster carer not supported/failure of caseworker/health professionals to validate foster carer's concerns	Doctor/health professional who listens in non-judgmental way
Staff turnover within DCP	
Possible social stigma	
Lack of follow-through on management	Health professional who listens and helps with a plan
Financial restraints	
Time restraints for carer	
Foster carer fatigue	
	Other foster carers – validation and information
Lack of communication of specific information between DCP and health professional	Access to specific information
Lack of FASD specific services	

Carers reported variable experiences in their interactions and relationships with health professionals. Lack of knowledge of FASD and lack of experience of health providers was reported as a barrier. Some carers also reported that while FASD was raised, the health professional either failed to follow-up on this or declined to 'go down that route'. The failure to pursue a full assessment for FASD was perceived as related to multiple factors. One factor reported was the perceived social stigma for the birth mother and also for the child in applying a 'label'. On the other hand obtaining a specific diagnosis was viewed as positive by carers in achieving validation of their concerns and recognition that the child has a disability. Carers were optimistic that a specific diagnosis could assist in accessing support services, including educational support and disability services. Some carers were already accessing educational support or disability services for the child on the basis of a co-occurring or alternative diagnosis including intellectual disability or autism. There was ambivalence regarding other diagnoses e.g. on the one hand the health system is set up to provide support to children with specific diagnoses such as 'autism' but on the other hand, these diagnoses may obscure an underlying FASD. Carers acknowledged the lack of a well-known pathway for diagnosis within the health system and a lack of specific FASD services. Carers highlighted the existing unfairness of the system at present in which FASD is not a recognised disability. Carers acknowledged that other syndromes are easier to recognise and diagnose e.g. *"a child born with Downs, that's easy to recognise"*.

Some carers reported the experience of their child undergoing assessments, but a failure of ongoing management with one reporting:

"clinical psychologist produced a 20 page report, not a lot acted on from that".

In contrast, one carer praised her psychologist. Foster carers valued relationships with health professionals who they felt listened to their concerns in a non-judgmental way.

"When I have had enough she listens and helps with a plan."

"Having a doctor who doesn't judge me and is taking time to listen is huge."

A few carers also reported good support from the school and their DCP case worker.

"We changed to education support and that was just fantastic, education support teachers and principals know their stuff."

"The school psychologist has been excellent."

"The case worker has been great and really supportive."

However, these positive experiences were outweighed by the negative experiences.



The availability of case notes and medical records was viewed as an enabler for obtaining services. Carers also valued good communication between agencies, *“everyone talking to everyone else who is a professional”*; although within the group the overall experience was that good interagency communication was rare.

Emotional experiences of carers

Carers expressed a great deal of emotion when discussing their journey in finding strategies for managing the children in their care. One carer emphatically stated, and was applauded by her fellow carers:

“We are not warehousing these children; we are parenting/raising them”.

One facilitator reported that these women confront significant challenges in their everyday life and it was ethical to allow them ‘space’ to talk about issues that were off the ‘direct topic’ of the discussion. This did seem to help the women feel more comfortable about sharing their experiences and to feel validated by all the ‘research people’.

The general consensus was that it was difficult to get anyone to listen to you and it is a shame that carers have to fight so hard. One carer commented:

“It’s a battle we are fighting and we are being muted”.

Participants across the three focus groups universally agreed that having a child with FASD can be a “living hell” and they have cried when they read what other women write about their experiences with their children. All questioned their ability to look after the children and their parenting skills. Statements included:

“Some days I used to think, well I must be making all this up, must be a hypochondriac.”

“I sometimes think what an awful parent I am.”

“I was so naïve. I thought that everything will go away, they just need a dose of mum and routine care.”

There was also annoyance at the attitude of some health professionals and frustration with the health and welfare system. Carers commented that you have to push and beg for everything, but you get tired and can’t always be that assertive person. One carer stated that she felt sad *“your heart is on your sleeve when you go into bat for them.”* Emotion comes up and the foster carer is perceived as *“just bleating again”*. Another parent stated:

“nothing shatters you more than being judged”.



These statements illustrate the emotional investment that carers have in their role and the increased emotional demands of caring for a child with FASD within what is perceived as a mostly unresponsive and unsupportive system.

Q3 and Q4. What information and resources are helpful and what would you like to be available?

The highest priority for foster carers was someone to listen to them and somewhere to take their children for a diagnosis. Participants hoped that obtaining a FASD diagnosis would enable a plan to be put in place for the child with respect to services required, school support and interventions to prevent other problems in the future. Also a high priority for carers was face-to-face workshops, testimonials and information on what works and how these children learn based on real life experiences. Table 7 encapsulates the discussion by foster carers on what resources they would like to see available with respect to human resources, practical items and print and visual resources.

Table 7: Carers’ preferences for FASD information and resources

Resources	Format/Availability
<ul style="list-style-type: none"> • Human resources <ul style="list-style-type: none"> ✓ paediatrician to diagnose FASD ✓ access to occupational therapist, speech pathologist, psychologist ✓ another foster carer ✓ support group ✓ school aide 	<ul style="list-style-type: none"> • Accessible to children in urban, regional and remote areas • Services available in a timely manner
<ul style="list-style-type: none"> • Practical resources <ul style="list-style-type: none"> ✓ weighted blankets ✓ iPad ✓ apps for children with learning disabilities 	<ul style="list-style-type: none"> • Financial assistance to provide resources that have been identified as practical, useful and relevant for these children
<ul style="list-style-type: none"> • Education and training <ul style="list-style-type: none"> ✓ conferences ✓ seminars ✓ workshops 	<ul style="list-style-type: none"> • Financial assistance to attend conferences and seminars • Priority for face-to-face workshops, particularly strategies for managing children, what works and how they learn, hear from others in the same situation, things to try
<ul style="list-style-type: none"> • DVD 	<ul style="list-style-type: none"> • Australian • Strategies for managing children, what works, learn from others in the same situation, things to try, real life scenarios • Visual – not just someone talking
<ul style="list-style-type: none"> • Paper based resources 	<ul style="list-style-type: none"> • Visual • Not just facts and figures • Language that everyone can understand



<ul style="list-style-type: none"> • Websites/internet 	<ul style="list-style-type: none"> • Reputable sources – need to know based on evidence • Constantly updated • Visual • Language that everyone can understand • Australian • Strategies for managing children, what works and how they learn, hear from others in the same situation, things to try, real life scenarios
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Focus group and interview feedback sessions

One feedback session was held in the regional centre and one in the metropolitan centre. As listed in Table 8, of the original 16 focus group participants in the regional centre 11 foster carers attended the feedback session and in the metropolitan area one of the original 11 participants attended the feedback session. Tables 2 – 7 in this report were used as the basis for the presentation which highlighted the main themes, issues and barriers identified in the analysis of the combined transcripts. Participants were provided with an opportunity to revisit the questions. However no further issues, barriers or enablers were raised. Carers confirmed that the findings were an accurate reflection of their perceptions and they were provided with a copy of the presentation slides. The foster carers thanked the researchers for providing this feedback and asked if there was a plan for developing any of resources that they highlighted as being important or services that were required for the children in their care.

Table 8: Feedback session attendance

Venue	Focus group/interview participants	Feedback session participants
Metropolitan area	11	1
Regional centre	16	11
	27	12



Discussion

In the past 12 years there have been several surveys of Australian health professionals, including paediatricians, Aboriginal health workers, allied health professionals, community nurses, general practitioners and obstetricians, about their knowledge, attitudes and practice about fetal alcohol syndrome [25, 27, 28, 34]. In addition women have been questioned on their knowledge, attitudes and practice with respect to alcohol and pregnancy, and there has been research on dose, timing and patterns of alcohol consumption during pregnancy [35]. However there has been no published Australian research with parents and carers raising children with a FASD.

Although no information was requested from participating foster carers on the number of children they had fostered, were currently fostering or how many children had been diagnosed with a FASD, emerging from the focus group and interview discussions it was evident that the majority of participants had cared for numerous children over many years with at least one child remaining in their care for an extended period of time. Their children ranged in age from infancy through to adulthood. The women participating in the focus groups appeared to be strong and resilient and had faced multiple challenges. It was perceptible from the dialogue that a person currently in their care, whether short or long term, was the reason they attended the focus group.

Foster carers who participated in this project provided salient comments and real life experiences with a number of themes emerging across the focus groups. These were:

- Acknowledgement of the parenting role of foster carers
- Diagnosis and support
 - Lack of knowledge and understanding of FASD by health professionals
 - Importance of a diagnosis
 - Stigma/labelling of children with FASD
 - Issues within the child protection system
- FASD information and resources available in Australia

While the emphasis of the study was on identifying and evaluating FASD information and resources, the foster carers were primarily concerned with the pathway to a diagnosis and specific services and support. Many of the long term carers commented that the children coming into care in more recent years are presenting with behaviours and challenges that were not evident in children a decade ago. In observing these children and talking to other carers they were concerned they had some sort of disability. The pathway to finding out what this disability may be has been challenging to the carers and one that has been vexing, wearying and disappointing.

Acknowledgement of the parenting role of foster carers

Carers were aligned with the views expressed by Dr Dan Dubovsky at the 'It's a Matter of Justice' conference in Canada in April 2012, that foster families are often dismissed or seen as over protective and interfering [36]. In speaking about how we ensure social justice Dr Dubovsky noted that we need to ask "*what does this person need in order to be successful and how do we provide it for him or her*". Carers were unanimous in agreement that they only wanted to find out what was wrong with the child and how they could best help. They were prepared to accept the diagnosis if it meant they could better understand the person and their strengths and weaknesses. Success for each person is not the same and carers wanted to know what was reasonable to expect at different



ages, seeking integrated pathways to all services required for different aspects and more information that informs them how they can effectively care for FASD children. There is a perceived need for recognition of foster carers and their commitment and level of expertise. Many carers expressed sadness that they were not acknowledged and it was difficult to get someone to listen to them. This sentiment was expressed by one carer:

"I came out nearly crying, they shut you down."

Research on risk factors for children with FASD and foster parent perceptions [19, 37, 38] reports on the seminal importance of 'inclusion' for foster carers and the influential protection factor of a nurturing home environment. The Australian Foster Care Association report *Supporting strong parenting in the Australian foster care sector* also referred to the 'self-perceptions' of foster carers [1]. It was recounted that *"many foster carers are suffering a degree of dissonance brought about by a conflict between their perceptions of themselves as competent and informed foster carers and the treatment they receive from people in administrative and/or 'worker' positions."* Foster carers must be nurtured and not made to feel inadequate or blame themselves. They require information, training and support or peer mentors to enable them to feel competent and to continue in their role as a parent to these children.

"We don't want to lose carers because we don't have support."

Diagnosis

Knowledge and understanding of FASD by health professionals

In surveys conducted in 2006 and 2007, only 40% of paediatricians and 28% of other health professionals responded that they were very prepared or fairly prepared to deal with FAS [27, 28]. Participants in the focus groups reported encountering a high level of resistance from many health professionals to deal with the question of *"could my child have a fetal alcohol spectrum disorder?"*

The majority of foster carers who had managed to get an appointment with a paediatrician reported that they were not prepared to deal with FASD or FAS. Carers formed this view through paediatricians' comments such as:

".. he has FASD but [let's] deal with the problem, let's put him on Ritalin and Catapres, let's fix his behaviour"

Carers felt that this reflected the paediatricians' lack of understanding and reticence to make this diagnosis. Carers also stated that the conversation usually stops when you ask about the role alcohol may have as a cause for the child's complex health and behavioural problems, even in one case when the psychiatrist had evidence of the mum's alcohol abuse. The few carers who indicated that they had a supportive paediatrician, general practitioner or psychologist, espoused how valuable they had been and at times a life line to maintaining their sanity. One carer commented that the psychologist



was as much for her as for the child. Elizabeth Russell founder of the Russell Family Fetal Alcohol Disorders Association (rffada) offers salient advice to parents and carers to be proactive about their own physical and mental health.

Importance of a diagnosis

While not specifically a FASD ‘resource’, carers placed access to well informed health professionals who can discuss FASD and make an appropriate diagnosis for each child, as a high priority. Contrasted with the dominant foster carer views that diagnosis will help them better understand the child and what interventions are necessary, the 2007 survey of paediatricians reported only 65.9% agreement with the statement that an early diagnosis of FAS may improve treatment plans for the affected child [27]. Leading FASD experts in the fields of psychiatry and behavioural sciences support early diagnosis and have concluded that the likelihood of avoiding harmful and life affecting outcomes are increased two to four fold by receiving the diagnosis of FAS at an earlier age [19]. The case for early diagnosis of FASD is strongly supported by NOFASARD. In her many presentations and workshops Ms Sue Miers AM, the NOFASARD Chair, has advocated for diagnosis as the catalyst that opens the door to meeting the child’s needs, brings relief and provides a reason for the child’s difficulties and paves the way for different parenting approaches and to see their child as one who maybe ‘can’t do’ rather than one who ‘won’t do’.

Stigma/labelling children with FASD

Stigmatising or labelling children was raised as a reason for health professionals not making a diagnosis of FAS or FASD. Experiences of foster carers in the focus groups with health professionals was consistent with the evidence from the surveys of paediatricians and other health professionals that reported levels of agreement from 45% to 64% with the statement that the diagnosis of FAS may lead to a child or their family being stigmatised [27, 28]. Foster carers provided examples of what health professionals had said to them when discussing a diagnosis:

“FASD [is] probable, but let’s not go down that road, let’s stick to autism”
“... not going to be of any value to him really should come under the heading of autism”
“.. this child has FASD but let’s not pursue”

Carers were also of the view that DCP had concerns about diagnosing children in care with FASD as this may further stigmatise the child. As support groups for people with FASD and their parents and carers, NOFASARD and rffada have gathered many stories from both birth mothers and foster carers raising children with FASD. As passionate campaigners both Elizabeth Russell and Sue Miers say that respect is paramount to successful treatment and that we need to build a non-judgmental environment in which health professionals and service providers can discuss the issue of prenatal alcohol exposure.

Issues within the Child Protection System

Compounding the issue of diagnosis of children in care was the perception by foster carers of significant barriers due to attitudes and processes within DCP. Research which described the outcomes of children assessed for FASD in the UK found that it was difficult to obtain detailed information on a child in care’s early health and development [21]. The lack of information about family history and alcohol consumption, which form part of any assessment for FASD, resulted in



many cases being designated 'indeterminate'. Many carers were of the view that DCP does not provide information to the health professionals to assist in assessing and diagnosing children. Several carers reported that their doctor was exasperated in trying to deal with DCP who promised to provide previous health records but this was not expedited and in some cases never provided. While acknowledging that they would like to have access to the child's medical history so they could provide this to the health professional, carers considered DCP to be too protective of the parents, concerned about offending the mother and not providing the best opportunity for the child. The general consensus was that DCP had a policy of not acknowledging FAS or FASD. Many carers were of the belief that this was based on the breadth of the problem and that these children will require considerable support and services. In his presentation at the April 2012 'It's a Matter of Justice' conference in Canada, Dr Stephen Greenspan made the statement that *"disability classification definitions emerge from a political process in which economic considerations play a prominent (and maybe most prominent) role"* [39].

Availability of information and resources

Foster carers take on the caring role as they feel they have something to offer. Although receiving basic funding to cover the immediate needs of the foster child, which has financial benefits for governments, they are viewed as volunteers [1]. Carers bring different experiences and training to their roles as carers of children in need. While basic training is provided to potential carers before they commence their new role they very quickly learn that they need to acquire different skills to meet the challenges of caring for these children.

Of relevance to the majority of carers was the need for face-to-face training and workshops. Carers reinforced the view that the information had to be practical, based on real life experiences of what works for children, adolescents and adults. The requirement for education and training to support families raising children affected by FASD is supported in the literature [19, 37, 38]. The 2001 Australian Foster Care Association report refers to the lack of opportunities for further training and if they (foster carers) do attend training it is usually at their own cost with little recognition in return and no recompense [1]. The preponderance of foster carers use their own parenting skills, however there is a requirement for specific training for people caring for children with a FASD.

Some of the foster carers expressed a view that there should not be a reliance on web based information as not all carers had access to or used computers. Others commented that they were:

"too busy coping and trying to manage, rather than doing the research to find out what they should be doing."

However other carers commented that they had found the majority of their information on FASD from international on-line sources. Information that was highly visual, testimonials and real life experiences were viewed as 'must haves' in print and on-line FASD resources.

Focus group evaluation

Evaluation forms were received from 22 of the 27 participants (82%). Participants unanimously agreed (100%) that the issue was of importance to them and valued the opportunity to participate in the focus group. The open-ended questions evoked 40 statements from participants with many



highlighting the need for, and importance of workshops and information sessions on this topic. Participants also commented that FASD is still not widely understood by all medical practitioners and there is a lack of support for diagnosis. Foster carers were concerned that it was difficult for them to get support and information and they need understanding as foster carers dealing with a very difficult problem. The outcomes are presented in Table 9.

Table 9: Combined results of focus group evaluation

Question	Response		
	<i>Very Important</i>	<i>Important</i>	<i>Not important</i>
How important is this issue to you?	19	3	
	<i>Yes</i>	<i>No</i>	
Was the purpose of the focus group discussion clear to you?	22		
Did you feel encouraged to participate in the discussion?	22		
Did you feel you were given sufficient opportunity to contribute your point of view?	22		
Did the discussion help you to understand other points of view?	22		
Would you be interested in receiving information about Telethon Institute for Child Health Research projects, seminars and community activities?	17	2	
What are two or three things you learned from the discussion today that you were not aware of before:	<ul style="list-style-type: none"> • Links to sites for information on FASD • Name of paediatrician who can assess your child • I learnt today that FASD is still not widely understood by all medical practitioners • I was also made aware of how little support there is • That something is being done • The Institute's involvement • Recognition of the syndrome • I can go to Rheola Street and get a diagnosis • To keep pushing for help • To keep looking into websites • Lack of support for diagnosis • Other resources available • How wide spread FASD is • How you want to help us • Very good information very nice easy to talk to Tracy, Amanda and Heather well done • Not alone • Was aware, was good to have a revisit • How difficult for other carers to get support and information 		



	<ul style="list-style-type: none"> • Was unaware the Telethon Institute for Child Health Research were working on FASD recognition and management • It's very common • Where to get help neuro science unit (children can be assessed) • There needs to be more information available to all carers, professionals and schools • It's wide spread
<p>Are there any issues that you feel were not discussed today that should have been?</p>	<ul style="list-style-type: none"> • Would like to have covered symptoms and strategies, but understand this was not the goal of today's meeting • Maybe nutrition for children with FASD – very important • Alternative therapies that work – naturopath etc • Given the common trait of 'lack of impulse control' what behavioural management programs work • Not really I felt it was well covered
<p>Do you have any other comments you would like to add?</p>	<ul style="list-style-type: none"> • Thank you for your time to present today • I am very hopeful that Australia will catch up with the rest of the world re FASD • Keep up the good work – get the message out there • Thank you for the petrol money it was much appreciated • Please visit us again • It would be great to have information about supports for families moving into upper teen years – where to go, what works in relation to 'working' what could that look like • Perhaps have someone who has 'been there, done that' speak to foster carers • With the new health passport for children, carers should be able to ask the health nurses to put their suspicions for FASD. Without diagnosis (which is hard to get) they generally won't put it down • It was good to be listened to • Tracy was fantastic • More information groups like this • I feel we need more support and understanding as foster carers dealing with a very difficult problem



Current Australian FASD Resources

Methods

Identification of Australian FASD resources for foster carers was undertaken in three ways:

1. Members of the Reference Group
2. Focus Group participants
3. Project team

Reference Group

Members of the Reference Group were asked to provide links or copies of FASD information and resources for foster carers and parents that they had read or accessed via the internet to the project team.

Focus Group

Prior to participating in the focus groups, carers were asked to complete a paper-based 'FASD Websites, Resources and Services Evaluation Form' (Appendix 5). This evaluation form asked participants to circle responses which best matched their views on websites and resources with a ranking scale of 1 being very informative, useful and relevant to 6 being very poor, not useful and not relevant. Participants were also asked to use a rating scale of 1 – 6 for services and organisations with respect to their personnel, outcomes, waiting time for response and advice or support.

Project Team

The project team undertook a review of publicly available Australian specific FASD resources for parents and carers. This search included resources available via the internet or in hard copy. The on-line search included resources available from not-for-profit organisations; the Western Australian Departments of Communities, Education and Training, Child Protection and Health and their interstate counterparts; and other organisations. The search was conducted using combinations of the following terms: alcohol effects, fetal/foetal alcohol effects, Fetal Alcohol Syndrome/FAS, Fetal Alcohol Spectrum Disorders/FASD, foster carers, parents, Western Australia, Australia, resources and information. The search excluded resources which were primarily tools for primary prevention such as alcohol and pregnancy brochures and resources that are principally for health professionals.

Results

Reference Group

Several members commented that they had found Sue Miers, the spokesperson for NOFASARD and the NOFASARD website very helpful. Sue was able to talk to them about real life experiences and make practical suggestions for trying to get a diagnosis and managing the children. One member of the Reference Group identified several international websites that she had accessed to find out about FASD. These websites are included in the list of international websites on pages 55-56 of this report.



Focus Group

The FASD Websites, Resources and Services Evaluation Form was completed or partially completed by 10 carers. The results are presented in Table 10. One person referred to a website which included photos of children with FAS but did not provide the actual website link. One carer referred to 'Grog babies' as a resource and another called it an organisation, however as the forms were completed anonymously we have been unable to identify the organisation to which the person was referring. Researchers were aware of 'FAS dolls' used in workshops by Lorian Hayes and NOFASARD to demonstrate the facial features of a baby with FAS. Only one person reported a negative experience with an organisation. Princess Margaret Hospital was given a ranking of 4 for personnel, outcomes, waiting time for response and advice/support.

Table 10: Results of the foster carer evaluation of resources (n=10)

NOFASARD (n=3)						
	<i>Positive</i>					<i>Negative</i>
	1	2	3	4	5	6
Informative	1 (33%)	2 (67%)				
Useful		3 (100%)				
Relevant		3 (100%)				
Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorder: A Resource for Health Professionals (n=2)						
	<i>Positive</i>					<i>Negative</i>
	1	2	3	4	5	6
Informative	1 (50%)	1 (50%)				
Useful	1 (50%)	1 (50%)				
Relevant	1 (50%)	1 (50%)				
Foster Care Association (n=2)						
	<i>Positive</i>					<i>Negative</i>
	1	2	3	4	5	6
Informative		2 (100%)				
Useful	1 (50%)	1 (50%)				
Relevant	2 (100%)					
Let's talk FASD (n=2)						
	<i>Positive</i>					<i>Negative</i>
	1	2	3	4	5	6
Informative		2 (100%)				
Useful	1 (50%)	1 (50%)				
Relevant	1 (50%)	1 (50%)				



Grog Babies (n=1)						
	<i>Positive</i>					<i>Negative</i>
	1	2	3	4	5	6
Informative		1 (100%)				
Useful		1 (100%)				
Relevant	1 (100%)					
FASD Photos website (n=1)						
	<i>Positive</i>					<i>Negative</i>
	1	2	3	4	5	6
Informative		1 (100%)				
Useful		1 (100%)				
Relevant		1 (100%)				
Other meetings and seminars for foster carers (n=1)						
	<i>Positive</i>					<i>Negative</i>
	1	2	3	4	5	6
Informative		1 (100%)				
Useful			1 (100%)			
Relevant		1 (100%)				
Princess Margaret Hospital for Children (n=1)						
	<i>Positive</i>					<i>Negative</i>
	1	2	3	4	5	6
Informative				1 (100%)		
Useful				1 (100%)		
Relevant				1 (100%)		

Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs (n=1)						
	<i>Positive</i>					<i>Negative</i>
	1	2	3	4	5	6
Personnel		1 (100%)				
Outcomes						
Waiting time for response						
Advice /support						



Department for Child Protection training (n=2)						
	Positive					Negative
	1	2	3	4	5	6
Personnel	1 (50%)	1 (50%)				
Outcomes		2 (100%)				
Waiting time for response						
Advice /support	1 (50%)	1 (50%)				
NOFASARD/Sue Miers (n=2)						
	Positive					Negative
	1	2	3	4	5	6
Personnel		2 (100%)				
Outcomes	1 (50%)	1 (50%)				
Waiting time for response		2 (100%)				
Advice /support	1 (50%)	1 (50%)				
Fostering Service Conference 2011 (n=2)						
	Positive					Negative
	1	2	3	4	5	6
Personnel	1 (50%)	1 (50%)				
Outcomes	1 (50%)	1 (50%)				
Waiting time for response	1 (50%)	1 (50%)				
Advice /support	1 (50%)	1 (50%)				
Grog Babies (n=1)						
	Positive					Negative
	1	2	3	4	5	6
Personnel		1 (100%)				
Outcomes		1 (100%)				
Waiting time for response		1 (100%)				
Advice /support		1 (100%)				



Project Team

Having reviewed over 50 websites and resources the Lead Investigator and Project Manager identified the following Australian FASD resources which are primarily for parents and carers of children with a FASD. A summary of each resource is provided on pages 29-48 of this report.

Support Organisations:

- National Organisation for Fetal Alcohol Syndrome and Related Disorders
- Russell Family Fetal Alcohol Disorders Association

Websites:

- National Organisation for Fetal Alcohol Syndrome and Related Disorders
- Russell Family Fetal Alcohol Disorders Association
- Telethon Institute for Child Health Research: Alcohol, Pregnancy and FASD
- Government of South Australia, Women's and Children's Health Network
- Physical as anything

Booklets and brochures:

- Fetal Alcohol Spectrum Disorders (FASD) The Preventable Disability
- Foetal Alcohol Spectrum Disorder (FASD) Information for People Working with Children and Families
- Living with Fetal Alcohol Spectrum Disorder: A Guide for Parents and Caregivers
- Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorders: A Resource for Health Professionals
- Government of Queensland, Care Plan for FASD
- Fostering Services Fact Sheet: Foetal Alcohol Spectrum Disorder

DVDs:

- Drinking for Two
- Tristan: Hopes, dreams and challenges of a young boy living with a FASD

Training Courses:

- National Organisation for Fetal Alcohol Syndrome and Related Disorders
- Russell Family Fetal Alcohol Disorders Association
- National Indigenous Australian Foetal Alcohol Syndrome Education Network
- Rural Health Education Foundation

Churchill Fellowship Reports:

- Education of Students with Fetal Alcohol Spectrum Disorder
- Models of Care for children with Foetal Alcohol Syndrome
- Prenatal alcohol exposure and the impact on parenting affected children especially in Aboriginal communities in Canada and the United States of America



National Organisation for Fetal Alcohol Syndrome and Related Disorders

Organisation: National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD)

NOFASARD is the peak national non-government organisation representing the interests of parents, carers and others interested in or affected by FASD.

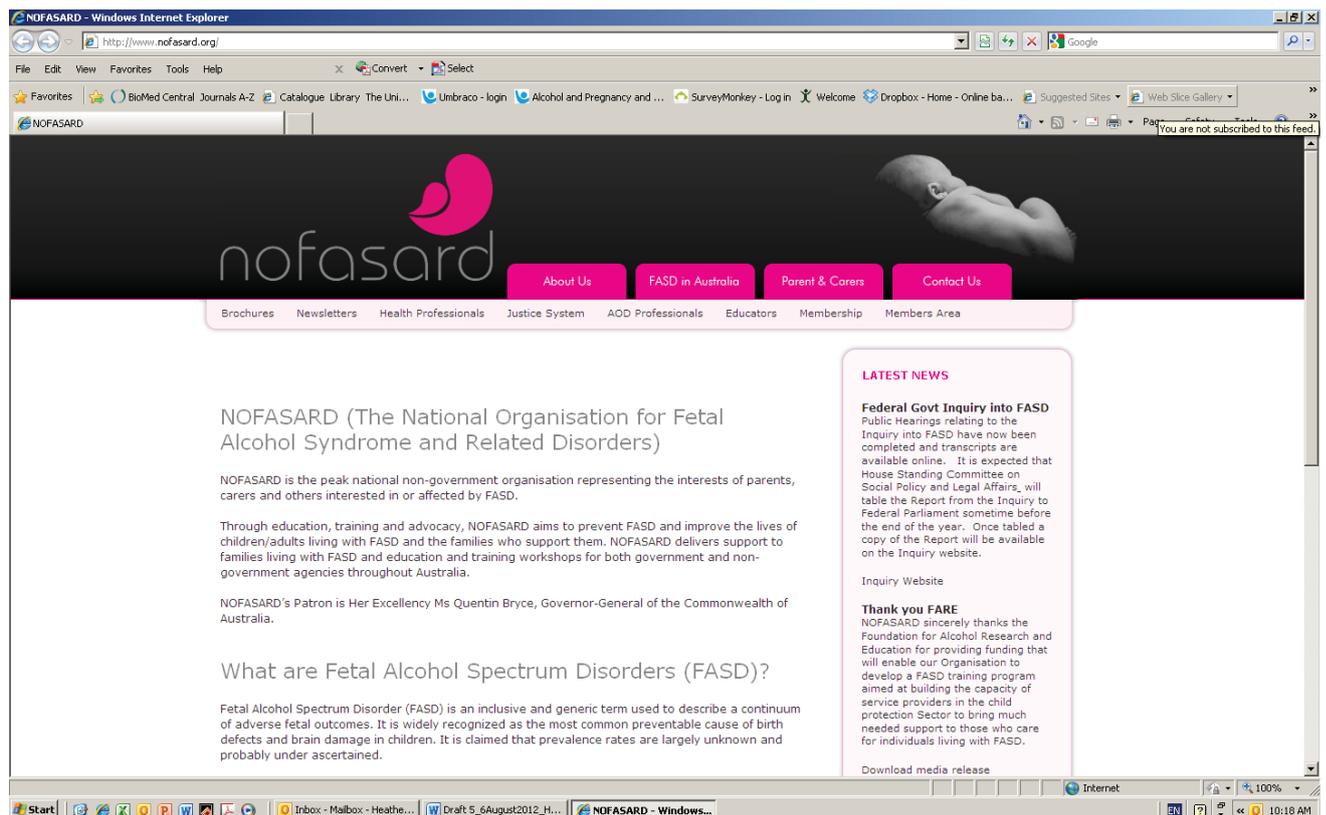
Through education, training and advocacy, NOFASARD aims to prevent FASD and improve the lives of children/adults living with FASD and the families who support them. NOFASARD delivers support to families living with FASD and education and training workshops for both government and non-government agencies throughout Australia.

Contact:

Email: admin@nofasard.org.au

Phone: 1300 306 238

Type of Information: Website <http://www.nofasard.org/au>



Date of publication: Current

Cost: No cost

Accessibility: Computer access, however advice is available over the phone and information can be mailed to people without computer or printer access.

Target audience: Parents, carers, service providers, professionals, community groups, policy makers

Content: Newsletters, information on FASD for parents and carers, health professionals, educators, justice and other professionals. Links to other organisations and sources of information

Language: English

Cultural sensitivity: Australian mainstream

Very good source of information for parents and carers. Contacts have friendly manner, extremely knowledgeable, approachable and offer practical advice and service to parents and carers.



Russell Family Fetal Alcohol Disorders Association

Organisation: Russell Family Fetal Alcohol Disorders Association (rffada)

rffada is a not-for-profit health promotion charity dedicated to ensuring that individuals affected prenatally by alcohol have access to diagnostic services, support and multidisciplinary management planning in Australia and that carers and parents are supported with a “no blame no shame” ethos.

Contact:

Email: Elizabeth (Anne) Russell anne@trainingca.com.au

Phone: 1800 733 232

Type of Information: Website <http://rffada.org/>

The screenshot shows the website for the Russell Family Fetal Alcohol Disorders Association (RFFADA) in a Windows Internet Explorer browser window. The browser's address bar shows the URL <http://rffada.org/>. The website has a dark blue header with the RFFADA logo on the left, the text "Russell Family Fetal Alcohol Disorders Association" in the center, and a search bar on the right. Below the header is a navigation menu with links for Home, FASD, About RFFADA, Parents and Carers, Health Professionals, Training, Partners & Resources, and a red "Donate" button. The main content area features the RFFADA logo, a description of the organization as a not-for-profit health promotion charity, and a list of six goals for the future of FASD prevention and management in Australia. A "Donate" button with logos for Bank, Visa, and Mastercard is also visible. The footer contains "Drinking Guidelines" and "Fetal Alcohol Spectrum Disorder information for all Australians". The browser's taskbar at the bottom shows the Start button, several open applications, and the system clock displaying 10:19 AM.

Date of publication: Current

Cost: No cost

Accessibility: Computer access, however advice is available over the phone and information can be mailed to people without computer or printer access.



Target audience: Parents and carers, health professionals, educators and justice professionals

Content: Newsletters, information about FASD, newsletters, information for health professionals, educators and justice professionals.

Language: English

Cultural sensitivity: Australian mainstream

Very good source of information particularly for birth mothers. Links to many international sites containing information for a range of professionals, parents and carers.



Alcohol, Pregnancy and FASD

Organisation: Telethon Institute for Child Health Research (Telethon Institute)

Contact:

Email: fasd@childhealthresearch.org.au

Phone: 08 9489 7724

Type of Information: Website <http://alcoholpregnancy.childhealthresearch.org.au/>



Date of publication: Current

Cost: No cost

Accessibility: Computer access, however if contacted by phone information can be mailed to people without computer or printer access.

Target audience: Consumer and community, health professionals, justice and other professionals and researchers

Content: Current Telethon Institute projects on FASD, previous projects, other FASD projects in Australia, alcohol and pregnancy resources for health professionals, Alcohol Guidelines, information for parents and children living with a FASD, where to go for assistance, links to sources of Australian and international information for parents/carers, health professionals, workers in the health, educational and justice sectors, parliamentary inquiries and reports



Language: English

Cultural sensitivity: Australian mainstream

Provides good information on the current research in FASD throughout Australia and links to many sources of information in Australia and other countries for parents and carers

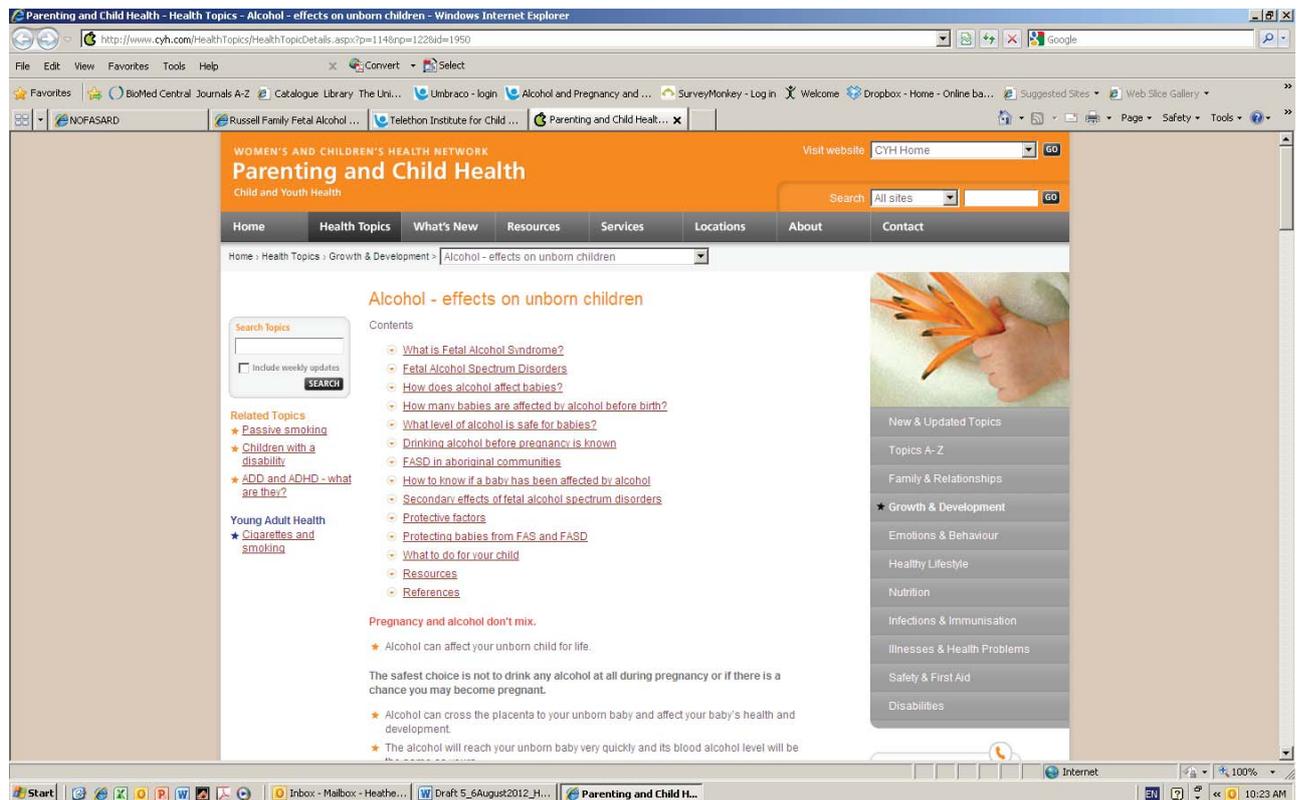


Alcohol – effects on unborn children

Organisation: Government of South Australia, Women’s and Children’s Health Network

Type of Information: Website

<http://www.cyh.com/HealthTopics/HealthTopicDetails.aspx?p=114&np=122&id=1950>



Date of publication: Current

Cost: No cost

Accessibility: Computer access

Target audience: Pregnant women and families

Content: What is FAS and FASD, how does alcohol affect babies, how do I know if a baby has been affected by alcohol, secondary effects of FASD and what to do for your child

Language: English

Cultural sensitivity: Australian mainstream

Provides good information for women and families

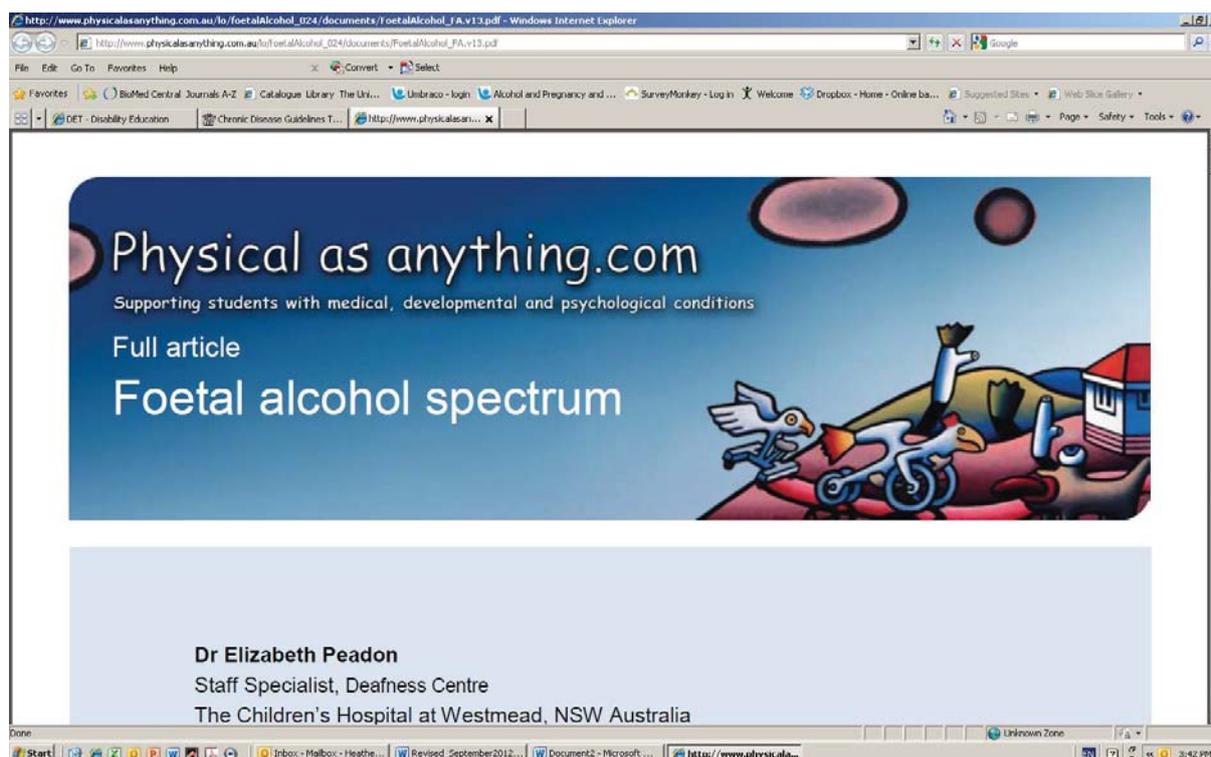


Physical as anything

Organisation: NSW Department of Education and Communities and the Children's Hospital at Westmead

Type of Information: Website

http://www.physicalasanything.com.au/lo/foetalAlcohol_024/documents/FoetalAlcohol_FA.v13.pdf



Date of publication: Current

Cost: No cost

Accessibility: Computer access

Target audience: Parents and carers

Content: Information on FASD, how students are affected by FASD and helping students affected by FASD. There are links to NSW Department of Education website, including student support disability programs

Language: English

Cultural sensitivity: Australian mainstream

Good source of general information on FASD and helping children with FASD



Fetal Alcohol Spectrum Disorders (FASD) The Preventable Disability

Organisation: National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD)

Type of Information: Booklet



Date of publication: Current

Cost: No cost for booklet however postage and handling is charged if mailing the booklets

Accessibility: Can be ordered from the NOFASARD website <http://www.nofasard.org> or [phoning 1300 306 238](tel:1300306238)

Target audience: Service providers

Content: Describes FASD, what are some of the signs that might indicate a child has FASD, diagnosis and prognosis, what is different about the way adults with FASD may behave, secondary issues and FASD

Language: English

Cultural sensitivity: Australian mainstream

Although targeted at service providers this booklet also provides an overview of FASD and would be suitable for parents and carers

Foetal Alcohol Spectrum Disorder (FASD) Information for People Working with Children and Families

Organisation: Government of Western Australia Department for Communities

Type of Information: Booklet

Date of publication: Current

Cost: No cost

Accessibility: Can be downloaded from Department for Communities website

http://www.communities.wa.gov.au/parents/parentingresources/Documents/Foetal_Alcohol_Spectrum_Disorder_FASD_Booklet.pdf



Target audience: People working with children and families

Content: What is FASD, what causes it, effects of alcohol on the unborn child, signs of FASD, behaviour challenges caring for children with FASD, helping children with FASD,

Language: English

Cultural sensitivity: Australian mainstream

Excellent source of information about FASD and some guidance on caring for children with FASD



Living with Fetal Alcohol Spectrum Disorders: A Guide for Parents and Caregivers

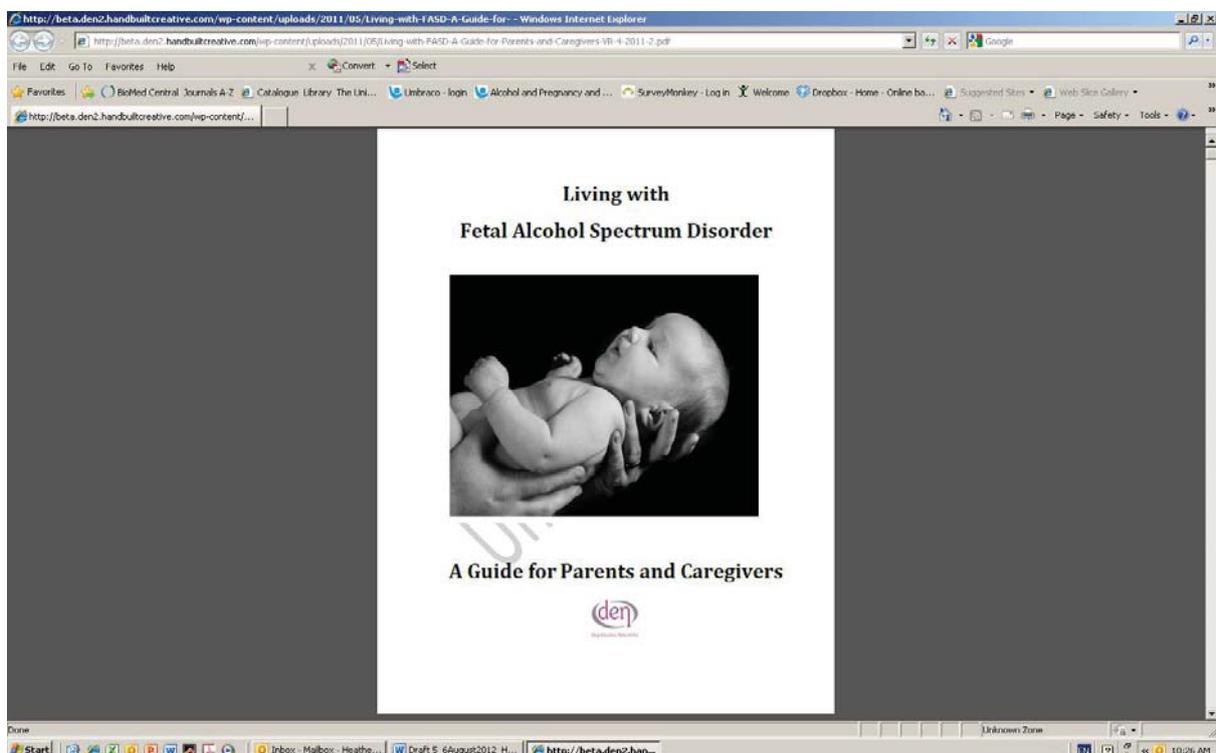
Organisation: Drug Education Network Inc

Type of Information: Booklet

Date of publication: Current – under review

Cost: No cost

Accessibility: Can be downloaded from website <http://beta.den2.handbuiltcreative.com/wp-content/uploads/2011/05/Living-with-FASD-A-Guide-for-Parents-and-Caregivers-VR-4-2011-2.pdf>



Target audience: Parents and carers of children with FASD

Content: Understanding FASD, primary disabilities, referral, screening and assessment, advocacy, care strategies, supervision, educating a child with FASD, care of caregivers and families

Language: English

Cultural sensitivity: Australian mainstream

Excellent source of FASD information for parents and carers in easy to read format



Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorder: A Resource for Health Professionals

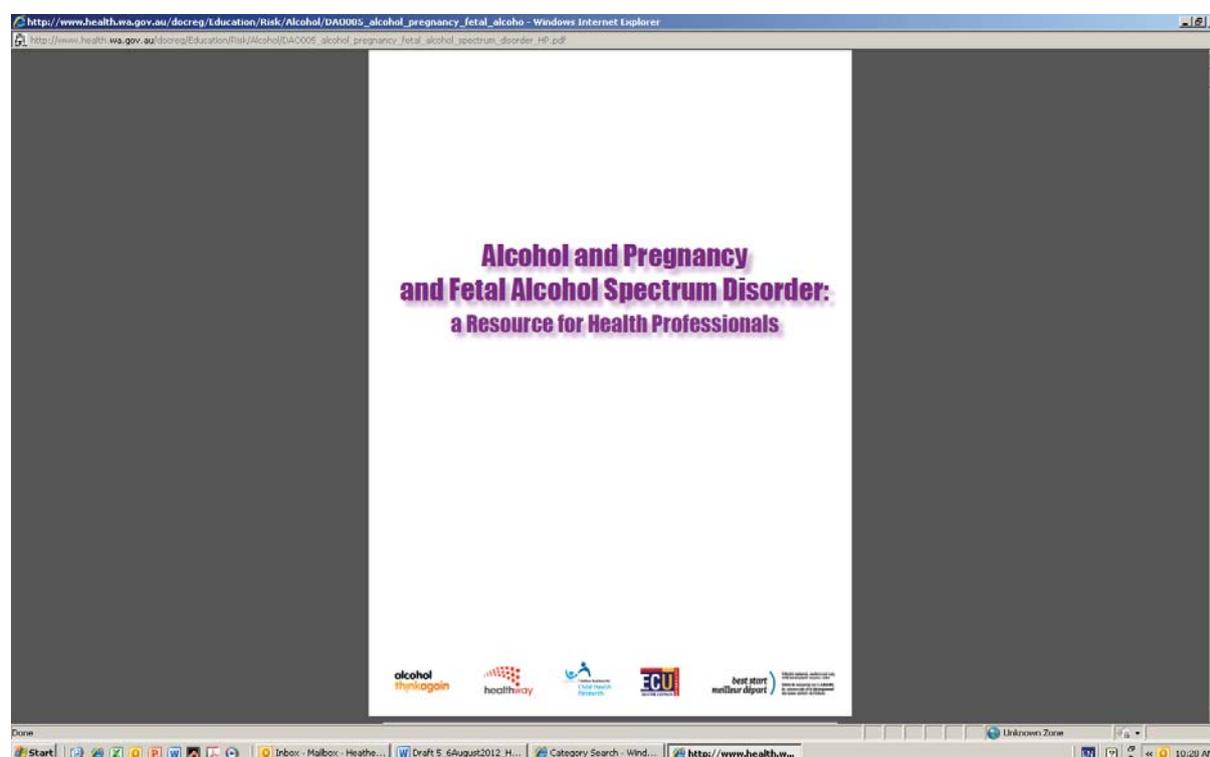
Organisation: Telethon Institute for Child Health Research (Telethon Institute)

Type of Information: Booklet

Date of publication: 2007, First revision 2009

Cost: No cost

Accessibility: Can be downloaded or ordered free of charge from Department of Health Online publication ordering website <http://www.dohpackcentre.com.au/DOH/LoginMain.aspx>



Target audience: Health professionals, however contains information that could be read by parents and carers

Content: Information about alcohol use in pregnancy, consequences of drinking alcohol in pregnancy, role of the health professional, asking, advising and assisting women during pregnancy, suspecting FASD, families affected by FASD

Language: English

Cultural sensitivity: Australian mainstream

Excellent source of information on alcohol, pregnancy and FASD for health professionals but can also provide general information for parents and carers



FASD Care Plan

Organisation: Government of Queensland, Department of Health

Type of Information: Care Plan

http://www.health.qld.gov.au/cdg/docs/careplan_fas_dis.pdf

Active	Frequency	
	Dx	Ongoing
Height	Dx	All each immunisation check to 18 months then at scheduled reviews
Weight	Dx	All each immunisation check to 18 months then at scheduled reviews
Head circumference	Dx	All each immunisation check to 18 months then at scheduled reviews
Education about FASD and profile of development	ABC	At each appointment and providing anticipatory guidance at significant points such as birth, early childhood, school entry, puberty, transition to adulthood
Social emotional wellbeing	Dx	For carer and child at every contact
Hearing	*	Neonatal universal screening. Audiology mandatory in suspected developmental delay at presentation (and if parental speech or chronic middle ear disease)
Vision	GVE	With routine health checks. Consider formal testing if concerns about developmental delay.
History	Dx	At each child health check
Physical exam (including BP)	Dx	At each child health check
Neurobehavioural assessment and testing	Dx	As guided by clinical need. Consider formal testing around time of school entry if significant concerns
Developmental assessment	Dx	Brief screening at times of immunisation checks. Further assessment if concerns
ORU/ HW	Dx	All routine child health checks from birth
Speech therapist	Dx	As required
Dietitian	Dx	As required
Physiotherapist / OT	Dx	As required
Paediatrician	Dx	At time of 'red flag' being identified or concerns about development or risk. Ongoing care shared with MO as arranged
Psychiatrist	Dx	As required
Multidisciplinary care plan (carer or family member, HW, MO, GPs) and paediatrician (if FASD), psychologist, social worker	Dx	Age 3 years, age 5 years, prepubertal, school leaving

Date of publication: Current

Cost: No cost

Accessibility: Computer access

Target audience: Health professionals, however contains information that could be read by parents and carers

Content: Chronic Disease Tools/Fetal Alcohol Spectrum Disorder, what assessments are required

Language: English

Cultural sensitivity: Australian mainstream

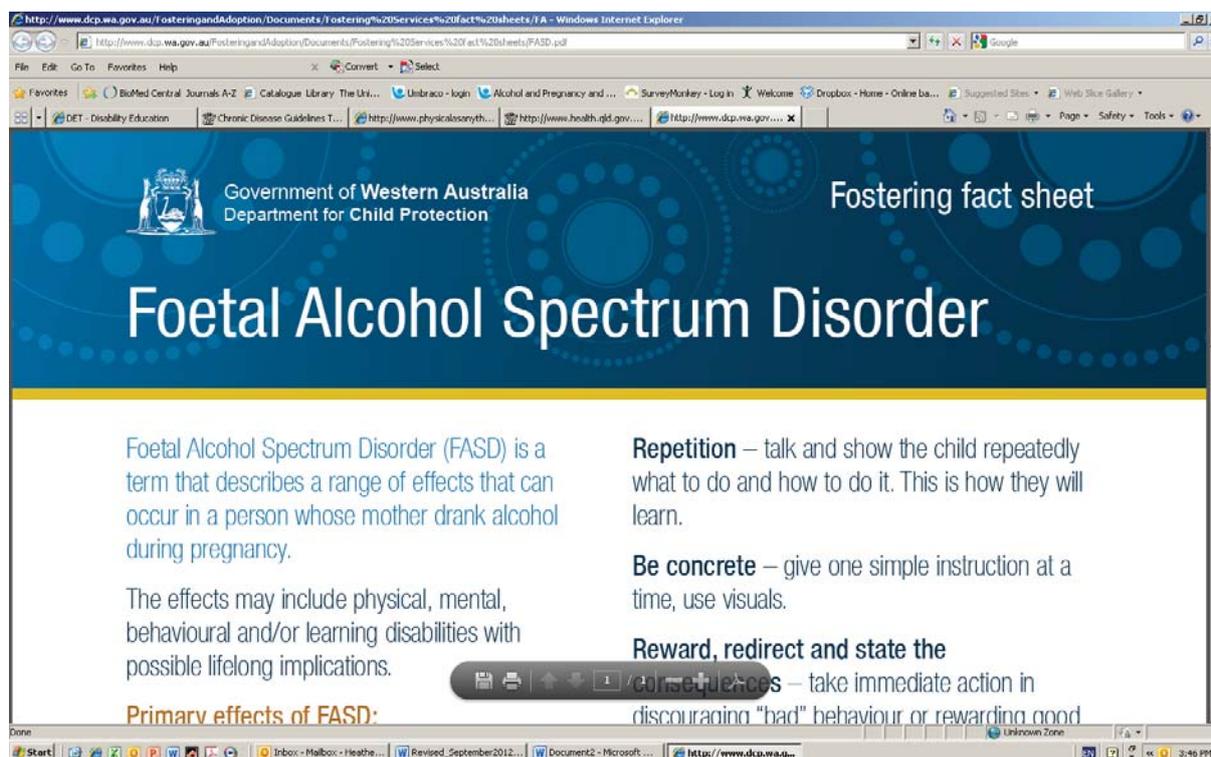
Provides guidance for health professionals on assessments required for FASD diagnosis

Fostering Fact Sheet: Foetal Alcohol Spectrum Disorder

Organisation: Government of Western Australia, Department for Child Protection

Type of Information: Fact Sheet

<http://www.dcp.wa.gov.au/FosteringandAdoption/Documents/Fostering%20Services%20fact%20sheets/FASD.pdf>



Date of publication: Current

Cost: No cost

Accessibility: Computer access

Target audience: Foster carers

Content: Primary and secondary effects of FASD and helping children with FASD

Language: English

Cultural sensitivity: Australian mainstream

Provides easy to understand information for foster carers



Drinking for Two

Organisation: Rural Health Education Foundation

Type of Information: DVD (26 minutes)

Date of publication: Produced 2007

Cost: DVD \$110.00 to purchase or can be viewed via website at no cost

Accessibility: Order DVD or view DVD from website http://www.rhef.com.au/programs/program-1/?program_id=17

Target audience: Parents, carers, pregnant women and families

Content: Overview of FASD, vignettes of Australian families with FASD individual, overview of prevention programs for Aboriginal communities

Learning Outcomes:

- Understand the potential impact on the unborn child of drinking alcohol in pregnancy.
- Recognise the ongoing developmental consequences for a child with FASD.
- Identify the issues for ongoing management and support for a child or adult with FASD.
- Identify the links between education, health professionals and community involvement when enabling preventative strategies for FASD.

Language: English

Cultural sensitivity: Australian, inclusive of Aboriginal perspectives

Excellent audio-visual resource, Australian content



Tristan: Hopes, dreams and challenges of a young boy living with a FASD

Organisation: Marninwarntikura Women's Resource Centre and Nindilingarri Cultural Health Services

Type of Information: DVD

Date of publication: 2011

Cost: \$50 plus postage

Proceeds go towards supporting the Tristan Foundation

Accessibility: Order through Marninwarntikura Fitzroy Women's Resource Centre

Phone: 08 9191 5284

Fax: 08 9191 5611

Email: Projects@mwrc.com.au

Target audience:

Content: Story of a 12-year old boy born with FASD and the challenges he faces living in the north-west of Western Australia

Language: English

Cultural sensitivity: Aboriginal

Excellent real-life story, personal point of view of an affected child and his family and community



Community Education and Training Workshops

Organisation: National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD)

Type of Information: Face-to-face workshops

Date of publication: Current

Cost: NOFASARD is a not for profit organisation. Cost per day is negotiable (approximate \$500.00 per day)

Accessibility: Contact Vicki Russell on 1300 306 238 or email admin@nofasard.org.au

Target audience: Training workshops may be tailored to the audience of interested professionals and/or community groups.

Content: Community education sessions aim to inform and raise awareness of FASD and the implications for individuals, carers and families. FASD training workshops are developed with a community development approach aimed at building skill capacity and strategies to enable appropriate responses to local need.

Language: English

Cultural sensitivity: Australian mainstream

High quality presentations, valuable for practical strategies and real life experiences



FASD for Parents and Carers (Module 3)

Organisation: FASD Training is conducted in partnership between the Russell Family Fetal Alcohol Disorders Association and the Australia-wide Registered Training Organisation, Enterprise Management Group trading as Training Connections Australia (TCA).

Type of Information: Training workshops

Date of publication: First developed in 2002, revised in 2009

Cost: One day's training which includes Module 1 (The Facts of FASD) and Module 3 (FASD for Parents and Carers) is \$180.00 per person for 10 people including handouts and workbooks. For fewer than 10 people the cost will be \$1,800.00 on a per day basis. Each additional participant can attend at a cost of \$100.00 per person.

Accessibility: <http://rffada.org/training/>

Target audience: Module 3: Parents and carers

Content:

Module 1 topics include:

- Alcohol and pregnancy
- Fetal development and alcohol consumption
- Terminology
- The gin epidemic and where FASD began
- Alcohol in society
- Parental factors
- Who are the birth mothers?
- Common FASD myths
- The disabilities of FASD
- A diagnosis is not a label
- Prevalence and incidence
- Diagnosis and management
- Positive developments in Australia
- A framework for action

Module 3 topics include:

- Review of the primary behavioural and physical disabilities
- Strategies and Interventions
- Early Intervention
- FASD and the brain
- The physical environment
- Structure and routine
- Managing behaviour
- Care strategies
- Framework for action

Language: English

Cultural sensitivity: Australian mainstream

Specific resources for carers, inclusive of the experiences of birth mothers



National Indigenous Australian Foetal Alcohol Syndrome Education Network

Organisation: National Indigenous Australian Foetal Alcohol Syndrome Education Network (NIAFASEN)

Type of Information: Training

Date of publication:

Cost:

Accessibility: Contact Lorian Hayes on l.hayes3@uq.edu.au

<http://fas-lorian-hayes.tripod.com/index.html>

Target audience: Training workshops may be tailored to the audience of interested professionals and/or community groups.

Content: Tailored to suit specific audiences

Language: English

Cultural sensitivity: Australian, inclusive of Aboriginal perspectives

Excellent real-life story, personal point of view particularly focussed on Indigenous communities



Fetal Alcohol Spectrum Disorders Program

Organisation: Rural Health Education Foundation

Type of Information: DVD or web based learning module (85 minutes)

Date of publication: Produced 2006

Cost: DVD \$110.00 to purchase or can be viewed via website at no cost

Accessibility: Order DVD or view DVD from website http://www.rhef.com.au/programs/program-1/?program_id=17

Target audience: Health professionals, especially general practitioners

Content: Presentation of FASD, testimonies from Australian individual. Information on prevention program targeted at Aboriginal communities, panel discussion by FASD experts including Professor Elizabeth Elliott (paediatrician), Dr Lara Wieland (general practitioner), Sue Miers (NOFASARD) and Lorian Hayes (NIAFASEN).

Learning Outcomes:

- Identify incidence of FASD in Australia.
- Understand criteria for diagnosis of disorders contained under the umbrella of FASD.
- Identify primary, secondary and tertiary prevention strategies for FASD.
- Understand how to develop community-based strategies that support young women and teenagers through education about FASD and that focus on managing alcohol programs.
- Understand the issues for ongoing management and support for a child with FASD.

Accreditation: This program is accredited for CPD/CPE by the Royal Australian College of General Practitioners (RACGP), the Australian College of Rural and Remote Medicine, the Pharmaceutical Society of Australia, the Royal College of Nursing Australia and the Australian Physiotherapy Association. This program is also eligible for Women's Health points with the RACGP.

Language: English

Cultural sensitivity: Australian, inclusive of Aboriginal perspectives

Some of the content is appropriate for carers and families, mainly for health professionals



Education of Students with Fetal Alcohol Spectrum Disorder

Organisation: Kym Crawford, Principal Karratha Education Support Centre (Western Australia)

Type of Information: Churchill Fellowship Report, Churchill Fellow 2007

Date of publication: September 2008

Cost: No cost

Accessibility: Can be downloaded from website

http://www.churchilltrust.com.au/site_media/fellows/Crawford_Kym_2008.pdf

Target audience: Parents and carers of children with FASD and staff of the Departments of Community Development and Education, including teachers and policy makers

Content: FASD and impact on educating children, strategies used on North America and recommendations for Western Australia, educational strategies for indigenous children

Language: English

Cultural sensitivity: Australian mainstream, inclusive of Aboriginal perspectives

Excellent source of information about education for children with a FASD



To Study Models of Care for Fetal Alcohol Syndrome

Organisation: Prudence Walker, Manager Out of Home Care and Youth at Risk Teams (Northern Territory)

Type of Information: Churchill Fellowship Report, Churchill Fellow 2008

Date of publication: 2009

Cost: No cost

Accessibility: Can be downloaded from website

http://www.churchilltrust.com.au/site_media/fellows/Walker_Prudence_2008.pdf

Target audience: Departments of Communities and Child Protection, including child protection workers and policy makers in the Northern Territory

Content: A summary of North American models of care for FASD, best practice in guardianship of children with FASD and opportunities to improve service delivery to children and families affected by FASD in Central Australia, including Aboriginal families

Language: English

Cultural sensitivity: Australian mainstream

Not an appropriate resource for carers or families



Prenatal alcohol exposure and the impact on parenting affected children especially in Aboriginal communities in Canada and the United States of America

Organisation: June Councillor, Principal Indigenous Liaison Officer, Ombudsman WA (Western Australia)

Type of Information: Churchill Fellowship Report, Churchill Fellow 2009

Date of publication: January 2011

Cost: No cost

Accessibility: Can be downloaded from website

http://www.churchilltrust.com.au/site_media/fellows/Councillor_June_2009.pdf

Target audience: Department for Child Protection and Department of Health Western Australia, policy makers and Aboriginal community

Content: Summary of North American and Australian indigenous practices in child rearing, historical trauma and relationship between colonization and alcohol. Also a section on sudden infant death and possible links with alcohol exposure. Discussion of FASD diagnostic support programs in North America and intervention strategies.

Language: English

Cultural sensitivity: Aboriginal cultural sensitivity; writing style in mainstream Australian

Some content would be relevant for carers and families



Australian State Education Department websites specific to disabilities

Australian Capital Territory: Disability education

http://www.det.act.gov.au/school_education/disability_education

New South Wales: Disability programs

<http://www.schools.nsw.edu.au/studentsupport/programs/disability.php>

Northern Territory: Special education and disability

<http://www.det.nt.gov.au/parents-community/students-learning/special-education-disability>

Queensland: Learning and disability support

<http://education.qld.gov.au/student-services/learning/index.html>

South Australia: Guidelines for supporting children with disabilities and additional needs in preschool setting

http://www.decd.sa.gov.au/speced/files/links/DECS_PAP_Guidelines_final.pdf

Tasmania: Students with disabilities

http://www.education.tas.gov.au/parents_carers/schools-colleges/Programs-Initiatives/Pages/Students-with-Disabilities.aspx

Victoria: Students with disabilities

<http://www.education.vic.gov.au/healthwellbeing/wellbeing/disability/>

Western Australia: Inclusive education

<http://www.det.wa.edu.au/inclusiveeducation/detcms/navigation/category.jsp?categoryID=305033&page=3#toc3>



International Websites, Resources and Organisations

In addition to the international sites referred to by members of the Reference Group and focus group participants, the project manager conducted a search and reviewed over 100 international sites and resources. Some key support groups, organisations and parenting websites have been listed in this report and a more extensive list has been provided on the Telethon Institute Alcohol, Pregnancy and FASD website under international links <http://alcoholpregnancy.childhealthresearch.org.au/links.aspx>.

The websites and resources listed are internationally recognised support groups. The resources have been developed in consultation with parents and carers and reputable organisations, and/or state, provincial or federal government agencies.

Support Groups

National Organisation for Fetal Alcohol Syndrome NOFAS - UK

The National Organisation for Foetal Alcohol Syndrome UK (NOFAS-UK) is dedicated to supporting people affected by foetal alcohol spectrum disorders (FASD), and their families and communities. It promotes education for professionals and public awareness about the risks of alcohol consumption during pregnancy <http://www.nofas-uk.org/>

National Organisation for Fetal Alcohol Syndrome NOFAS – USA

The National Organization on Fetal Alcohol Syndrome (NOFAS) is the leading voice and resource of the Fetal Alcohol Spectrum Disorders (FASD) community in the USA. <http://www.nofas.org/>

Organisations

Asante Centre (Canda)

The website offers links to extensive lists of resources for parents, educators and professionals. <http://www.asantecentre.org/>

Parenting

Parenting children affected by FASD, A Guide for Daily Living

Ministry for Children and Families, British Columbia (Canada)

This book includes sections outlining special considerations for parenting children and adolescents, as well as a section on parents needs and caring for the caregiver – an important task that often gets overlooked when parenting children with special needs. Many sources of information are written by parents and professionals. http://www.fasaware.co.uk/education_docs/daily_guide_for_living.pdf

Strategies parents find helpful in raising their children with FASD

St Michaels Fetal Alcohol Spectrum Diagnostic Clinic (Canada)

The booklet outlines several strategies that parents have identified as helpful in raising their children living with FASD. It is important to note that the strategies provided in this booklet are examples of approaches that have worked for individual families and children, and may not necessarily work with your child. <http://come-over.to/FAS/PDF/TorontoStrategiesParents.pdf>



Strategies not solutions

Edmonton and Area Fetal Alcohol Network (Canada)

The purpose of this resource is to educate caregivers and the community in managing the behaviours associated with FASD. This project has relied heavily upon caregivers and professionals who have provided information, advice, and feedback during the development of this booklet.

http://www.faslink.org/strategies_not_solutions.pdf

FASD Finding Hope DVD for Parents (USA)

A one-hour documentary examining the challenging reality of families with young children who live with Fetal Alcohol Spectrum Disorder <http://knowledge.ca/program/fasd-finding-hope>

A Child for Life: A film on families coping with children with Foetal Alcohol Spectrum Disorder (UK)

Contains interviews with experts, families and children affected by FASD

Produced by NOFAS-UK. The DVD can be ordered through NOFASARD Australia

admin@nofasard.org.au

Let's Talk FASD (Canada)

Parent driven strategies for caring for children with FASD

http://www.von.ca/fasd/fasdtool_fullproof_final.pdf

8 Essentials for Success (USA)

Developed by Deb Evensen and Jan Lutke (parents of children with FASD) and adapted by the Minnesota Organisation on Fetal Alcohol Syndrome

<http://www.mofas.org/wp-content/uploads/2010/12/8-Essentials-for-Success.pdf>



Discussion

As indicated in the findings from the three searches and the foster carer focus groups there are few Australian resources suitable for foster carers and parents. There are two excellent FASD support organisation websites and two DVD's targeted towards parents and carers and the general community. The findings from the focus groups were that carers had a preference for audio-visual materials, for real-life testimonies and practical interventions. Therefore, although several brochures were also identified, these are likely to be less utilised than internet resources and DVD's.

Several carers had also seen the UK DVD "A Child for Life" which provides good coverage of FASD, real-life testimonies and also a preventative health message. However, they stated that they would prefer a DVD with Australian content. They also reported that none of the currently available print or audio-visual resources that they had accessed met their needs for assistance with practical strategies and support.

In analysing the results from the survey form and focus groups, it is apparent that there is also a low level of awareness amongst foster carers of existing resources. While some carers were self-directed to find resources via the internet, most relied on personal contact or meetings held by foster care organisations.



Survey of Service Providers

The original submission included a proposal to survey staff from key government and non-government foster care and support agencies to identify the type of resources and information available to them to understand, advise and address relevant aspects of FASD with foster carers and parents. Participants in the survey were to be asked to respond to the survey based on the work they perform and what is available to them with respect to FASD.

The project team planned to work with these organisations to distribute the questionnaire with a covering letter explaining the purpose of the survey and encouraging their participation. The survey was to be offered as a paper-based survey or on-line via Survey Monkey™. Permission to survey staff within the Department for Child Protection was sought, however a response was not provided and this aspect of the project was not pursued.

Contact was not made with the WA Department of Health as three working groups (primary, secondary and tertiary prevention) had been established to progress the implementation of the WA FASD Model of Care. Initial discussions were held with several people from the WA Department of Education. The project team was of the view that a specific project on FASD knowledge, attitudes and practice should be conducted within the WA education sector. A project is currently underway to ascertain FASD knowledge, attitudes and practice within the WA criminal justice system.



Workshops for Foster Carers

Across the three focus groups and interview, foster carers highlighted the need for face-to-face workshops with an expert in the field of FASD who could talk to them about understanding children with FASD and strategies for managing their often complex and difficult behaviours. In the focus group evaluation one carer commented that she *“would like to have covered symptoms and strategies but understand this was not the goal of today’s meeting”*. Combined with other feedback such as *“it was good to be listened to”* and *“I was not aware that you [Telethon Institute] want to help us”*, when planning the feedback sessions for focus group participants, we considered the option of adding a workshop to the session.

Methods

NOFASARD was contacted to discuss the feasibility of a presenter coming to Western Australia to conduct a workshop with foster carers. The opportunity to have a workshop was also discussed with representatives from the foster care organisations involved in the focus groups. Having received a positive response from all groups, a series of potential venues and dates were identified after the July 2012 school holidays. The locations were the same as the focus groups with one workshop in the regional centre and one workshop in the metropolitan area. Consideration was given to carers daily time restrictions with school drop offs and pickups and babies’ and young children’s needs. It was agreed that the workshop should commence at 10.30am which was directly after the feedback session and conclude at 12.30pm. Child care facilities were provided for children at both locations. Lunch was also provided to the participants and children in the crèche.

Invitations to attend the focus group feedback session and workshop were extended to all focus group participants via email and mail (Appendix 7). The invitation also extended the opportunity to attend the workshop to carers who had not attended the focus groups.

Evaluation

All participants were asked to complete an evaluation form comprising 7 Likert statements (Appendix 8). Participants could also provide information on issues that they would like discussed and any other comments, plus the opportunity to join the mailing list for the Telethon Institute and NOFASARD.

Workshop Content

The content for the workshop ‘Understanding children with a Fetal Alcohol Syndrome’ was developed by NOFASARD. It included primary disabilities, defensive behaviours and secondary conditions, tertiary conditions, risk assessment, interventions and appropriate support, changing our way of thinking, strategies for success, and the opportunity for carers to share their stories and ask questions. A 20 minute DVD developed in the UK ‘A Child for Life’ was shown at the end of the workshop.



Workshop Presenter

Vicki Russell, National Project Coordinator with NOFASARD in Australia, conducted the workshop. Vicki has trained in fetal alcohol assessment and diagnosis; in fetal alcohol-neurobehavioural conditions; the application of screening and assessment in community settings; and in support services for those living with an FASD. She has worked on the prevention of fetal alcohol exposure and FASD for the past 9 years; delivered national education and training on aspects of FASD; and presented on FASD at international events. Vicki has post graduate qualifications in the FASD policy arena and is a current PhD candidate researching fetal alcohol exposure prevention in three countries. Vicki has previous employment experience in counselling children, adolescents and adults who had experienced trauma and has worked in a community development role in the alcohol and drug sector. She is a Churchill Fellow.

Results

The workshop in the regional area was attended by 14 foster carers and three carers attended the metropolitan area workshop. There were an additional eight carers who had indicated that they would attend but were unable to attend the workshops on the day due to family illness, issues with children in their care, including one carer who had to go to the hospital to pick up a new born baby who had been placed in her care, and one person whose flight from country WA was cancelled early on the morning of the workshop. The carers were active participants in the workshop and engaged in the conversations with the presenter.

Evaluation

Evaluation forms were returned by 15 of the 17 workshop participants with 87% indicating that the workshop was relevant to their role as a foster carer and the remaining participants rating it as mostly relevant. Carers commented that the information was practical and down to earth, useful, and it was great to hear real life examples. Participants also commented positively on the presenter noting that she was *“a really good teacher”*. Both in the evaluation and in conversations after the workshop, carers commented that they would have liked the session to have been longer so they could ask more questions. The outcomes of the foster carer workshop evaluation are presented in Table 10.



Table 11: Foster carer workshop evaluation

Question	Response				
	<i>Completely</i>	<i>Mostly</i>	<i>A fair amount</i>	<i>Slightly</i>	<i>Not at all</i>
Was the workshop relevant to your role as a foster carer?	13	2			
Was the information and content informative?	15				
Was the information practical and useful?	13	2			
Did you feel encouraged to participate in the discussion?	11	4			
Did you feel you were given sufficient opportunity to ask questions?	9	6			
Are there any issues that you feel were not discussed today that should have been?	No comments				
Do you have any other comments you would like to add?	Vicki was informative and a really enjoyable teacher Love Vicki Vicki was excellent Vicki you are a wealth of knowledge Having PowerPoint slides printed was very useful Excellent time Informative Useful Very practical ideas Down to earth advice It was covered really well Was great to speak/listen on a practical basis with real life stories and examples Loved it and feel encouraged It could have been longer and then we would have had more time for questions and discussions Thank you it was great More please				
	<i>Yes</i>	<i>No</i>			
Would you be interested in receiving information about Telethon Institute for Child Health research projects, seminars and community activities?	13	2			
Would you be interested in our work/receiving our newsletter or joining the NOFASARD network?	13	2			



Discussion

The purpose of the project, which was to evaluate information and support for parents and carers of children with a FASD, was included in the original invitation to participate in the focus group and also enunciated by the facilitator at each focus group. Of the 22 evaluation forms received from participants all participants responded that the purpose of the focus group discussion was clear to them. Having analysed the focus group and interview conversations it was evident that while there are only a few Australian resources which discuss FASD, foster carers are using their own networks and ingenuity to access information and services. Focus group participants indicated that having the opportunity to talk was greatly appreciated, although as researchers we were concerned about managing carers' expectations of how this information would be used and what outcomes we, as the Telethon Institute, could deliver. As identified in earlier sections of this report access to services for the children in their care was a high priority for carers. We will use this information to advocate on behalf of the carers, engage with service providers and support alcohol and pregnancy awareness campaigns. The workshop for foster carers in the metropolitan area and one regional centre fulfilled another of the recognised deficiencies with respect to FASD resources for foster carers. The knowledge gained by foster carers at the workshop will be shared with other carers and has identified resources that many were not aware of previously. It has also provided them with contacts for support and advocacy groups for parents and carers supporting those living with FASD such as NOFASARD.



Workshops for Department for Child Protection Staff

Foster carers identified a number of barriers to obtaining information about FASD. Several participants commented that there seems to be a great deal of mystery about FASD within the community and DCP and a reluctance to discuss or provide information to foster carers. Carers also commented that they were “*not listened to*” or recognised for their skills and knowledge of children. Having documented the need for a workshop for foster carers and the feedback about a perceived lack of knowledge within DCP, NOFASARD was invited to conduct workshops for DCP staff in the regional centre and metropolitan area.

Methods

Contact with key DCP staff in the regional centre and metropolitan area was made via the foster care organisations. Team leaders and senior officers extended an invitation to their staff to attend the workshop (Appendix 9). Cognisant of the participant’s time and that this was an introductory workshop the session time was kept to two hours.

Evaluation

All participants were asked to complete an evaluation form comprising 7 Likert statements (Appendix 10). Participants could also provide information on issues that were would have like discussed and any other comments, plus the opportunity to join the mailing list for the Telethon Institute and NOFASARD.

Workshop Content

The content for the workshop ‘Understanding children with a Fetal Alcohol Syndrome’ was developed by NOFASARD. It included values and beliefs about women and alcohol, primary disabilities, defensive behaviours and secondary disabilities, tertiary conditions, risk assessment, interventions and FASD systems, supporting a child and carer, case studies, viewing the DVD ‘A Child for Life’ and opportunity for questions.

Workshop Presenter

Vicki Russell, National Project Coordinator with NOFASARD in Australia, conducted the workshop. A biography for Vicki can be found on page 52 of this report.

Results

A total of 58 DCP staff attended the workshops with 14 at the regional centre, 29 in the metropolitan area and 15 people participating via videoconference during the metropolitan area session. The project team is extremely appreciative of the team leaders and senior officers within DCP for supporting this workshop and extending an invitation to their staff.



Evaluation

Evaluation forms were returned by 33 of the 43 people attending the workshops in person (77%). Not all attendees completed all questions on the evaluation form. Unfortunately the evaluation form was not circulated to people attending via teleconference. The majority of participants (88%) rated the workshop as completely relevant to their work and 79% rated it as very informative. The outcomes of the workshop evaluation are presented in Table 11. Participants raised a number of issues that they would have liked to see discussed, including more strategies for supporting the child and carer, information on diagnosis and the cross over between trauma and poly drug use. The general comments can best be referenced to one participant's statement "*Vicki was fantastic and enthusiastic and knowledgeable presenter who was generous with her information and her experiences*".

Table 12: Department for Child Protection workshop evaluation

Question	Response				
	Completely	Mostly	A fair amount	Slightly	Not at all
Was the workshop relevant to your role as a person working with children and families?	29	2		1	
Was the information and content informative?	26	6		1	
Was the information practical and useful?	18	13		1	
Did you feel encouraged to participate in the discussion?	14	12	4		
Did you feel you were given sufficient opportunity to ask questions?	16	9	4	1	
Are there any issues that you feel were not discussed today that should have been?	<p>How to work with behaviours associated with FASD</p> <p>I liked the session. I would have liked some information and discussion regarding supporting the child and carer.</p> <p>Strategies to manage defensive behaviours</p> <p>More focus on supporting carers with strategies – a bit rushed at the end</p> <p>Correlation between FAS/FASD and impact of abuse related trauma</p> <p>Poly drug use – how do CP workers or health workers determine if it is alcohol, heroin, meth or cannabis that has caused the damage to the brain – most of my mums use all of these excessively – difficulty with diagnosis</p> <p>Cross over with trauma symptoms and impact</p> <p>Diagnosis information</p> <p>It would be good to look at what's happening in WA regarding diagnosis</p> <p>Useful tools/visuals etc to ensure/create safe space for children with FASD etc</p>				



	No covered all areas of interest				
Do you have any other comments you would like to add?	<p>Vicki was fantastic and enthusiastic and knowledgeable presenter who was generous with her information and her experiences</p> <p>Thanks for coming – very informative</p> <p>Great presentation – would have liked to attend something longer perhaps on strategies on deciding FASD issues ie accessing support, what can we do</p> <p>Very, very informative and interesting</p> <p>The information was very informative but the time was very short</p> <p>Would have been good to have seen the FASD tool for diagnosis</p> <p>More discussion on FASD and CP system – what it means for policy and practice</p> <p>Thank you</p> <p>I feel I know a lot more about FAS</p> <p>Well presented</p> <p>Very pertinent information</p> <p>Good strategies in my work supporting foster carers</p> <p>It helped us explore our own values and how alcohol is emerging in our culture and socially accepted</p> <p>Thank you for sharing your knowledge</p> <p>Thank you, very well presented, relevant and good information</p> <p>Very informative and interesting, learned a lot. Many thanks</p> <p>Was great, very interesting. I will go on the website and read</p> <p>Serana – rehab facility in Perth where mothers can live in with their kids – long wait list</p>				
	Yes	No			
Would you be interested in receiving information about Telethon Institute for Child Health research projects, seminars and community activities?	19	14			
Would you be interested in our work/receiving our newsletter or joining the NOFASARD network?	22	11			



Discussion

We acknowledge that a course for community service staff would be more extensive and offer significantly more information over 2 days, however within the boundaries of this project and time available it provided the genesis for their FASD knowledge and provided direction to access further information. Participants were interested in the FARE funded work currently being conducted by NOFASARD to develop a FASD training program aimed at building capacity of service providers with the child protection sector.



Conclusions

This project aimed to identify what services and information are available to parents and carers of children with a FASD in Australia and to investigate the specific information needs of the parents and foster carers. Foster carers participating in the focus groups and interview related some key issues confronting them and their children. The priority for carers was access to 'human resources'. They expressed a need for health professionals to diagnose FASDs and someone to talk to who understands the complex needs of these children and the feelings of the carers. Above all carers wanted acknowledgement of their parental role and validation of their concerns for the child.

Carers stated a preference for the delivery of general information about FASD via face-to-face training and workshops which include real life experiences and strategies that work for children with FASD. Carers said that they would like visual and easy to read print materials, and DVDs and websites that included testimonials and credible information on FASD and how to manage the strengths and challenges of people with FASD.

The study identified a limited number of print, audio-visual and website resources appropriate for the Australian context. While the findings in this project indicate a lack of awareness of existing resources in Australia, the overall response rate was not high enough to make generalised statements. All the resources identified are relevant and should be promoted to foster care organisations and foster carers. The project team also see value in working with NOFASARD to finalise the Living with FASD: A Guide for Parents and Caregivers resource. In conducting this project the Telethon Institute has developed new and close relationships with foster care organisations and individual foster carers in Perth and the south west of WA. A communication strategy for raising awareness of the current and potentially new resources could include; the provision of lists of resources to the foster care organisations and support groups for use at training workshops and seminars and inclusion on their websites; hard copies of materials in organisation offices and on display at workshops and seminars; and emailing updates and links to individual foster carers. Foster carers seek information and support from each other and this information would be passed on to the wider foster carer community not on the Telethon Institute database. Information and links would also be provided on the Telethon Institute Alcohol, Pregnancy and FASD website, NOFASARD, rrfada, FARE and other interested organisations' websites. The existing training programs and DVDs also require promotion as outlined above.

The study indicates that there is a demand for an Australian DVD which includes an overview of FASD, real-life testimonies and practical strategies for living with FASD. Such a resource could be used within a workshop context, within informal discussion groups or by individual carers and their families in their own time. The development of an Australian DVD would require extensive consultation with, and participation by FASD support groups, parents and carers to ensure they meet the expectations and requirements identified in this project. A campaign to raise awareness of these new resources would also involve a range of media to launch and promote the DVD.

All of the identified resources were in English and therefore, additional resources are required for culturally and linguistically diverse subpopulations in Australia.



The resources are also relevant to service providers such as DCP. Awareness of the resources will not only be useful for staff development but will enable case managers to discuss strategies for foster carers to try with a child in their care and to provide a copy of, or link to the resources. Given foster carer concerns about developmental delays and behaviour of children in their care, FASD professional development is imperative for DCP staff in a range of roles. Project investigators noted DCP interest in the training program for service providers currently being developed and trialled by NOFASARD.

Clearly in order to meet the carers' needs for specific information about the affected children in their care, there is a great need for specific FASD training for health, education and welfare professionals. There is also a need for improved communication between welfare workers and health professionals and for the development of clear referral pathways. The establishment of a diagnostic service and interagency collaboration on referral guidelines is a priority. While the WA FASD Model of Care was developed within the Department of Health, the implementation needs to occur across government sectors. We would recommend the development of similar models across Australia and funding to enable implementation. In the private sector, there is need for professional development for GP's and paediatricians.

At a broader community and national level, it is important to acknowledge FASD as a disability and to advocate for support services for individuals and their families.

In conclusion we would like to quote the carers:

*"Wish something would come together
Here is a route, here is a course, and here are the links
Everyone on the same page
Everyone talking to everyone else who is a professional
This is the way we are going to manage this child"*

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Appendix 1: Focus Group Registration and Consent Forms





**Fetal Alcohol Spectrum
Disorder (FASD)
Resources for Foster Carers
A Focus Group**

Date: Thursday 16 February 2012

Time: 6.45pm – 8.45pm

Venue: Bunbury Tower, 61 Victoria Street Bunbury

OR

Date: Friday 17 February 2012

Time: 9.30am – 11.30am

Venue: Bunbury Tower, 61 Victoria Street Bunbury

Information on the focus group is available on pages 2-3

Child care facilities will not be available at either session

If you have any questions or would like more information please contact Heather Jones on 9489 7724 or hjones@ichr.uwa.edu.au

To register to attend the focus group, please complete the registration and consent forms and send to Heather Jones by 9 February 2012 (Please indicate which session you would like to attend)

✉ PO Box 855, West Perth WA 6872

📧 hjones@ichr.uwa.edu.au

Registration Form

FASD Resources for Foster Carers Focus Group

Bunbury Tower, 61 Victoria Street Bunbury

Name: _____
First name Surname

Postal address: _____

Email address: _____

Phone number: _____

Please indicate which session you would like to attend

Thursday 16 February 2012 (6.45pm – 8.45pm)

Friday 17 February 2012 (9.30am – 11.30am)

If you have any questions or would like more information please contact Heather Jones on 9489 7724 or hjones@ichr.uwa.edu.au

Please complete the registration and consent forms and send to Heather Jones by 9 February 2012

✉ PO Box 855, West Perth WA 6872

📧 hjones@ichr.uwa.edu.au





Fetal Alcohol Spectrum Disorder (FASD) Resources for Foster Carers A Focus Group

Date: Tuesday 14 February 2012

Time: 9.30am – 11.30am

Venue: McCall Centre, 2 Curtin Ave Cottesloe

OR

Date: Tuesday 21 February 2012

Time: 6.45pm – 8.45pm

Venue: McCall Centre, 2 Curtin Ave Cottesloe

Information on the focus group is available on pages 2-3

Child care facilities will not be available at either session

If you have any questions or would like more information please contact Heather Jones on 9489 7724 or hjones@ichr.uwa.edu.au

To register to attend the focus group, please complete the registration and consent forms and send to Heather Jones by 9 February 2012 (Please indicate which session you would like to attend)

✉ PO Box 855, West Perth WA 6872

📧 hjones@ichr.uwa.edu.au

Registration Form

FASD Resources for Foster Carers Focus Group

McCall Centre, 2 Curtin Ave Cottesloe

Name: _____
First name Surname

Postal address: _____

Email address: _____

Phone number: _____

Please indicate which session you would like to attend

Tuesday 14 February 2012 (9.30am – 11.30am)

Tuesday 21 February 2012 (6.45pm – 8.45pm)

If you have any questions or would like more information please contact Heather Jones on 9489 7724 or hjones@ichr.uwa.edu.au

Please complete the registration and consent forms and send to Heather Jones by 9 February 2012

✉ PO Box 855, West Perth WA 6872

📧 hjones@ichr.uwa.edu.au



**EVALUATION OF INFORMATION AND SUPPORT FOR PARENTS AND CARERS OF CHILDREN
WITH A FETAL ALCOHOL SPECTRUM DISORDER (FASD)**

**A project conducted by the Telethon Institute for Child Health Research
Funded by a grant from the Foundation for Alcohol Research and Education (FARE)**

FOSTER CARER FOCUS GROUP INFORMATION SHEET

We are inviting you to participate in a focus group as part of a research project conducted by the Telethon Institute for Child Health Research, Centre for Child Health Research, the University of WA. You have been sent this letter as a foster carer for child/children with a FASD or you suspect may have a FASD. The lead researcher is Dr Amanda Wilkins. Dr Wilkins is a paediatrician who works in child development and as a researcher at the Telethon Institute. The Project Manager is Heather Jones.

Project objectives

- To evaluate currently available Fetal Alcohol Spectrum Disorder (FASD) resources and information for parents and carers
- To evaluate currently available FASD resources and information for key government and non-government foster care and support agencies
- To investigate specific information needs of parents and foster carers of children with a FASD

The Institute strongly endorses the Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research.

What will you be asked to do?

You will be asked to participate in a focus group. The purpose of the focus groups is to gather information from foster carers on how you found out about FASD, where did you find information, what information was useful and what would you like to see in new Australian materials.

Participation is voluntary

Participation in the focus group is voluntary and you are free to withdraw from the research at any time without prejudice in anyway. Should you withdraw your details will be removed from the database and no further contact will be made unless you specifically request a copy of the final report.



What are the risks and benefits of participating?

There is a small risk that you may be inconvenienced by taking time to participate in the focus group. However, by participating you will have contributed your knowledge, experience and insight into future resources and support for foster carers supporting children with a FASD. We acknowledge that talking about this issue could raise some feelings of grief, shame or distress related to your personal experiences.

How will your privacy be protected?

Focus group participants' identifying information is stored securely to protect individual confidentiality. Responses to questions at the focus group will not be recorded or transcribed with any names attached to statements. See the full Telethon Institute for Child Health Research privacy statement [here](#).

Ethics Approval

This project has been approved by the Human Research Ethics Committee of The University of Western Australia.

Concerns or complaints about this research

If you have any concerns or complaints about this research project, you may contact the Human Research Ethics Office at The University of Western Australia on (08) 6488 3703 or by email to hreo-research@uwa.edu.au

How will your information be used?

Your information will be used to prepare a report to the Foundation for Alcohol Research and Education. The results of this project will be reported at scientific conferences, in scientific journals and possibly the media. Individual participants will not be identified in any publications or reports arising from the project.

The advice from the focus groups will also be used guide future development of resources and support services for parents, foster carers and for government and non-government agencies working with parents and foster carers.

Questions and further information

If you have any questions about this project or the focus group please contact the Project Manager, Heather Jones on 08 9489 7724 or via email at hjones@ichr.uwa.edu.au



Focus Group Participant Consent Form

I (the participant) have read the information provided and any questions I have asked have been answered to my satisfaction. I agree to participate in this focus group, realising that I may withdraw at any time without reason and without prejudice.

To assist in transcribing the information gathered at the focus group the session will be recorded (audio only). No names will be included when the information is transcribed. The recorded information will be destroyed on completion of the project.

I understand that all information that I provide is treated as strictly confidential and will not be released by the researcher or project team in any form that may identify me. The only exception to this principle of confidentiality is if documents are required by law.

I have been advised as to what information is being collected, the purpose for collecting the information, and what will be done with the information upon completion of the research.

I agree that research data gathered for the study may be published provided my name or other identifying information is not used.

Participants Name: _____

Participant's Signature: _____

Date: _____

"Approval to conduct this research has been provided by The University of Western Australia, in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time.

In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Research Ethics Office at The University of Western Australia on (08) 6488 3703 or by emailing to hreo-research@uwa.edu.au

All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project."



Appendix 2: Letter from facilitators to confirmed focus group participants



7 February 2012

Dear

Thank you for agreeing to participate in a group discussion about the resources and information on Fetal Alcohol Spectrum Disorders (FASD) available to families and foster carers.

Confirmation of date and venue

We wanted to take the opportunity to introduce ourselves before the discussion group and thought it was important to let you know what is involved so that you can be assured that your participation is treated with respect and confidentiality. Jenny Dodd and I are external researchers to this study, working on behalf of the research team conducting the research to ensure a neutral stance. Even so, as researchers ourselves we understand this is a difficult area in terms of recognition and acceptance of Fetal Alcohol Spectrum Disorders and community attitudes to drinking alcohol during pregnancy.

This is why it is so important that your views are heard by us so that the project team can combine the information from a number of discussion groups to form a clear picture of what carers are experiencing, what information you have access to and how this helps you.

In the discussion groups we will be asking two or three key questions and seeking input from all members of the group. We will not be asking for personal information about you or the children in your care. Rather, the questions will be broadly based about when and how you go about getting information and assistance.

We will lay out some ground rules for the discussion at the beginning of the session, including a request to everyone present that what is said in the room stays in the room. In this way we aim to preserve confidentiality for everyone. We also want to assure you that when the results of the discussion is written up, these will not identify anyone who was present and no identifying information will be provided to or known by any agency or person outside of the research team.

We look forward to meeting with you and hope that you are able to attend and assist us with this very important research as your unique experiences and perspectives are invaluable to this research.

Yours sincerely



Appendix 3: Information Pack





Information Pack

Foster Carer Focus Groups

- Tuesday 14 February 2012 Perth
- Thursday 16 February 2012 Bunbury
- Friday 17 February 2012 Bunbury
- Tuesday 21 February 2012 Perth

Telethon Institute for Child Health Research

Evaluation of Fetal Alcohol Spectrum Disorders (FASD) Resources for Foster Carers

Lead Investigator: Dr Amanda Wilkins

Project Manager: Heather Jones

You can contact us via:

Phone: 08 9489 7724

Email: hjones@ichr.uwa.edu.au

Mail: PO Box 855, West Perth WA 6872



Evaluation of FASD Resources for Foster Carers

Project Objectives

- To evaluate currently available Fetal Alcohol Spectrum Disorder (FASD) resources and information for parents and carers
- To evaluate currently available FASD resources and information for key government and non-government foster care and support agencies
- To investigate specific information needs of parents and foster carers of children with a FASD

Focus Group Purpose

The purpose of the focus groups is to gather information from foster carers on how they found out about FASD, where they found information, what information was useful and what they would like to see in new Australian materials.

Funding

This project is funded by the Foundation for Alcohol Research and Education (FARE)

Dissemination of the Project Findings

A final report will be provided to FARE. A paper will also be submitted for publication in a professional journal that is freely available on-line. Prior to the public release of information on the report outcomes the project team will provide feedback to focus group participants. This will be via a presentation in Perth and Bunbury and a short written report which will be mailed/emailed to participants.

You were invited to participate in this focus group because you have important knowledge, experiences, needs and perspectives as a foster carer and we hope to learn from you.

Thank you for time and participation. The information you have shared is valuable for this project and we hope in the development of future resources and information for foster carers.



Fostering Services

Foster Care Association of Western Australia

The Foster Care Association strives to promote the interest of foster carers with all Care Agencies of Western Australia.

McCall Centre, 2 Curtin Avenue Cottesloe WA 6011

Phone: (08) 9384 5577/Country Callers: 1800 64 1911 (Freecall)

Email: admin@fcawa.com.au

Website: <http://www.fcawa.com.au/>

Foster Families South West

Foster Families South West is a not-for-profit association supporting foster families throughout the South West.

Gay Pritchard

Email: gpritchard@westnet.com.au

Wanslea

Wanslea is a not-for-profit, non-government agency providing services to children and families in Western Australia

Scarborough: 110 Scarborough Beach Road, Scarborough WA 6019

16 offices in Perth and regional areas of WA

Phone: (08) 9245 2441

Website: <http://www.wanslea.asn.au/>

Department for Child Protection (Fostering Services)

General Foster Care

Phone: 1800 024 453

Email: fostering@dcp.wa.gov.au

The Department provides care for children from birth to 18 years, for emergency, respite, short, medium and long term care. Fostering Services recruits assesses trains and supports foster carers across the State.

Respite Program

Phone: 1800 024 453

Email: fostering@dcp.wa.gov.au

Respite Carers look after children for short periods of time to give their full time Carers a break. They look after children in their own home for a few hours, a weekend or a few weeks. They undertake the same training, assessment and approval process as general foster carers.



Specialised Care

Phone: 1300 133 705

Email: specialisedfostering@dcp.wa.gov.au

Specialised Fostering mainly provides long-term care for children aged 6 to 17 years. The service assesses and trains suitable foster carers to care for children with complex needs and challenging behaviours. Specialised foster carers get extra training and support, including a higher subsidy.

Pre-Adoptive Foster Care

Phone: (08) 9222 2555

Email: adoptions@dcp.wa.gov.au

Mainly for new born babies while the birth parents are considering long-term care options. The period of care ranges from a few days to several months. You need to have had experience caring for a new born baby, and the main caregiver cannot be in paid employment.

Anglicare

Phone: (08) 9263 2008

Email: teensharestaff@anglicarewa.org.au Web: www.teenshare.org.au

Emergency short term care for young people aged 12 to 17.

Futures

Phone: 1300 663 298 (freecall)

Email: futures@unitingcarewest.org.au

Web: www.unitingcarewest.org.au

Long-term placements to children with disabilities aged 0 to 12 years. A service of UnitingCare West.

Key Assets (state-wide)

Phone: (08) 9431 9300

Email: info@keyassetswa.com.au

Web: www.keyassetswa.com.au

Wide range of services for children aged 0 to 18, including specialised care.

Life Without Barriers (state-wide)

Phone: (08) 6226 9900

Email: info@lwb.org.au

Web: www.lwb.org.au

Wide range of services for children aged 0 to 18, including placements for children with disabilities and in crisis.

Mercy Family & Community Services

Phone: (08) 9208 4444

Email: fostercare@mercyare.com.au Web: www.mercyare.com.au

Medium to long-term care for children aged 0 to 17.



Parkerville Children & Youth Care

Phone: (08) 9295 4400

Email: admin@parkerville.org.au

Web: www.parkerville.org.au

Medium to long-term care for children aged 0 to 18.

Yorganop Childcare Aboriginal Corporation

Phone: (08) 9321 9090

Email: admin@yorganop.org.au

Web: www.yorganop.org.au

An Aboriginal agency for children aged 0 to 15.

Advocate for Children in Care

Judy Garsed

Phone: (08) 9222 2518, 1800 460 696 (freecall), 0429 086 508

Email: judy.garsed@dcp.wa.gov.au

The Department for Child Protection wants to protect and promote the interests of children and young people in care, and the Advocate for Children in Care has been created especially to focus on them, their views and their concerns.

Create Foundation WA

Phone: (08) 9470 6155 or 1800 655 105

Web: wa@create.org.au

Create WA connects and empowers children and young people in care and improves the care system through policy advice, programs and activities

Consumer and Community Organisations**Health Consumer Council**

The Health Consumers' Council (HCC) is an independent community based organisation, representing the consumers' voice in health policy, planning, research and service delivery.

They advocate on behalf of consumers to doctors, other health professionals, hospitals and the wider health system.

<http://www.hconc.org.au>

FASD Support Organisations**National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD)**

The National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) is a Commonwealth charity and the peak community organisation for FASD in Australia. They provide information, advocacy and referral options for families supporting children/adolescents and adults who have or are suspected of having FASD. NOFASARD has well established national and international networks and collaborative relationships with other committed organisations and interest groups. For more information please visit the [NOFASARD website](http://www.nofasard.org/)

<http://www.nofasard.org/> or contact Sue Miers on 0418 854 947 or email sue@nofasard.org.au



Russell Family Fetal Alcohol Disorders Association (rffada)

RFFADA is a not-for-profit health promotion charity dedicated to ensuring that individuals affected prenatally by alcohol have access to diagnostic services, support and multidisciplinary management planning in Australia and that carers and parents are supported with a "no blame no shame" ethos. Visit the [RFFADA website](http://rffada.org/) <http://rffada.org/> or contact Elizabeth Russell on 0412 550 540.

Telethon Institute for Child Health Research

The Telethon Institute for Child Health Research is dedicated to the prevention of childhood diseases and disability. Information on alcohol and pregnancy and FASD is available from the Telethon Institute for Child Health Research website <http://alcoholpregnancy.childhealthresearch.org.au>

The website includes links to a large number of Australian and international websites:

The website provides general information on Alcohol and Pregnancy and FASD in addition to the following:

- Current Telethon Institute projects on FASD
- Previous projects
- Contributions to policy and practice
- Other Alcohol and Pregnancy and FASD projects in Australia
- Alcohol and pregnancy publications involving Telethon Institute researchers
- Profiles on our Telethon Institute researchers
- Alcohol and pregnancy resources developed by Telethon Institute researchers
- Community participation
- Alcohol Guidelines and 'What is a standard drink?'
- Information from parents and children on living with a child with a FASD
- Where to go for assistance
- Links to sources of Australian and international information for parents/carers, health professionals, workers in the health, education and justice sectors, politicians and researchers

Focus on FASD in WA Seminar

The Telethon Institute and the Western Australian Government Drug and Alcohol Office are hosting a 'Focus on FASD in WA' seminar

- Monday 27 February 2012
- 9.00am – 4.00pm

The seminar will be held in the Bill Walker Room at Patersons Stadium (formerly Subiaco Oval) through Gate 5 off Subiaco Rd.

For information please contact Heather Jones on 08 9489 7724 or go to our website to download the registration form available on the home page <http://alcoholpregnancy.childhealthresearch.org.au>.

There is no charge to attend the seminar however you need to register as there are limited spaces and we need to know how many to cater for lunch.



Alcohol, Pregnancy and FASD

Alcohol can alter the normal development of the fetus (unborn baby). Researchers use the term teratogen when referring to alcohol. A teratogen is a drug, chemical or even infection that interrupts or alters the normal development of a fetus, including development of the brain or other major organs. Other examples of teratogens include measles, radiation, mercury and thalidomide. The effects of fetal alcohol exposure are life-long and may not be seen at birth.

The possible effects of fetal alcohol exposure include:

- Brain damage
- Birth defects
- Poor growth
- Social and behavioural problems
- Delayed development
- Low IQ

Is any alcohol in pregnancy safe?

As researchers we don't know how much alcohol, if any, is safe to drink during pregnancy. Evidence shows that the risk of harm to the fetus is greater the more alcohol the mother consumes and that binge drinking is harmful.

In 2009 the National Health and Medical Research Council (NHMRC) released an updated version of the *Australian Guidelines to Reduce Health Risks from Drinking Alcohol*. These guidelines aim to communicate evidence concerning these risks to the Australian community to allow individuals to make informed decisions regarding the amount of alcohol they choose to consume. There are four key guidelines in the document.

Guideline 1: Reducing the risk of alcohol-related harm over a lifetime

Guideline 2: Reducing the risk of injury on a single occasion of drinking

Guideline 3: Children and young people under 18 years of age

Guideline 4: Pregnancy and breastfeeding

Guideline 4: Pregnancy and breastfeeding

Maternal alcohol consumption can harm the developing foetus or breastfeeding baby.

- A. For women who are pregnant or planning a pregnancy, not drinking is the safest option.
- B. For women who are breastfeeding, not drinking is the safest option.

For full details read the NHMRC *Australian Guidelines to Reduce Health Risks from Drinking Alcohol* http://www.nhmrc.gov.au/files_nhmrc/file/publications/synopses/ds10-alcohol.pdf



Fetal Alcohol Spectrum Disorders (FASD)

Fetal Alcohol Spectrum Disorder (FASD) is not a clinical diagnosis in itself but represents a range of diagnoses that fall under the spectrum.

- Fetal Alcohol Syndrome (FAS)
- Partial Fetal Alcohol Syndrome
- Neurodevelopmental Disorders – alcohol exposed

Some research will refer to Alcohol Related Neurodevelopmental Disorders (ARND) and Alcohol Related Birth Defects (ARBD)

Fetal Alcohol Syndrome

Fetal Alcohol Syndrome (FAS) is a complex condition caused by alcohol exposure during pregnancy. It is at the most severe end of the spectrum of fetal alcohol disorders. The facial features include small eye openings, a thin upper lip, a flat midface and an absence or elongated groove between the upper lip and nose. Babies with FAS will have a low birth weight and fail to thrive despite receiving adequate nutrition after birth; and children may be small for their age. Babies born with FAS will have a small head and brain abnormalities. The damage to the brain can result in behavioural problems; language and speech problems; vision and hearing problems; and problems with thinking, judgement and reasoning.

There is no biomarker for the diagnosis of FAS. (A biomarker is a term used to describe a test such as a blood, urine or faeces to identify the severity or presence of a disease.)

Facial Features

The facial development of the fetus occurs mainly between weeks 4 and 8. The distinctive facial features of Fetal Alcohol Syndrome and Partial Fetal Alcohol Syndrome are included in the photos below. Photos have been reproduced with permission from Dr Susan Astley, University of Washington. For more information please go to the [University of Washington FAS Diagnostic & Prevention Network website](#)



- A smooth philtrum (no groove between the upper lip and nose)
- Thin vermilion border (thin upper lip)
- Short palpebral fissures (small eye openings)

Partial Fetal Alcohol Syndrome

A baby or child with Partial Fetal Alcohol Syndrome (pFAS) will have some but not all of the symptoms of FAS.

Neurodevelopmental Disorders – alcohol exposed

The majority of babies and children with FASD will fall within this category. These babies and children will not have the facial features of Fetal Alcohol Syndrome but will have a range of symptoms caused by damage to different parts of the brain. These symptoms can include a delay in reaching milestones such as walking and talking; poor hand eye coordination; unable to complete complex tasks that involve planning, problem solving and judgment; and difficulties with motor function and social interactions. Children may also have poor academic performance and lack the ability to control their emotions.

Children with diagnoses included under the fetal alcohol disorders spectrum often have:

- Brain damage
- Low IQ
- Birth defects
- Poor growth
- Developmental delay
- Language and speech deficits
- Problems with sensory systems - vision, hearing, touch
- Motor coordination problems
- Difficulty sleeping
- High levels of activity
- Difficulty remembering and are not able to generalise their learning
- A short attention span
- Problems with abstract thinking
- Poor judgment and not able to understand the consequences of their actions
- Social and behavioural problems
- Difficulty forming and maintaining relationships and indiscriminately friendly

Babies and infant symptoms can include:

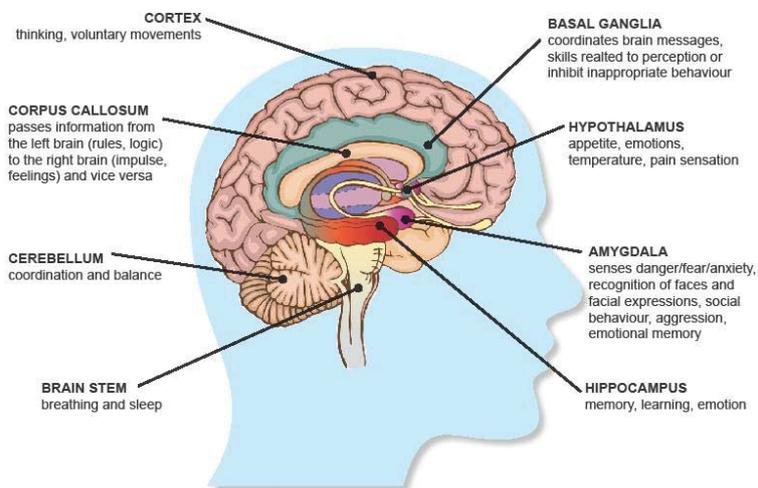
- Irritability
- Poor feeding
- Low birth weight
- Decreased muscle tone and poor coordination
- Delayed development such as walking and talking
- Hypersensitivity to noise, light and touch
- Bonding problems



Researchers and parents say that it is not 'bad behaviour' but the actions of an infant or child who has damage to their brain and who is unable to control what they do.

Brain Development

- Alcohol affects the development of the unborn baby's brain
- The brain continues to develop throughout the pregnancy and until we reach the age of 19 or 20
- Many children will have neurodevelopmental disorders (impairment of the growth and development of the brain)
- Children with neurodevelopmental disorders don't learn from their mistakes and they don't understand cause and consequence and they can't be disciplined in the normal way.



Did you know?

47% of Australian women do not plan their pregnancy (Alcohol consumption during pregnancy in non-indigenous West Australian women. Colvin L, Payne J, Parsons D, Kurinczuk JJ, Bower C. Alcohol: Clinical and Experimental Research. 2007; 31(2):276-284.)

There is an association between binge drinking & unplanned pregnancy (Women's knowledge and attitudes regarding alcohol consumption in pregnancy: a national survey. Peadon E, Payne J, Henley N, D'Antoine H, Bartu A, O'Leary C, Bower C, Elliott J. BMC Public Health. 2010 Aug 23: 10:510)

80% of Australian women report drinking alcohol in the first 3 months of pregnancy (Alcohol consumption during pregnancy in non-indigenous West Australian women. Colvin L, Payne J, Parsons D, Kurinczuk JJ, Bower C. Alcohol: Clinical and Experimental Research. 2007; 31(2):276-284.)

59% of Australian women drink alcohol in at least 1 trimester of pregnancy (Alcohol consumption during pregnancy in non-indigenous West Australian women. Colvin L, Payne J, Parsons D, Kurinczuk JJ, Bower C. Alcohol: Clinical and Experimental Research. 2007; 31(2):276-284.)

79% of Australians believe drinking while pregnant can be harmful to the developing fetus ([AERF 2012 Annual Alcohol Poll Community Attitudes and Behaviours](#))

93% of Australian women agree alcohol can affect the unborn child (Women's knowledge and attitudes regarding alcohol consumption in pregnancy: a national survey. Peadon E, Payne J, Henley N, D'Antoine H, Bartu A, O'Leary C, Bower C, Elliott J. BMC Public Health. 2010 Aug 23: 10:510)

16% of Australian women do not know that the effects of alcohol on the fetus are permanent (Women's knowledge and attitudes regarding alcohol consumption in pregnancy: a national survey. Peadon E, Payne J, Henley N, D'Antoine H, Bartu A, O'Leary C, Bower C, Elliott J. BMC Public Health. 2010 Aug 23: 10:510)

34.1% of Australian women drank during their last pregnancy (Attitudes and behaviours predict women's intention to drink alcohol during pregnancy. The challenge for health professionals. Peadon E, Payne J, Henley N, D'Antoine H, Bartu A, O'Leary C, Bower C, Elliott EJ. [BMC Public Health. 2011. 11:584](#))

31.6% of Australian women intended to drink if planning a pregnancy (Attitudes and behaviours predict women's intention to drink alcohol during pregnancy. The challenge for health professionals. Peadon E, Payne J, Henley N, D'Antoine H, Bartu A, O'Leary C, Bower C, Elliott EJ. [BMC Public Health. 2011. 11:584](#))

23.7% of Australian women intend to drink if pregnant (Attitudes and behaviours predict women's intention to drink alcohol during pregnancy. The challenge for health professionals. Peadon E, Payne J, Henley N, D'Antoine H, Bartu A, O'Leary C, Bower C, Elliott E. [BMC Public Health. 2011. 11:584](#))



For women aged between 18 and 24 years, 11% consumed alcohol at risky levels for the short term at least once a week in the previous 12 months ([Australian Bureau of Statistics. Alcohol Consumption in Australia: A Snapshot 2004-05](#))

In the 2008 Victorian Population Health survey 37.2% of females consumed alcohol (weekly, monthly or yearly) at levels that were risky or high risk for short term harm ([Victorian Population Health Survey 2008. Selected Findings: Health and Lifestyle Part 1](#))

In the 2008 Victorian Population Health survey 17.1% of females between 18 and 24 years were drinking alcohol at risky or high risk levels at least weekly ([Victorian Population Health Survey 2008. Selected Findings: Health and Lifestyle Part 1](#))

Only 45% of health professionals routinely ask about alcohol use in pregnancy (Health professional's knowledge, practice and opinions about Fetal Alcohol Syndrome and alcohol consumption in pregnancy. Payne J, Elliott E, D'Antoine H, O'Leary C, Mahony A, Haan E, et al. Aust N Z J Public Health. 2005; 29(6):558-564.)

Women expect health professionals to ask and advise them about alcohol and pregnancy (Impacts of alcohol use in pregnancy. The role of the General Practitioner. Peadon E, O'Leary C, Bower C, Elliott E. Aust Fam Physician. 2007; 36(11):935-939.)

Some health professionals acknowledge that they were not directly asking women about alcohol intake and hence were making an assumption that women knew to minimise alcohol consumption during pregnancy (Health professionals addressing alcohol use with pregnant women in Western Australia: barriers and strategies for communication. France K, Henley N, Payne J, D'Antoine H, Bartu A, O'Leary C, Elliott E, Bower C. Subst Use Misuse 2010; 45: 1474-1490)



Appendix 4: Evaluation of Focus Group Form



Evaluation of FASD Information and Services for Foster Carers

Focus Group Evaluation

1. Please indicate which focus group you attended:

Tuesday 14 February 2012

Thursday 16 February 2012

Friday 17 February 2012

Tuesday 21 February 2012

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

2. How important is this issue to you?

Very important Important Not important

3. Was the purpose of the focus group discussion clear to you?

Yes No

4. Did you feel encouraged to participate in the discussion?

Yes No

5. Did you feel you were given sufficient opportunity to contribute your point of view?

Yes No

6. Did the discussion help you to understand other points of view?

Yes No Unsure

7. What are two or three things you learned from the discussion today that you were not aware of before:



8. Are there any issues that you feel were not discussed today that should have been?

9. Do you have any other comments you would like to add?

10. Would you be interested in receiving information about Telethon Institute for Child Health Research projects, seminars and community activities?

Yes No

If yes, please let us know the best way to contact you:

Email:

Mail:

Thank you for your time and participation in the focus group. The information you have shared is valuable for this project and we hope in the development of future FASD resources and information for foster carers.



Appendix 5: Evaluation of Resources Form



FASD Websites, Resources and Services

Evaluation Form

In the following section please provide the names of websites, sources, organisations that you have accessed or used. If you have not used any please write 'none known'

Please circle the responses which best match your view

Add more websites, resources or services/organisations if required

Website name

The website was:

POSITIVE	→			OR			→	NEGATIVE
a. Informative		1	2	3	4	5	6	very poor
b. Useful		1	2	3	4	5	6	not useful
c. Relevant		1	2	3	4	5	6	not relevant

Is there anything else you would like to add?

Resource name

The resource was:

POSITIVE	→			OR			→	NEGATIVE
a. Informative		1	2	3	4	5	6	very poor
b. Useful		1	2	3	4	5	6	not useful
c. Relevant		1	2	3	4	5	6	not relevant

Is there anything else you would like to add?

Service/Organisation name

The service/organisation was:

POSITIVE	→			OR			→	NEGATIVE
a. Personnel			1	2	3	4	5	6
b. Outcomes			1	2	3	4	5	6
c. Waiting time for response			1	2	3	4	5	6
d. Advice/support			1	2	3	4	5	6

Is there anything else you would like to add?



Appendix 6: Thank you letter to focus group participants



20 February 2012

Dear

Evaluation of Fetal Alcohol Spectrum Disorders (FASD) Information and Services for Foster Carers – Focus Group

On behalf of the project team thank you for your participation and very valuable time in attending the focus group. Your comments and advice are based on many years experience and offered us the real life perspectives of foster carers.

We look forward to talking with you on the outcomes of this study later in the year.

Yours sincerely

Heather Jones
Manager, FASD Projects



Appendix 7: Invitation to focus group feedback session and workshop for foster carers



12 July 2012

Dear

I am writing to you as a participant (or someone who expressed interest and was unable to attend) in the Focus Groups on Fetal Alcohol Spectrum Disorders (FASD) Resources for Foster Carers in February this year in Perth and Bunbury. At the focus group Dr Amanda Wilkins advised that we would discuss the outcomes of the project with you prior to submitting the final report. One of the key issues and requests arising from the focus groups was having a workshop or meeting with experts in the field who could talk to the group about strategies that work for children.

I am pleased to advise that Vicki Russell from the National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) will be in WA on 30 and 31 July. NOFASARD is the peak national non-government organisation representing the interests of parents, carers and others interested in or affected by FASD. Vicki has worked as a volunteer with NOFASARD for many years and is recognised for her expertise in the area and regularly conducts education and training for parents, carers and community sectors workers.

Dates:	Bunbury Monday 30 July Perth Tuesday 31 July
Venue:	Bunbury – Hudson Road Family Centre, 95 Hudson Road Bunbury Perth – WA Foster Care Association, McCall Centre 2 Curtin Ave Cottesloe Crèche facilities are available at the Bunbury and Perth venues
Time:	10.00am – 10.30am What’s in the report? Dr Amanda Wilkins and Heather Jones Previous Focus Group Participants - outcomes from focus groups held in February 10.30am – 12.30am Workshop Vicki Russell Strategies for managing children with a FASD or suspected of having a FASD 12.30pm – 1.00pm Lunch



RSVP:	Heather Jones Email: hjones@ichr.uwa.edu.au Phone: 9489 7724 Please let me know if you wish to use the crèche facilities, the number of children and their ages
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The **‘What’s in the report’** session (10.00am – 10.30am) is open to everyone who attended the focus groups or was interviewed in Perth and Bunbury in February. We will discuss the findings from the focus groups and some brief information about our report to the Foundation for Alcohol Research and Education (FARE) who funded this project. As we did with the focus groups a small payment will be provided to those attending the feedback session to assist with your travel and parking etc.

The **‘Workshop’** (10.30am – 12.30pm) is open to anyone who has an interest in this area. If you have a friend who may be interested in attending the workshop please let them know the dates and times.

Vicki Russell will also be conducting a separate session for Department for Child Protection staff in Perth and Bunbury.

For seating and catering purposes we would like people to let us know if they will be attending. If you have any questions please contact me via email on hjones@ichr.uwa.edu.au or phone 9489 7724. If I am not at my desk please leave a message.

We look forward to seeing you.

Yours sincerely

Heather Jones
Manager, FASD Projects



Appendix 8: Foster Carer Workshop Evaluation Form



Understanding children living with a Fetal Alcohol Spectrum Disorder

Workshop Evaluation

1. Please indicate which workshop you attended:

Monday 30 July 2012	<input type="checkbox"/>
Tuesday 31 July 2012	<input type="checkbox"/>

2. Was the workshop relevant to your role as a foster carer?

Completely Mostly A fair amount Slightly Not at all

3. Was the information and content informative?

Completely Mostly A fair amount Slightly Not at all

4. Was the information practical and useful?

Completely Mostly A fair amount Slightly Not at all

5. Did you feel encouraged to participate in the discussion?

Completely Mostly A fair amount Slightly Not at all

6. Did you feel you were given sufficient opportunity to ask questions?

Completely Mostly A fair amount Slightly Not at all

7. Are there any issues that you feel were not discussed today that should have been?

8. Do you have any other comments you would like to add?



9. Would you be interested in receiving information about Telethon Institute for Child Health Research projects, seminars and community activities?

Yes No

If yes, please let us know the best way to contact you:

Name:

Email:

Mail:

10. Would you be interested in our work/receiving our newsletter or joining the National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) network

Yes No

If yes, please let us know the best way to contact you:

Name:

Email:

Mail:

Thank you for your time and participation in attending the workshop.



Appendix 9: Invitation to Department for Child Protection FASD Workshop



WHERE → McCall Centre, Cottesloe
2 Curtin Avenue

Fetal Alcohol Spectrum Disorder

The Telethon Institute for Child Health Research is pleased to announce a workshop for DCP staff by International Speaker VICKI RUSSELL of the National Organisation for Fetal Alcohol Syndrome & Related Disorders (NOFASARD)

Vicki has worked for NOFASARD for many years, and is recognized for her expertise in this area.

Vicki has extensive experience in FASD, child protection, corrective services and policing.

DATE → 31/7/2012

TIME → 2 - 4.00pm

RSVP → By 27th July 08 9286-5200
OR fosterworkshops@dcp.wa.gov.au



Appendix 10: Department for Child Protection Workshop Evaluation



Understanding children living with a Fetal Alcohol Spectrum Disorder

Workshop Evaluation

1. Please indicate which workshop you attended:

Monday 30 July 2012	<input type="checkbox"/>
Tuesday 31 July 2012	<input type="checkbox"/>

2. Was the workshop relevant to your role as a person working with children and families?

Completely Mostly A fair amount Slightly Not at all

3. Was the information and content informative?

Completely Mostly A fair amount Slightly Not at all

4. Was the information practical and useful?

Completely Mostly A fair amount Slightly Not at all

5. Did you feel encouraged to participate in the discussion?

Completely Mostly A fair amount Slightly Not at all

6. Did you feel you were given sufficient opportunity to ask questions?

Completely Mostly A fair amount Slightly Not at all

7. Are there any issues that you feel were not discussed today that should have been?

8. Do you have any other comments you would like to add?



9. Would you be interested in receiving information about Telethon Institute for Child Health Research projects, seminars and community activities?

Yes No

If yes, please let us know the best way to contact you:

Name:

Email:

Mail:

10. Would you be interested in our work/receiving our newsletter or joining the National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) network?

Yes No

If yes, please let us know the best way to contact you:

Name:

Email:

Mail:

Thank you for your time and participation in attending the workshop.





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