



# Alcohol and Pregnancy & FASD Research Team



PREVENTION



DIAGNOSIS



THERAPY & MANAGEMENT

## RESEARCH SUMMARY

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Evaluation of information and support for parents and carers of children with FASD

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*Fetal Alcohol Spectrum Disorder (FASD) is characterised by brain damage from prenatal alcohol exposure, the effects are lifelong and may not be seen at birth.*

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**Project contact:**  
[Heather Jones](#)  
08 9489 7724

### What was this research about?

The purpose of the study was to find out what FASD information and resources were available to parents and carers, were these useful, and what were the parents' and carers' specific needs with respect to information and resources to support them raising a child with FASD.

### What did we do?

We conducted:

- 3 focus groups with a total of 26 foster carers in the metropolitan area and a regional centre
- a face to face interview with one foster carer in the metropolitan area
- a paper-based survey of foster carers to evaluate the information and resources they had accessed with input from 10 foster carers
- a review of accessible paper-based, audio-visual and electronic resources specific to Australia

### Who took part in this research?

- Researchers
- Reference Group
- Foster carers

### How did consumers and the community participate in this research?

We had two consumer representatives on our Reference Group, to assist us in providing the lived experience of a family caring for a child or young person with FASD. They also assisted with the recruitment and conduct of carer focus groups and review of available materials.

### What did we find out?

#### **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.
- 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.

As researchers, we learned from the women who shared their important knowledge, needs and perspectives as foster carers of children with, or suspected of having, a FASD. Their participation in the focus groups made a significant contribution to this project.

### What did we do next?

Since the completion of this project we have conducted:

- 2 interactive workshops with 17 foster carers attending
- 2 workshops with staff from the Department for Child Protection
- sponsored 2 foster carers to attend the Australasian FASD Conference

Read the [Final Report](#)

This project was funded by the Foundation for Alcohol Research and Education

### 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.

### Alcohol and Pregnancy & FASD Research Team at Telethon Kids Institute

We have a comprehensive program of research in partnership with community & stakeholders to achieve our goals of developing prevention strategies; building the capacity of health, justice and other professionals to recognise and diagnose FASD; and implementing and evaluating programs for children and young people with FASD and their families.

For information on alcohol & pregnancy, FASD, our research projects, resources and publications visit our website: [www.alcoholpregnancy.telethonkids.org.au](http://www.alcoholpregnancy.telethonkids.org.au)

There is no safe time or amount of alcohol to drink while planning a pregnancy, when pregnant and when breastfeeding which is why the Australian Guidelines state 'not drinking alcohol is the safest choice'.

