# Evaluation of information and support for parents and carers of children with a Fetal Alcohol Spectrum Disorder

## Researchers

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## Summary

The aims of the research were to:

1. identify the Fetal Alcohol Spectrum Disorders (FASD) information and resources foster carers had accessed;
2. evaluate current Australian FASD information and resources; and
3. investigate the specific needs of foster carers with respect to information and resources to support them raising a child living with FASD.

The research study sought to identify and evaluate the information and resources through:

* focus groups with 26 carers in Western Australia (in metropolitan and regional areas);
* a paper based survey of 10 foster carers to evaluate the information and resources they had accessed; and
* a review of Australian FASD information and resources relevant to foster carers and parents. This included specific alcohol and pregnancy primary prevention posters, booklets, brochures, DVDs, websites and advertising campaigns.

In addition, two workshops were held in response to needs identified by foster carers for information on FASD through face-to-face settings. 17 foster carers attended. Carers’ response to the workshops was overwhelmingly positive with participants commenting on the benefits of real life stories and practical strategies for supporting children living with FASD. Two additional workshops were held with staff from the Department for Child Protection, with 97% of staff attending indicating that it was useful and practical, and relevant to their work with children and families.

## Outcomes

Overall the foster 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 was inadequate and this lack of support contributed significantly to carer stress and fatigue.

Carers often 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; and
* a lack of recognition of FASD as a disability, the social stigma of a FASD diagnosis and a lack of specific services to either diagnose FASD or provide services after diagnosis.

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.

Health professionals were identified as being the main source of information for carers on FASD and on the needs of the individual child. In addition the majority of carers gained information on FASD through contact with other carers and attendance at meetings organised by foster care services. Carers also accessed information through the internet rather than by being provided with printed materials.

The study identified a number of high quality print, audio-visual and website resources appropriate for the Australian context. However the awareness of these existing resources was low. It was recommended that all the resources included in the study be promoted to foster carers.

[view the report](/wp-content/uploads/Telelthon-FASD-Evaluation-of-information.pdf)