

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



This information sheet summarises the findings of a research project undertaken in 2011/2012 by researchers at the Telethon Institute for Child Health Research, with the participation of foster carers in Western Australia.

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

The purpose of the study was to find out what FASD information and resources were available to parents and carers and 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.

Key Findings

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.

Project Investigators

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Project Reference Group

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Methods

- Focus groups with a total of 26 foster carers held 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, audiovisual and electronic resources specific to Australia

Australian FASD information and resources identified by project team

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.

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 Fetal Alcohol Spectrum Disorder. Their participation in the focus groups made a significant contribution to this project.

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.

For more information about this project or other alcohol, pregnancy and FASD projects please contact Heather Jones

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