# Improving services to families affected by Fetal Alcohol Spectrum Disorders (FASD)

## Researchers

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## Summary

This research report examined ways to improve services to families affected by Fetal Alcohol Spectrum Disorders (FASD).

Between October 2011 and March 2012, 29 semi-structured telephone interviews were conducted with parents and carers of children with FASD on their experiences and recommendations to improve service delivery. Respondents were from all states and territories (except the ACT); from major cities (n=10), regional areas (n=13) and remote or very remote areas (n=6).

26 women and four men participated in the interviews. Participants ranged from 34 to 68 years in age, with a median of 50 years. The majority (n=21) cared for children under 18 while eight participants reported on caring for adult children, aged 18 to 32 years.

Thirteen participants were foster parents, three were biological parents, four were adoptive parents, five were relative carers and four were guardians.

## Outcomes

The research found that:

* carers are often labelled and stigmatised as bad parents by services that expect them to ‘try harder’ and believe that the issues with the child are due to poor parenting rather than the child having FASD.
* obtaining a diagnosis was very important to parents and carers.
* parents and carers need access to multiple health services and currently there is poor communication between those practitioners.
* there is also little knowledge about FASD, particularly among health practitioners, in the education system and criminal justice system. The most common issue raised by carers was that health professionals lacked knowledge about FASD.

## Recommendations

To improve services to families affected by FASD, there is a need to:

* inform women about the effects of alcohol use in pregnancy and intervene to prevent additional alcohol exposed pregnancies.
* increase community awareness of FASD and what it means for affected individuals. Little is known about FASD in the general community, it is considered to be the ‘invisible disability’ and it is not formally recognised as a disability.
* increase awareness and improve education and training of professionals in health, education and justice. Information on FASD needs to be included in the curriculum of university and other courses that involve training professionals in health, education and justice. On-going training of professionals in these sectors is also required
* the expertise of professionals to diagnose individuals affected by fetal alcohol exposure needs to be increased. Establish diagnostic services and train professionals on use of the diagnostic instrument.
* educate professionals dealing with carers to listen more to carers and refer them to other professionals as required. Provide funding support to agencies and organisations that support carers including online support groups (eg.  National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) and the Russell Family Fetal Alcohol Disorders Association (RFFADA).
* provide carers with adequate information about biological mothers’ alcohol use and potential effects on children in their care.
* more detailed maternal histories need to be provided by foster care agencies to carers.
* provide parents and carers with strategies to deal with alcohol-affected children.

## Further research

Future research is required:

* into effective treatments for treating women with alcohol problems and pregnant women specifically.
* to address the dearth of high quality evidence of the benefits of specific interventions for children with FASD. Interventions that have been shown to be effective in other countries need to be trialled and evaluated in the Australian context.
* to trial and evaluate effective interventions in the Australian context. Evidence suggests that women who have had one child affected by FASD are at greater risk of having another child affected. There is a need for interventions to prevent alcohol-affected pregnancies.
* regarding treatments for women of child bearing age are lacking, effective interventions could be piloted and evaluated in the Australian context.
* to explore the lack of interventions for biological parents who are coping with the loss of the children from their care. Interventions or programs that address this loss may help prevent further alcohol exposed pregnancies.

[view the report](/wp-content/uploads/Improving-services-for-Families-affected-by-FASD.pdf)