

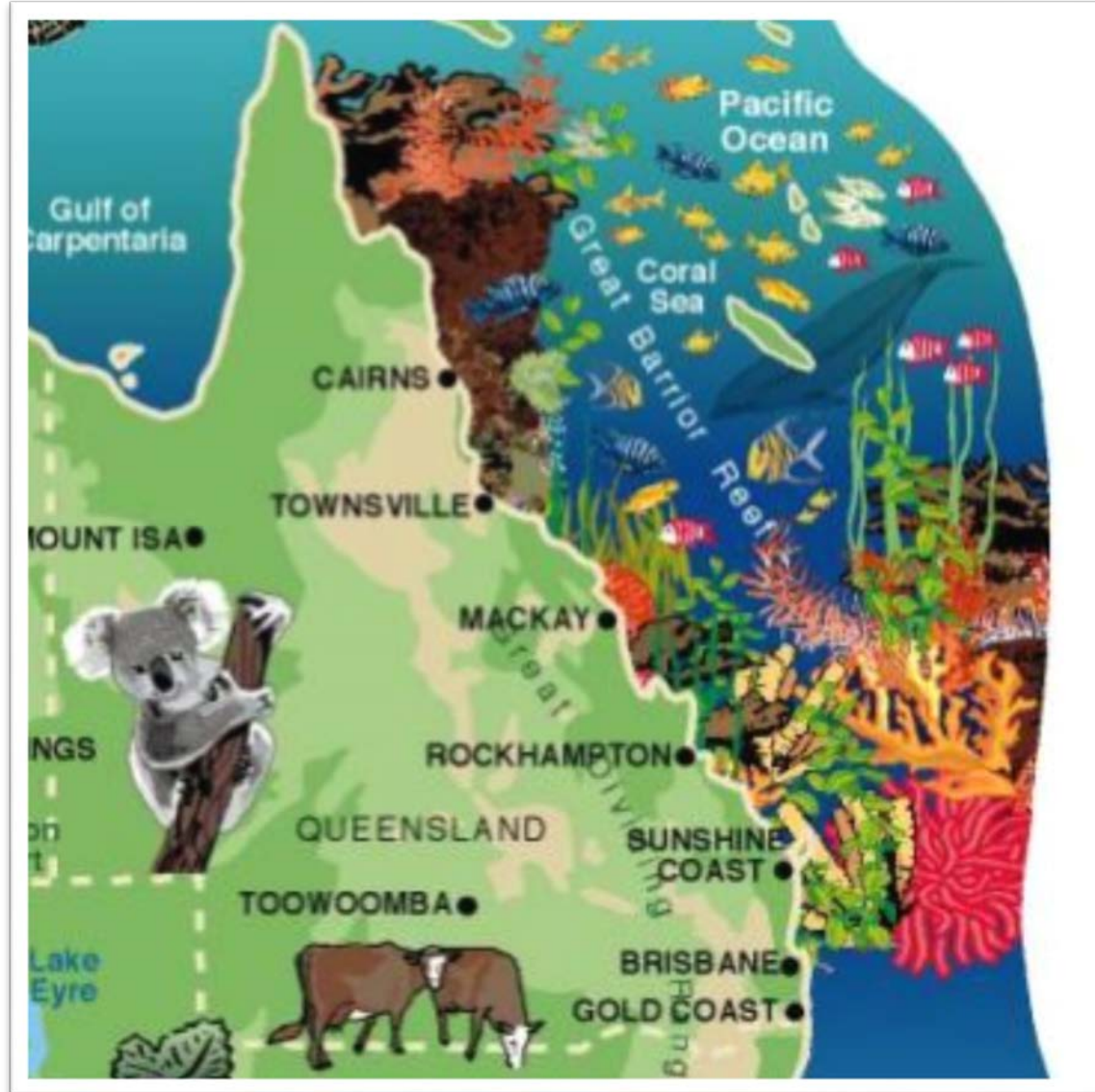


THE UNIVERSITY
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CREATE CHANGE

Queensland caregiver experiences: Part 1







Contents lists available at [ScienceDirect](#)

Research in Developmental Disabilities



A qualitative evaluation of caregivers' experiences, understanding and outcomes following diagnosis of FASD



Katrina Chamberlain^a, Natasha Reid^{a,*}, Judith Warner^b, Doug Shelton^b,
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Some key themes

- **Assessment provided validation and understanding**

“Validation from someone...I’m not just making these things up”

- **Process of FASD diagnosis as empowering**

“They listened to me in regards to my concerns and my concerns were never too small or insignificant”

- **Lack of societal knowledge and recognition of FASD**

“We had a lot of GPs and I think they were just thinking that I’m a neurotic mother”

- **Increased caregiver uncertainty**

“I was really thinking I know nothing about where to access services”



ELSEVIER

Contents lists available at [ScienceDirect](#)

Research in Developmental Disabilities

journal homepage: www.elsevier.com/locate/redevdis



Feasibility study of a family-focused intervention to improve outcomes for children with FASD

Natasha Reid^{a,*}, Sharon Dawe^a, Paul Harnett^b, Doug Shelton^c, Lauren Hutton^a, Frances O'Callaghan^d




Some key quotes

- “Once they are diagnosed they need to follow-up on these kids and do intervention...we need ongoing support.”
- “Just geographically it [FASD diagnostic clinic] is just so far away...we need something available here [closer to home].”
- “They [the school] say their hands are tied because there is no actual funding for her. They try to do what they can but with no funding available it is really hard.”
- “Do not write off mothers as being neurotic and that they wouldn’t know what they are talking about because we are not the professionals or because you haven’t heard about it [FASD] so there is no such thing as it.”
- “If you said to me do you think the medical profession has let [child’s name] down I would say totally.”


VIEWPOINT

Responding to fetal alcohol spectrum disorder in Australia

Doug Shelton ^{1,2} Natasha Reid,³ Haydn Till,¹ Francoise Butel¹ and Karen Moritz^{3,4}

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Journal of Paediatrics and Child Health 2018



QLD FASD SUPPORT GROUP
Queensland Fetal Alcohol Spectrum Disorders Support Group
 + supporting one another

[+ Join group](#) [... More](#) Join this group to see the discussion, post and comment.

About this group

Description
 Face to face support group open to anyone. Parents, carers, families, adults and young people living with FASD, educators, community members.

Members · 695

Activity

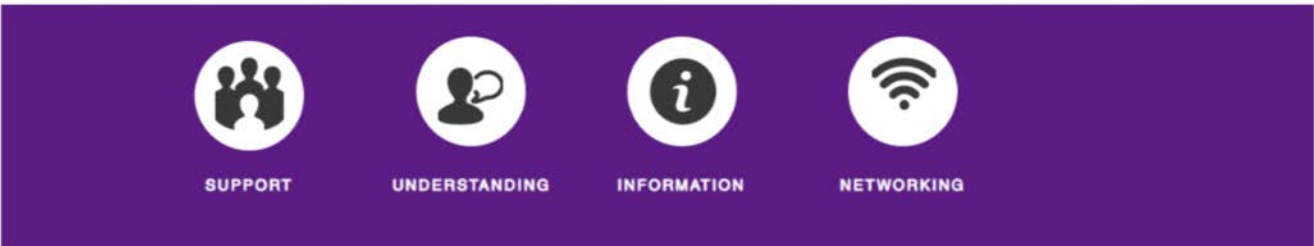
6 New posts today
 136 in the last 30 days

695 Members
 +0 in the last 30 days

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SUPPORT **UNDERSTANDING** **INFORMATION** **NETWORKING**

+ ABOUT US

The people behind QLD FASD Support Group:



Sam
 President and Founder



Claire
 Treasurer



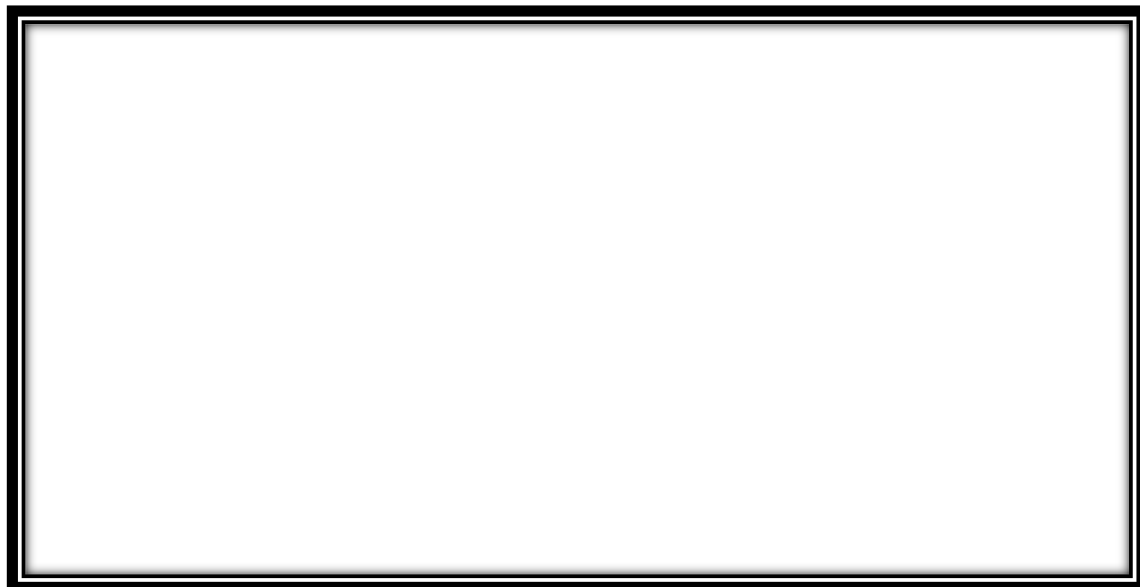
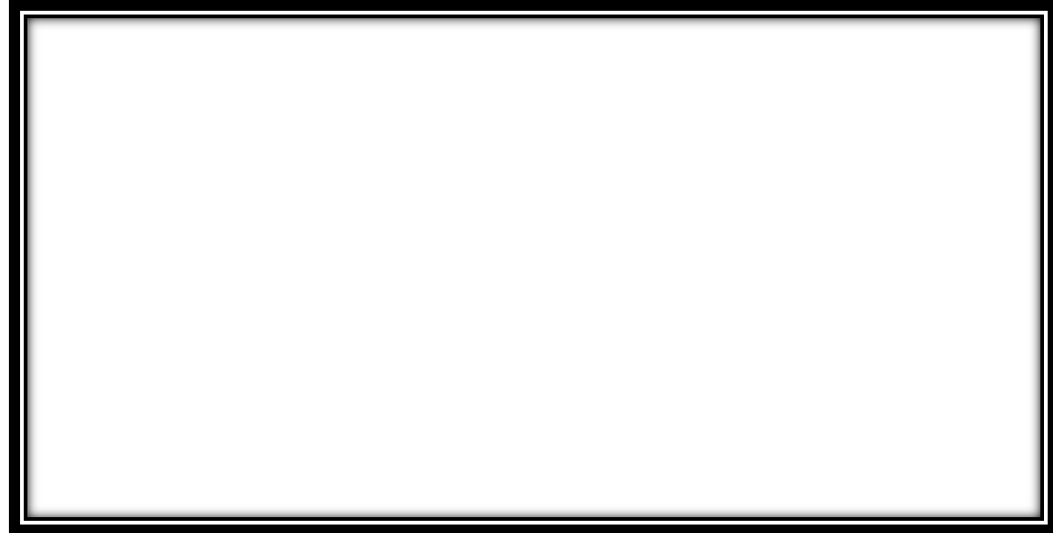
Jo
 Secretary

What caregivers would like to tell their paediatrician

- “We come to professionals hoping you know more than us.”
- “It shouldn’t take years to get a diagnosis when we could have been helping our kids and not wasting time. An early diagnosis can change things for us to start putting plans into place earlier.”
- “Don’t give up on our kids putting them in the too hard basket.”
- “We have good days, bad days, tired days and overwhelming days.”
- “This is one hell of a lonely journey.”

FASD & ME

Jazpa and Sam's Journey





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Thank you

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