Queensland caregiver experiences: Part 1
A qualitative evaluation of caregivers’ experiences, understanding and outcomes following diagnosis of FASD

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

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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.”
Responding to fetal alcohol spectrum disorder in Australia

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https://www.facebook.com/groups/QldFasd/
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.”
https://www.youtube.com/watch?v=WkokwZZRa4k
Thank you

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