

Case Studies

Email to NOFASARD 14.11.11

We are carers of an eight year old girl and have been her primary carer for eight years and will continue for always. xxxxx(our child) was eight weeks prem and weighed 1400gr at birth. We were concerned from about the second week of her coming into our life that she had some problems, (we were advised by FamilySA that she may have a problem when asked to accept her). To cut things short ,after lots and lots of fights with her paed. we were advised that she had significant developmental delay. She has received speech therapy, dietician, fine motor skill therapy, psychiatric assessments etc. Lisa started school with with SSO support with a diagnosis of Global Developmental Delay and for the past 12 months has been in a Special Junior Primary Class. Now she has turned eight according to DECS she no longer can use GDD as a diagnosis so all funding has been cut. Our latest PAED at the Womens and Children's Hospital Adelaide has stated firmly that she believes that Lisa has FAS and has been misdiagosed for years. Lisa has all the signs of FAS plus she has severe incontinence of both bowel and bladder. My biggest concern is that their is no funding available thru DECS for Lisa or any other child that has FAS as it seems that know one knows what it really is. FAS is a Disability that a child has that is not brought on by anything the child has done. An Invetro child has no say in the matter of what is consumed by the parent, they have no voice in the community and are left to their own devices as to furthering their Education and peer supports. I know that Lisa is now going to be put into a class next year with mainstream students and be expected to keep up. If you require any further information please feel free to email or call regards xxxxxxx.

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As carers of a nine year old child with global developmental delay, toileting issues, severe separation anxiety and sensory processing disorder we have faced many challenges. In many respects, every day is like Groundhog day.

FASD was first mentioned at kindy but pediatricians' have been reluctant to name anything at all.

We have a very good psychologist and GP but it has been impossible to access proper assessments.

Our biggest hurdle is by far the public education system, their current criteria for disability in SA is that the child must be functioning at below the first percentile in more than two key areas. Fortunately our son started school when it was the third percentile so he has SSO support for three hours a week (whoopdefrickendoo).

I know that my child may not have FASD but I do know how difficult it is for any one with a disability to access services particularly after the age of seven when it seems the government believes they will be magically cured or no longer need a range of services I.e. Speech, OT. Etc.

Constant debate on how much one should drink whilst pregnant is very frustrating as I know that it is not worth the risk at all if the child faces a future anything like that of our foster son.

Keep up the fight We need you