# Every epiphany counts, but…

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### It will be a grand day when there are no more “FASD epiphanies”

It will be a grand day when there are no more “FASD epiphanies”. The definition of an epiphany, leaving aside the religious connotation, is the moment you suddenly feel that you understand something, a moment of sudden revelation or insight. A Eureka moment!

It is nearly 50 years since the first Eureka moment for Fetal Alcohol Spectrum Disorder (FASD), it is 20 years since NOFASD Australia was formally founded, and it is seven years since the last national parliamentary inquiry into FASD.

Over this period, incredible work has been done by extraordinary people to respond this complex, preventable disability; however, there is a long way to go to better manage and prevent FASD.

Which is why it is pleasing to see South Australian Senator Stirling Griff’s recent epiphany, which has put FASD back in the spotlight through a new Senate Select Committee inquiry into FASD.

This Senate Inquiry provides renewed impetus for action on implementing the recommendations from the 2012 Inquiry, and establishing the necessary framework with attached funding, for prevention awareness and diagnosis, treatment and support services.

FASD is often not recognised, under-diagnosed, completely missed, misdiagnosed and disregarded. And new issues have emerged over the past decade, including the challenges of accessing the NDIS. Meanwhile, globally alcohol sales continue to rise, supported by aggressive marketing to women and young people, increasing the risks of alcohol-exposed pregnancies.

Many people who work in the area of FASD, or who have a professional or personal connection with FASD, describe epiphanies as being a regular occurrence. Talking about FASD first intrigues the listener and then leads to a sudden exhalation of breath – the realisation that they know exactly what FASD is. Sometimes this is because of a client they have been working with, sometimes it’s a family member or relative, sometimes a friend, but the recognition that they have seen FASD suddenly and clearly becomes apparent.

In an ideal world this would not happen, because, as a disability, the early indicators would be recognised and early intervention plans put into place. To reach that ideal world, increased awareness would be gained from national awareness and prevention campaigns clearly articulating that in pregnancy and planning for pregnancy, no alcohol is the clear message from the point of conception to the end of breast feeding.

For parents and carers no more epiphanies will mean that they no longer have to educate each health professional, educator, disability support worker and many others that they come in contact with. Many parents say that they have had to educate every single person who has ever sought to assist their child. To the credit of many health professionals their personal epiphany results in careful listening, deep commitment and a search to improve their own knowledge and patient well-being. However, not everyone reacts this way. Many do not have the time to educate themselves and many refuse to accept the severity and impact of the disability. In our over-worked foster system it is often easier to blame the parenting skills of the carer rather than seriously consider that the demonstrated behaviours are underlying brain damage caused by pre-natal alcohol exposure. For our justice systems it is easier to churn people through a revolving door rather than stopping to investigate the possibility of brain damage.

For parents and carers the end of epiphanies and increased community-wide awareness will mean that when they turn to national  and state websites seeking information about FASD support, they will find lists of developmental disabilities serviced or supported by that organisation – which will include FASD, name it correctly, spell it correctly and thus create confidence in service users.

Parents and carers do not want to have to educate health professionals and disability service providers. They want professionals to have knowledge of FASD, to recognise that the signs might be hidden or hard to see, and to recognise that the parent is providing accurate information. They want professionals to be FASD-informed and to use their knowledge to promote well-being and positive outcomes for their affected clients and families.

So, it will be a great day in Australia when every health professional in service provision knows that there is an [Australian Diagnostic Guide for FASD](https://www.fasdhub.org.au/siteassets/pdfs/australian-guide-to-diagnosis-of-fasd_all-appendices.pdf) and has studied it themselves. Hopefully, this will prevent parents and carers from being turned away from health professionals while being informed that the child does not have FASD because “there are no facial features”. This is a very sad statement by a health professional indicating that they do not understand that more than 80 per cent of those affected by FASD have no physical or visible signs of the disability. Furthermore, this statement makes it clear that they do not understand the brain-based behaviours which often point to FASD and that they have not consulted the Australian Diagnostic Guide for FASD.

For parents and carers statements like this are soul-destroying because they are again left in the wilderness without the help and support which is so desperately needed and which must begin with being FASD-informed and knowledgeable.

My hope is that this FASD Inquiry will be a positive step towards ending the need for epiphanies, and to end FASD once and for all.

### Metadata

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