LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON HEALTH AND COMMUNITY WELLBEING
Mr Johnathan Davis MLA (Chair), Mr James Milligan MLA (Deputy Chair),
Mr Michael Pettersson MLA

# Submission Cover Sheet

## Review of ACT health programs for children and young people

**Submission Number:** 02

**Date Authorised for Publication:** 06 July 2021

## Snedden, Andrew

---

| | |
|---|---|
| **From:** | Katherine O'Sullivan [redacted] |
| **Sent:** | Wednesday, 9 June 2021 8:31 AM |
| **To:** | LA Committee - HCW |
| **Subject:** | Submission to the Review of ACT health programs for children and young people |
| **Categories:** | Red Category |

CAUTION: This email originated from outside of the ACT Government. Do not click links or open attachments unless you recognise the sender and know the content is safe.

To whom it may concern / Andrew Snedden,

My name is Katherine O'Sullivan. Last night I was made aware of the Review of the ACT health programs for children and young people. I went to the legislative assembly webpage to try and gain further information on the review. In particular I wanted to look at the details of the review, more specifically the guidelines for submissions and the inquiry's terms of reference. However both links came up with a '404 error' - page not found, despite having more time with submission closure on 25th June.

I have a daughter who was diagnosed aged 7 with FASD. I am therefore very interested in the committee's terms of reference and submission guidelines - so as to know if our experience over the last 10 years, in obtaining firstly a diagnosis and secondly finding therapists who know what FASD is, and how to design and implement a therapeutic program to support a child with FASD is something the review would be interested in. And if so what specific issues the review is interested in. However I have not been able to access the governments website. Would someone please be able to provide the information or a link that works?

My daughter has had (since the introduction of NDIS) a support package which we have been using to support her development, through Speech, physiotherapy, psychology and an inclusion support specialist. These supports have been extremely helpful, so much so that we often get told that currently people do not realise she has a disability, until they spend a longer period of time with her, and even then they comment that they realise 'something' isn't just right due to issues with communication, however they often say they would never have guessed at the severity of her disability. We have HUGE concerns that due to changes with NDIS, specifically due to the MASSIVE numbers of children now being diagnosed with level 2 ASD - there don't seem to be ANY level 1 ASD diagnosis's anymore and that level 2 ASD now includes children who are functioning within regular classrooms with little to no support, to children who are almost completely non-verbal. So I definitely agree there is a problem with the system, and they NEED to make changes, however due to the 'crack down' on children with what they refer to as 'psychosocial' issues - of which FASD is also classified, I am EXTREMELY concerned that our daughter will loose her support.

We know that we chose to adopt a child from the ACT Foster system with a disability, however when we were going through the extensive process we were essentially told that the ACT Government will provide NO on-going support as NDIS will provide it. We are very concerned that we will loose all supports for her - we will be able to supply limited supports due to the massive increase in therapist costs with the introduction of NDIS and the inability to get a therapist and pay privately- they ONLY accept NDIS participants, we are EXTREMELY concerned for her future. At this stage due to the changes that are happening within NDIS (and we believe does need to happen as there are just so many people who are continually pushing for more and more supports for their ASD children), we are concerned that our daughter will loose her supports - which will place her at MUCH higher statistical risk of run ins with the judicial system and the foster system, than these other children. We are slowly coming to the belief that we should have left her within the system so that she/we has continued access to these vital supports for her. And i would like to point out that I previously worked as an LSA (learning support assistant) within the ACT Public school system, working in all levels - preschool to college, and spent LARGE numbers of hours working at home one on one with our daughter, working on all her areas of development. These supports over the years have enabled my to provide the support to her daily, in a way that was structured and goal based. It gave me enough support, that I felt confident and comfortable and more importantly had the skills required to provide therapy that has been from what everyone who has worked with her (me) over the past 8 years, has been highly successful. I want to be able to continue to provide therapeutic supports to her, but with support myself so that we are successful at providing her with the skills to live independently, have positive social relationships and possibly even hold down a full time job. These are our long term goals and dreams for her. And most importantly avoiding any interactions with CYPS and the judicial system.

These concerns should also be of high concern to the ACT Government (and society at large) given the statistics of children who have been in 'the system' returning to it when they have children themselves. That continued cycle is what we are doing everything in our power to stop. However the possible lack of on-going supports - she is only 10 and statistically it is the teen years that individuals with FASD get into difficulties with the law and social issues such as pregnancy become an issue - due to their brain injuries resulting in low impulse control and high sexual drives.

As you can see there are a number of issues that my husband and I would like to share with the review committee and would therefore appreciate the information requested above - or at least a link to the information that works.

Kind regards
Katherine O'Sullivan

Sent from my iPhone