TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Swan Hill — 14 February 2017

Members

Ms Maree Edwards — Chair
Ms Cindy McLeish — Deputy Chair
Ms Chris Couzens
Mr Paul Edbrooke
Mr Bernie Finn

Witnesses

Ms Jane McLean.

The CHAIR — I welcome this morning Jane McLean. Thank you so much, Jane, for coming along today. All evidence at this hearing taken by the committee is protected by parliamentary privilege as provided by the Constitution Act 1975 and is subject to the provisions of the Parliamentary Committees Act 2003 and other relevant legislation. Any comments you make outside the hearing will not be afforded such privilege. It is a contempt of Parliament to provide false evidence. Recording of the proceedings will commence today and you will be sent a proof copy of the transcript and be able to make factual or grammatical corrections if necessary. We would like to invite you to make a 15-minute presentation. It is up to you whether you want to use all that time for yourself or if you are happy for us to ask questions. Thank you so much, Jane.

Ms McLEAN — I have got some pages to read. Thanks for having me here. I am the mother of Callum, 13, and Joel, 10, who were both diagnosed with autism in 2011. Before arriving in Swan Hill late in 2007 the family had been living in Dubbo, New South Wales. Callum had delayed development with crawling and walking but it was not until he was about two that we became concerned, mostly with his lack of speech and communication. We sought help through Dubbo Community Health Services and received early intervention involving attending early talking group sessions, a hearing test, which was normal, and a home program of activities to improve Callum's communication.

From the beginning of 2007 until we moved to Swan Hill Callum attended the early intervention class — part of Orana Heights primary school — two mornings a week. We had also been recommended to get a referral to a paediatrician, but knowing we were moving to Swan Hill decided to wait until we were here. On moving to Swan Hill when Callum was four and Joel was one I sought out early intervention services plus a referral and an appointment with a visiting paediatrician from Bendigo. Callum also began preschool at the beginning of 2008. The paediatrician confirmed a developmental delay but did not feel that specific investigations were warranted at that stage. I believe there has since been a shift with autism being diagnosed a lot earlier.

Callum ended up doing two years of preschool due to his slow progress. In this time we had approximately fortnightly early intervention sessions, both at home and at Noah's Ark. As I was new to Swan Hill I also put up my hand for any other groups or parent talks that were offered as a way to connect with the community. My favourite was MyTime run by Noah's Ark during each term once a week, in which the child as well as any siblings were looked after and given activities while the parents met as a group with a key worker facilitating both formal and informal discussions about different strategies and needs. I am not sure how it is now, but at the time the facilitators of Noah's Ark found it difficult to find suitable locations for these groups and would have to meet in football and racing clubrooms or anywhere they could find at little or no cost.

By the age of two our second son, Joel, was showing the same developmental delays and was referred to the same visiting paediatrician that had seen Callum. Again, while agreeing Joel had a significant developmental delay of at least a year, it was not clear that he would fit within the autism spectrum. The paediatrician also suggested some genetic testing — banded chromosomes and Fragile X — in light of both boys having the developmental delays. Nothing was found.

At six and a half Callum was assessed as meeting the department of education criteria for a student with disabilities, his IQ result being 62, and subsequently funding was provided for classroom support 2 hours a day. We had no indication from Callum or otherwise until September when we were called to the school to meet with teachers over concerns of him being regularly overwhelmed and finding new situations and changes to routine difficult to manage. He would become frustrated and cry inconsolably, taking considerable time to settle and re-engage. It was recommended by his teacher that we send Callum to the specialist school for the following year.

My husband and I felt that Callum had still progressed and did not want to give up on mainstream school yet, so for 2011 Callum was dual enrolled — three days at Swan Hill Specialist School and two days at Swan Hill North Primary School. We were just taking it term by term to see how it went, but it worked really well for Callum. Terms became years and a positive routine was developed for Callum, so he spent the rest of his primary years at red school and green school. I believe this dual enrolment worked well due to both schools being very supportive. Callum's teacher's aide at Swan Hill North was the same caring person from grade 1 through to grade 6 and his class peers were very accepting and helpful with him.

In the time since seeing the paediatrician Joel has received early intervention services through Noah's Ark. It also became evident that his development was more delayed than Callum's. With both boys' abilities and behaviours clearly trailing their peers and even younger relatives, we were looking for answers and clearer strategies for the future. This led us to Bendigo Early Diagnosis Autism Assessment and Referral Service, or BEARS. We had both boys assessed on the same day by a multidisciplinary team in March 2011 and both were given the diagnosis of autistic disorder.

By the time we had them formally assessed the results were no surprise, but it still hit hard and both of us went through a kind of grieving process, which in some ways continues to this day. Callum, being over seven, was not able to receive the FaHCSIA or HCWA funding but Joel was eligible for two years. The only therapies the boys have received have been through early intervention before attending the Swan Hill Specialist School, where they both now have the occasional speech and OT.

I was and am mostly unaware of other services we could access in Swan Hill. I guess once the boys were both attending the specialist school there was a big sense of relief that they were in good hands and receiving sufficient support for their needs. I cannot fault the quality of the Swan Hill Specialist School and the education my boys receive. I feel very blessed that the school is here, although I believe they could benefit from more funding and for easier pathways to be made for teachers adding special ed. to their training.

When Callum finished his primary years last year we all felt it best for him to attend the specialist school full time. I would also add that we have recently started visits to the Royal Children's Hospital in Melbourne for treatment on Callum's legs, due to his chronic toe walking and subsequent muscle and tendon issues.

Despite the support of family and friends it has been a difficult journey. Up until a couple of years ago my husband worked long hours and also suffered burnout, and I have struggled on and off with depression and anxiety.

Joel is a runner, and we have had the police involved at least four times when we have been unable to locate him. I realise that if I was more dedicated and had enough time and headspace to do more than just survive, I could seek out more help in the form of more therapies for the boys, after-school activities or respite for Matt and I, but I feel Swan Hill is limited in what is on offer and we would mostly need to travel to a larger regional centre, such as Bendigo.

We live in a tension between accepting the boys as they are and the ideal of changing them to be normal. I am also quite worried about what the future will look like for my boys when their schooling is finished because as yet I am doubtful, especially after hearing other parents' concerns, if the programs or services provided locally will be sufficient for them and their needs.

The CHAIR — Thank you very much, Jane. Just in relation to Callum and his surgery at the Royal Children's Hospital, we have heard through public hearings that our Victorian hospitals need to become more ASD friendly. I am just wondering what your experience has been at the Royal Children's in relation to Callum and his ASD.

Ms McLEAN — It was an amazing service, but I guess there was not a lot of understanding in terms of his autism and his speech. It seemed to take them by surprise, I guess, even though it was kind of obvious.

The CHAIR — So there was no specialist attention in that regard.

Ms McLEAN — No.

Ms McLEISH — So who did it take by surprise? Everybody down there or a certain type of staff?

Ms McLEAN— I guess, because with Callum it is his speech, they would be asking, 'How is the pain?', and they would not be able to understand what he said, they would sort of be frustrated and then Callum would be frustrated.

Ms COUZENS — Are you involved in any support groups with children with ASD?

Ms McLEAN— Not really, no. Not since they have started school.

Ms COUZENS — So there is nothing locally that you know of?

Ms McLEAN — Not that I know of.

The CHAIR — So the boys receive all of their therapy through the school now? Is that correct?

Ms McLEAN — Yes.

The CHAIR — So speech therapy and occupational?

Ms McLEAN — They have not had any OT. They were just assessed at the end of last year.

The CHAIR — And will the boys be eligible under the NDIS?

Ms McLEAN — I suppose so. I am not sure.

The CHAIR — Thank you so much, Jane. We really appreciate your time this morning.

Ms McLEISH — And for sharing your story.

The CHAIR — Thank you, and good luck.

Witness withdrew.