

# TRANSCRIPT

## FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

### **Inquiry into services for people with autism spectrum disorder**

Shepparton — 15 November 2016

#### Members

Ms Maree Edwards — Chair

Ms Cindy McLeish — Deputy Chair

Ms Chris Couzens

Mr Paul Edbrooke

Mr Bernie Finn

Ms Emma Kealy

#### Staff

Executive officer: Dr Greg Gardiner

#### Witnesses

Ms Meaghan O'Brien, and

Ms Michaela O'Brien.

**The CHAIR** — I welcome to today's public hearing, Ms Meaghan O'Brien. Meaghan, thank you so much 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. You will be sent a proof copy of the transcript and be able to make factual or grammatical corrections if necessary.

On behalf of the committee, I thank you, Meaghan, for your written submission to the inquiry. It was very informative. I note that you identify as having Asperger's syndrome. Meaghan, I would like to invite you to make a short presentation to the committee.

**Ms Meaghan O'BRIEN** — Yeah, no worries. Other than, hi, my name is Meaghan O'Brien, I am 34 years old and I have Asperger's syndrome; I was diagnosed when I was 15. I do not know what else I can really say.

**The CHAIR** — You do not have to say a lot actually, because we have your submission, so we can ask you a few things, if that is okay with you, from what you have already written and presented to us. I note that in your submission you have a couple of comorbid conditions, including anxiety and depression, which is often very common in people on the spectrum.

**Ms Meaghan O'BRIEN** — Yes, it is.

**The CHAIR** — You are registered with Centrelink, and you are looking for work; is that correct?

**Ms Meaghan O'BRIEN** — Yes, I am.

**The CHAIR** — Is that difficult for you to do that? Perhaps you can talk to us a little bit about your situation.

**Ms Meaghan O'BRIEN** — Yes, it is just hard to find work and I feel ashamed having to be on the DSP, because I have been brought up to have a strong work ethic. If you want something, you have to work for it.

**The CHAIR** — How long have you been on the DSP for?

**Ms Meaghan O'BRIEN** — Since I was 18.

**The CHAIR** — Have you ever had any employment?

**Ms Meaghan O'BRIEN** — Not really, no — no paid employment anyway.

**The CHAIR** — And what qualifications do you have?

**Ms Meaghan O'BRIEN** — I have a certificate III in business admin, medical. I have got an up-to-date first aid certificate.

**The CHAIR** — And where did you do your certificate III?

**Ms Meaghan O'BRIEN** — At TAFE.

**The CHAIR** — Was that difficult for you?

**Ms Meaghan O'BRIEN** — A bit.

**The CHAIR** — Did you have much support while you were doing that training?

**Ms Meaghan O'BRIEN** — The first time I did the course years ago, no, not really, because they did not get me. There was one counsellor there who thought I would be better off doing the course with intellectually disabled people, which totally offended me because there is nothing wrong with my intelligence. I am really bright.

**The CHAIR** — Clearly. Your submission proves that. Meaghan, what do you think employers should be doing to support people like you, particularly when it comes to the interview process for a job or supporting you to get into work?

**Ms Meaghan O'BRIEN** — Just understanding. Sometimes they use examples of their friend's child or relative or whoever, and they think that I have got what they have. Everyone is different. Just because that one you know does this, this and this, I am not like that. I do everything I can to fit in and blend in as best I can. I am quite anxious with the parents and stuff like that, because sometimes you think people can see things because with other people there are certain quirks you can pick out. I do not want to be in that. I try everything to avoid it. There are lots of self-confidence issues.

**The CHAIR** — What sort of work would you like to do?

**Ms Meaghan O'BRIEN** — I would just be happy doing backroom work, clerical stuff, filing, data entry. I do not get bored with that.

**The CHAIR** — Do you like IT?

**Ms Meaghan O'BRIEN** — Sort of.

**The CHAIR** — And when you said you were at TAFE and you only had one counsellor there to support you through that certificate III, how long did that take you to do?

**Ms Meaghan O'BRIEN** — Do you mean the first attempt?

**The CHAIR** — Okay, you have had a couple.

**Ms Meaghan O'BRIEN** — The first attempt at doing business admin was not a very good experience. The second time it was good, because I had matured a bit and I knew exactly what I wanted. I was like, this is what I am looking for in assistance, and I knew what I wanted. The disability liaison people at TAFE got me, because sometimes I can be very blunt and people take it the wrong way. Sometimes I know that you cannot just sugar-coat something, you just have to be: this is the thing, do something about it.

**The CHAIR** — And you said you were diagnosed when you were 15.

**Ms Meaghan O'BRIEN** — Yes.

**The CHAIR** — What led to that assessment and diagnosis?

**Ms Meaghan O'BRIEN** — I cannot really remember.

**The CHAIR** — Was it your parents' decision?

**Ms Meaghan O'BRIEN** — Yes, because when I was younger, doctors just thought I was a bit slow, and thought a bit of early intervention at a special school and a couple of years of kindergarten would fix that up. My mum did a lot of work with me as well in the early years. They did not really think there was anything wrong after that. I was brighter than the rest of the kids in class. I could read. My reading level was above average, and things like that.

**Ms McLEISH** — How was school for you?

**Ms Meaghan O'BRIEN** — Let's see; I have suppressed a lot.

**Ms McLEISH** — So you did okay academically, but was it the socialising or mixing with other kids?

**Ms Meaghan O'BRIEN** — It just was not very good.

**Ms McLEISH** — And that was locally?

**Ms Meaghan O'BRIEN** — Yes.

**Ms McLEISH** — Which school were you at?

**Ms Meaghan O'BRIEN** — I went to Gowrie Street Primary School and then I went to Notre Dame College for secondary school.

**Ms McLEISH** — And did you stay until year 12?

**Ms Meaghan O'BRIEN** — Yes. I have got VCE.

**Ms McLEISH** — You have got VCE. So in the middle of that when you had that diagnosis, did you feel any sense of relief or understanding of yourself?

**Ms Meaghan O'BRIEN** — A little bit. It was like, yes, there is something; they have got a name for it. But I still feel like I do not fit in. I just feel too smart for my own good sometimes.

**Ms Michaela O'BRIEN** — She did do her year 12 over two years, which helped her a bit so that there was not the — —

**Ms McLEISH** — The anxiety levels were lower.

**Ms Michaela O'BRIEN** — Yes.

**Ms McLEISH** — As a family, when Meaghan was diagnosed did you all think, 'Oh, yes, that makes sense to us', or did it change nothing?

**Ms Michaela O'BRIEN** — I am four years younger than Meaghan, and in retrospect it is has helped me a lot to develop too because I advocate for her a heck of a lot. I have had my own challenges that I have overcome; I still have them and I overcome them. I am actually an endorsed nurse by trade, but I am changing careers and studying certificate IV in education support at TAFE. That is a personal thing of not wanting to do shift work and all that anymore and also because I feel that that is where it is more focused now. As this inquiry shows, people have mentioned — I have gone blank; sorry.

**Ms McLEISH** — That is okay.

**Ms Meaghan O'BRIEN** — The need for services — specialised.

**Ms Michaela O'BRIEN** — The need for services — specialised. I have done some of my placement at Verney Road School, and there are ASD kids there and no two are the same. It is not a cookie cutter, not straight, everyone is the same, boom, boom, boom.

**Ms McLEISH** — Yes, everyone is quite different there.

**Ms Michaela O'BRIEN** — Exactly.

**Ms McLEISH** — Can I ask Meaghan, in trying to access work what are the processes when you are dealing with an agency that they go through?

**Ms Meaghan O'BRIEN** — I am sort of first off, 'Yes, I have a disability but I can work a regular job', because there is this whole thing of disability supported employment, and those sorts of services. It is like, 'No, don't put me there. I'm too bright'. It's like I feel ashamed.

**Ms Michaela O'BRIEN** — Do you feel stigmatised?

**Ms Meaghan O'BRIEN** — I still feel stigmatised.

**Ms McLEISH** — And do you think that people in the services do not get the nature of your ASD?

**Ms Meaghan O'BRIEN** — No, they do not.

**Ms McLEISH** — They think you have got more of an intellectual disability, do they?

**Ms Meaghan O'BRIEN** — Not really because I am up-front. It is like, 'Let's just get one thing clear. Yes, my disability is invisible, but my intellect is not impaired'. Sometimes if things get too much and there is too much sensory stuff, as a coping mechanism I sort of shut down. I do not speak. I just keep quiet. People might interpret that as being dumb when it is not.

**Ms McLEISH** — What sorts of things do the agencies do?

**Ms Meaghan O'BRIEN** — I have been to so many different job agencies. They just did not get me and they were trying to push me into areas I just really did not want to do at that time.

**Ms McLEISH** — Why do you think they were doing that?

**Ms Meaghan O'BRIEN** — Because we put this one with ASD in that one. I am not like them. And they are usually males.

**Ms McLEISH** — Okay. So they have had a success with somebody in a particular way and that is where they think you should go.

**Ms Meaghan O'BRIEN** — Yes.

**Ms McLEISH** — Do they talk a lot about networking and going directly to people and places where you would like to work?

**Ms Meaghan O'BRIEN** — I have tried that, but I feel like I would rather do things in what I consider the honest way: apply for the job and all that.

**Ms McLEISH** — Eighty-per cent of jobs are not advertised.

**Ms Meaghan O'BRIEN** — I know, but I feel like I do not want to use people. I am not a user. I do not really like thinking about myself too much because I do not want to be seen as a boastful person.

**Ms McLEISH** — Thank you very much.

**Ms COUZENS** — Thanks, Meaghan, for coming today. We really appreciate you telling us what is happening to you. Are you involved in any support groups?

**Ms Meaghan O'BRIEN** — No.

**Ms COUZENS** — In terms of Asperger's, are there any groups that you have been linked into to get a better understanding of what is happening?

**Ms Meaghan O'BRIEN** — I sort of do not want to. It is a stigma thing. Ones online I follow, but then I could be anybody on my Facebook.

**Ms COUZENS** — And do you find that useful for you?

**Ms Meaghan O'BRIEN** — Yes, because you can take time with your response. If you are talking to somebody to their face you can let out something you do not mean. At least with online you can read through it before you send it and edit it if you need to.

**Ms COUZENS** — In terms of what this inquiry looks at in recommendations to the government, what are some of the key things that you think we should be looking at?

**Ms Meaghan O'BRIEN** — I am not sure. It seems there is more focus on the younger ones and intervention and all the services they need. I have said about what my mum did with me and stuff like that when I was younger. Otherwise, after that I was just raised like any other kid.

**Ms COUZENS** — But there are problems for you getting work, though, now, aren't there?

**Ms Meaghan O'BRIEN** — Yes, there are.

**Ms COUZENS** — What would be some of the things as an adult that you see are important for this committee to take on board when we are making our recommendations?

**Ms Meaghan O'BRIEN** — I have not really thought about that. Everyone is different.

**Ms Michaela O'BRIEN** — I would be thinking about trying to get it out there that not everyone is the — —

**Ms McLEISH** — The cookie — —

**Ms Michaela O'BRIEN** — Yes, not the cookie-cutter thing, that everyone is the same. Destigmatise it a bit. Yes, you have got promotions like Don't DIS my ABILITY and that sort of thing. That is more aimed at the visual; you see it in front of you. Whereas you look at people with ASD and they are normal.

**Ms Meaghan O'BRIEN** — I try to look as typical as possible — —

**Ms Michaela O'BRIEN** — You hold up pictures saying, 'Who has got ASD?'

**Ms McLEISH** — Yes, that is right.

**Ms COUZENS** — Do you think maybe an advocate for adults that have got ASD?

**Ms Meaghan O'BRIEN** — Sometimes it can be an image thing. There is a stereotype of look. I am not shallow, but there is a thing there. It is like I put all this effort into looking like everyone else the best I can. You can be an individual and being yourself is fine, but that is not entirely true. You have got to blend in somewhat as well. You have got to meet people halfway.

**Ms COUZENS** — Do you think an advocate would play a role in that though on your behalf?

**Ms Meaghan O'BRIEN** — Yes.

**Ms COUZENS** — If you are uncomfortable about putting yourself out there — —

**Ms Meaghan O'BRIEN** — Which I am. I am scared to sort of come out of the ASD closet per se because people can treat you differently if they cannot see it. They think, 'Oh, you are dumb' and then they speak down to you and are patronising to you and it is offensive to me.

**Ms COUZENS** — But an advocate could do that on your behalf?

**Ms Meaghan O'BRIEN** — Yes.

**Ms COUZENS** — As well as a lot of other adults?

**Ms Meaghan O'BRIEN** — Yes.

**Ms COUZENS** — Okay. Thank you.

**The CHAIR** — I have no more questions, Meaghan. Thank you so much for coming along today to present to the committee. We really do appreciate it. Good luck with your plans.

**Ms Meaghan O'BRIEN** — I just hope I can help with something.

**The CHAIR** — I am sure your comments will be very helpful

**Ms Meaghan O'BRIEN** — I feel like I have got to do something because I am too bored sitting around doing nothing.

**The CHAIR** — You do a lot of volunteer work.

**Ms Meaghan O'BRIEN** — Yes.

**The CHAIR** — Good luck and thank you very much, Meaghan. Thank you very much for coming along and supporting her, Michaela.

**Ms Michaela O'BRIEN** — You are welcome.

**Witnesses withdrew.**