

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 12 September 2016

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Mr Ryan Kennedy.

The CHAIR — I welcome this afternoon to this public hearing Mr Ryan Kennedy. Thank you for attending 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. Ryan, thank you for your submission to our inquiry, no. 56. It is much appreciated.

Mr KENNEDY — I think I did not actually think about proofreading it before I sent it.

The CHAIR — That is okay. Some of us cannot read very well, so it is probably not a bad thing. I am joking. Perhaps, Ryan, you might like to have a little talk to us and tell us a bit about yourself to reinforce what you wrote to us.

Mr KENNEDY — About myself? I was diagnosed with having Asperger's syndrome in about 2002 or thereabouts.

The CHAIR — How old are you now?

Mr KENNEDY — I am 24. I was about 10 at the time — somewhere around there. I have yet to find out through a documented diagnosis I think, because I have been getting my records from the time. I have had a fair bit of experience with various things. One of the things that I think affected me was in primary school when I got the diagnosis. In primary school I got bullied. The programs were all about how socially you have to be able to stand up for yourself or whatever. The implied thing with that, in my opinion, was that it was saying that if you do not behave in the right way, you are asking to be bullied, which is just as bad as slut shaming.

When I went out of primary school there was less bullying, because I was able to go to the library and I actually found other autistic people to hang out with, which was good. But there are still issues that arise from it, like anxiety. Throughout high school and primary school there were, I suppose, pseudo accommodations. That is the term I would use to describe them because they felt like accommodations and for someone looking in from the outside, they would seem like they were accommodating and they felt like they were accommodating. They were not very much effort, but they were not actually accommodations.

I think what I would have preferred with a particular high school and in particular my English class — I am very good at making verbal statements, but I am not so good at writing it down or necessarily typing it, so I think that one of the things I did not get as an accommodation I suppose, but I am not sure if I would have thought of it back then — was access to either some sort of text-to-speech program or Ascribe for my English exams, because essays are not a strong point. Well, I cannot write essays. I write sentences and they are somehow joined together in some pattern and often do not make that much sense, so it just so happens that sort of thing would be more helpful so I could actually verbalise it and then someone else could be writing it down, as opposed to the accommodation of, 'You just have to write one every week', or something like that. I cannot do it anyway.

The CHAIR — Computers have come a long way now, so it is voice to text now. That would have been very handy for you.

Mr KENNEDY — Yes. It would have been a helpful accommodation when I was there, and it would be helpful for other students. I have got an autistic friend who recommends a service, the name of which is ECHO, for organisational help and, apparently, employment services.

The CHAIR — Can you tell us a little bit more about that?

Mr KENNEDY — Not particularly. I did not use it myself. I have just been through Centrelink when I have had to go through, and they have just gone, 'Okay, you can go to MAX Employment in Box Hill', which has been helpful enough. I think for my friend there was a lot of structure with school, but with English class there was not really any accommodation made or for saying, 'You can't do this very well, so we'll find another way for you to do it'. That was similar with some other classes, I think. It can vary from teacher to teacher, because some teachers are very laid back, which makes it a little bit easier to get away with not necessarily doing all the work in some classes, whereas English teachers seem to be a lot more, 'You've got to do it'. My autistic friend

left early. He went to open university because that suited him far better. He thought of the school as a bit of a circus. It was a bit. I suppose there are also potential pathways that way.

While I think of it, I have been picking up an attitude. My mum is a teacher, so I have been hearing every so often from her. She will start talking about school or this thing, that thing or another thing. Between that and my experience in primary school — she is a primary school teacher — I feel that regarding the current idea of teachers being out there to supervise, there is nothing particularly there to make sure they stop the bullying. It is all focused on the individual level, and there is no idea about the teachers having to be involved there. From my experience teachers are purely there so that if something happens, they can go and give first aid. There is nothing to say, ‘Okay, there are students who need assistance’. I was not very good socially at school, so when they said, ‘You need to stand up for yourself’, I could not do that. It did not help that basically the rest of the year level saw me as the weird kid. I got picked on for being the weird kid, in acting out in autistic ways that I did not necessarily know were autistic at the time, and also for the fact that I have got red hair.

The CHAIR — Which was worse: being bullied for having red hair or being bullied for having autism?

Mr KENNEDY — Probably being bullied for having autism, even though the prevalence is about the same in the overall community. I think one of the things that needs to happen, at least in education, is that there needs to be an approach where the teachers are informed, ‘No student should be bullied, and you should step in’. There should be clear guidelines for every school to handle it. So the first time it happens you warn the bully off and they get sent to a counsellor to see what the hell is going on with them. Sometimes it is merely that the bully needs boundaries. Some bullies are like that. They just do not have the boundaries. They are trying to see what they can get away with.

When I was in high school one of the people that bullied me rode along the same route I would walk to school sometimes. He rode along the same route on his bike. I stepped off the footpath — this happened twice — to let him pass, and he got off the footpath and rammed me with his bike. Then I got the police involved and it stopped, even though there was some occasion of us passing each other, because he knew there was a boundary. He had already been warned by the police so he knew that if anything more happened, wow, it was going to get worse next time, I think.

It was not just that. That was the physical stuff. Sometimes I like to walk home when it is sort of dark, so sometimes that has happened and he has been in his car with his mates or something. This was in late high school — what, 2010 sort of time. He would be around with his mates in a car or something, and he would be yelling from his car. It might have been late; I am not sure. But they tried to intimidate me by saying they were going to get out and do something. I just kept walking, which kind of helped. They drove off eventually. Things like that show that boundaries need to be respected. They need to know not just that it is not acceptable, but also they need to figure out why they are doing the bullying.

From my mum’s experience where she works, in Doncaster, the principal and the welfare coordinator are not exactly on her side when it comes to dealing with bullying. She knows how to handle problem students. She has handled myself and my two brothers, and she has had a few problem students herself that she has dealt with. Some of them have just been problematic and needed boundaries. Some of them have been severely more problematic. With the ones that have been more problematic where she has needed to take actual action to discipline them rather than just setting boundaries and saying, ‘That’s not acceptable’, the welfare coordinator, despite having better things to do, has come in and said, ‘That’s not acceptable’ and has tried to sweep it under the rug. I think in pressing for good schools with no tolerance of bullying, in some cases there is also a focus on trying to sweep whatever they can under the rug to make it seem like there is no bullying so they can get more money and more funding. That seems to be one of those potential issues that needs to be dealt with. I think that occurred a bit.

The CHAIR — Ryan, can I ask what you are doing now that you have left school?

Mr KENNEDY — When I left school I did a diploma of laboratory technology. I finished that in 2013. My work placement was at CSIRO, and then after I finished that I spent some time looking for work and found some work at RMIT. I did that for 16 months, which was good. Now I am working in the eastern suburbs.

The CHAIR — Did you have difficulty getting jobs?

Mr KENNEDY — Some. Things like cover letters are not exactly easy, because I am not so good with the written or the typed-up stuff. I have got an aunt who has done a lot of HR work — —

The CHAIR — Have you disclosed your autism to your employers?

Mr KENNEDY — No.

The CHAIR — Do you think if you did it would make a difference?

Mr KENNEDY — I am not sure. Possibly.

The CHAIR — Can I ask why you have not?

Mr KENNEDY — Up until recently I have been trying to figure out what to say about various things like that, because for the most part some things in my experience I have gotten used to so they seem normal to me, but I forget they are not normal to everyone else. It is like knowing who H. P. Lovecraft is. Do you know H. P. Lovecraft?

The CHAIR — No. Should I?

Mr KENNEDY — Most people, it turns out, do not know who H. P. Lovecraft is.

Mr FINN — So I am in the majority, then.

Mr KENNEDY — But around my friends, a lot of people do, so I fall into the habit of thinking everyone knows who H. P. Lovecraft is. I think that possibly might be part of it. It is normal. I do not see it as such an issue, I suppose.

The CHAIR — Have you faced any bullying in your workplace?

Mr KENNEDY — No.

The CHAIR — Do you think that if you had perhaps disclosed your autism you may have?

Mr KENNEDY — I suspect not. Most of the places I have been working, like CSIRO and RMIT, are in the science areas. Autism spectrum tends to be over-represented in those fields because of the specifics of — —

The CHAIR — Because of your specific focus. What is your focus?

Mr KENNEDY — H. P. Lovecraft is a bit of an interest, but also I enjoy gaming. I am a bit of a gamer.

The CHAIR — Ryan, thank you for coming in today. I will ask Paul if he has any questions for you.

Mr EDBROOKE — I have not got any questions, Ryan, but I have got an observation. I think you really hit the nail on the head as far as bullying goes in the fact that the bullying policies at schools cater for the person being bullied to change their behaviour and are not actually focusing on the bully changing their behaviour. I think that the sooner we sway that and make sure the school policies are, I guess, altered for that, the better. Also, you talked about sweeping bullying under the rug. In my limited experience in schools, you will find schools, or some principals, will do anything not to actually enact parts of their policy because it steps things up and things actually have to be reported and happen. I guess that is part of the reason why our government introduced Safe Schools as well, to stop this kind of thing happening and so there is more acceptance that people have differences that we need to appreciate.

Mr KENNEDY — That does help.

Mr EDBROOKE — That is good to hear.

Mr KENNEDY — Because I find in some cases it seems bullying is, ‘Oh, you’re acting weird. So we’ll bully you because you’re acting weird’, and then you go, ‘Well, you must hate autistic people’. But they say no, they do not hate autistic people; they hate that the autistic people are acting autistic, and it is being weird to

them. Actually that brings up another thought to mind. In my looking online I found that the funny thing about autistic people is they are the only community that has — —

You know the ‘ace’ community, the asexual community? According to what I have read, it is pretty much that having an autistic diagnosis or being autistic is a prerequisite of being ‘ace’ or ‘ace spectrum’, for the most part. Like, you cannot be ‘ace’ without necessarily being autistic, it seems, because there is none of the ‘ace’ in the allistic community, or the non-autistic community. So it seems like there is actually a potential there to actually include it in, say, Safe Schools, and expand that to go, ‘Okay, there are autistic people. We should consider they’ve got their own issues here, and it turns out they’re also represented in far greater numbers in the transgender community’ — by about five times. It is about 8 per cent in the transgender community compared to 1.5 per cent in the — —

The CHAIR — Okay. Where did you get those stats from, Ryan?

Mr KENNEDY — I got them online from a few different articles.

The CHAIR — Okay. It is really interesting, really useful.

Mr KENNEDY — They draw the connection between gender dysphoria and autism as well. I am trying to remember where I got the ‘ace’ one from. I cannot think of it off the top of my head.

The CHAIR — That is okay. It is just really good, useful information.

Mr KENNEDY — That sort of idea, if it has got a connection there, you could potentially say, ‘Well, if it’s part of that, we might as well add an extra module to the Safe Schools program as it is being rolled out’.

Mr FINN — I sympathise with you, having your road to life being burdened with bullying. It is not flash. I just wonder: you mentioned the Safe Schools program and adding another module to it. Would it make sense to just have an anti-bullying program, not just for little parts of what people might be picked on for, but just an anti-bullying program, full stop, which would reinforce the need for people to respect people who may be a little bit different or who may be not what they are used to? Would that make more sense?

Mr KENNEDY — I think that depends on what is the particular focus of that. Like, the Safe Schools is focused on educating people so that no longer the ‘These people are weird, and because they are weird they are going to get bullied’ sort of thing. Whereas if it is a whole anti-bullying program, the focus is on: if it happens, then you step in, as opposed to, like, a Safe Schools.

Mr FINN — No, I would have thought an anti-bullying program, with the emphasis on prevention, would be something we should be looking at.

Mr KENNEDY — So teaching people — —

Mr FINN — Yes.

Mr KENNEDY — Possibly.

Mr FINN — Based on respect, mutual respect, I think.

Mr KENNEDY — Yes, teaching people that differences are okay, for the most part. I mean, if you are trying to be a bigot, you cannot respect that sort of difference. But teaching people that these things are okay — that it is okay to not make eye contact, that it is okay to fidget and to be distracted sometimes. One of the terminology things that I have found is ‘stimming’ — or self-stimulatory activities, shortened to ‘stim’ — which is something that you do as an outlet for energy. Hand flapping is one of them, or moving about your hands or your feet.

Mr FINN — Jumping up and down on the one spot, yes.

Mr KENNEDY — Yes, something like that, or going on a sudden run, that sort of thing, or potentially rocking and back and forth as well. That is one of those things that I think also needs to be covered in any sort of module like that, that those sorts of behaviours are not harming anyone, so therefore do not annoy people

with them; do not annoy people that have those behaviours, because they are just expressing themselves in a particular manner.

Mr FINN — Okay, Ryan; thank you very much for coming in today.

The CHAIR — I just have one last question. Do you remember when you were diagnosed? Do you remember that process, and was it hard, and how do you think your parents managed that diagnosis?

Mr KENNEDY — I do not think it was that long. I am not sure. I remember going to — —

I cannot remember the name of the specialist that we went to. I can remember inside the house and the feel of it and a feeling that we were there to try and diagnose things, and it seemed a bit odd at the time. But I am not sure how long it took to actually get a formal diagnosis.

The CHAIR — Do you know what had prompted your parents to take you to be diagnosed?

Mr KENNEDY — There were issues in class. I had attention issues, which prompted them to investigate ADD as well, as well as other social issues and so on. So there were various issues across the board, and they just took me to a few specialists. I went to one guy at the Royal Melbourne Hospital as well, to do regular check-ups on how things were progressing with various regards. I am not sure I can provide that much information.

The CHAIR — That is all right. Are you still receiving any support?

Mr KENNEDY — Not specifically government support.

The CHAIR — No, you do not see a psychologist or a therapist?

Mr KENNEDY — I am currently seeing, under Medicare bulk-billing, a psychologist. That has been a bit more of a recent thing because as I have been growing older I have been sort of trying to adapt to find work and contribute, and things sort of trigger memories and they make me think, ‘Shit, I had a bit of a terrible childhood, and I think I might have some problems still from that’.

The CHAIR — Have you been involved with any support organisations, like I CAN Network or any of those organisations, for support and peer support?

Mr KENNEDY — I have not been involved with I CAN. Support-wise it has been a bit iffy, I think. There is not necessarily that much awareness of, ‘Oh, there is this sort of organisation’ or ‘there is that organisation’. In particular I think that can extend a bit to teachers. In high school at the start of the year all my teachers would have a meeting with my mum and myself and we would sit down and we would try and figure out what to do. It was not always the most productive, I suppose, because you were trying to figure out what to do inside the confines of the education system, and there is not really that much accommodation around, or necessarily that is advertised. Like, you can get 5 minutes extra time on exams or something, or some amount of extra time, or you can get breaks or something, but that would not be as helpful as a text-to-speech translator or something.

The CHAIR — Thank you very much, Ryan, for coming along today, and thank you very much for your written submission as well. It is really, really helpful for the committee to hear from people who have autism, who are on the spectrum, and to hear about their experiences. Good luck with everything you do in the future.

Mr KENNEDY — Thanks. Also, a friend of mine really wants me to recommend ECHO as a support organisation.

The CHAIR — ECHO, yes. We have noted that; we definitely have. Thank you very much, Ryan.

Witness withdrew.