TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 29 August 2016

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Mr James Tucker.

The CHAIR — Welcome this afternoon, Mr James Tucker. Thank you for attending this afternoon. 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. I would like to invite you now, James, to make a presentation to the committee and thank you again for your attendance.

Mr TUCKER — Thank you, Chair and committee members. I do not need to confirm that my name is James Tucker, because I can see it there, and my address is [redacted]. I am appearing before you today in a private capacity — I am a public servant — and I want to thank you all for the opportunity to give evidence at the inquiry. You will be pleased to know I am not going to re-read from my submission; you have it before you. Rather, I thought you would like to hear a little bit of my story and how it relates to some of the points that I have raised in writing.

I really have to congratulate Narelle. She did a wonderful job.

The CHAIR — She did indeed.

Mr TUCKER — It is a very brave thing to be up here, believe me, in front of such an august body.

The CHAIR — We are so scary.

Mr TUCKER — Absolutely. So I have been on your journey. I am tertiary educated with a masters degree. I have worked in the private sector and both the Australian public service and the Victorian public service as a senior officer — I hasten to say, not as an executive officer to be clear. I currently work full-time, 57, married. We have one son, who is 13 years old. My wife's age is a secret, even from this committee. She also, however, works full-time. So she is very much the mother of an autistic husband and child, and I think she normally says she has two children who are autistic. She is a professional and has worked both in the VPS, the Victorian public service, and the Australian public service as a senior officer. Accordingly, our income is well above average and we are buying our own home, so we are probably one of the fortunate ones.

I am known for my very high analytical skills and my frank and fearless advice, which I thought was what the act requires me to have. However, I am not very good at telling people what they want to hear, especially when there is very little evidence to support their position. It seems that there is little place for evidence-based advice in the modern workplace. I will not bother reminding you that I work in the public service. However, in the most recent incident I was told that I am too ethical — I am still working on that one — by my supervisor, might I say, and that I lack communication and social skills. I will leave it to you to decide whether that is true.

I became deeply depressed, and depression is the story of my life. In fact I now know what it is but before I just thought it was normal, and I lodged a bullying claim. I was immediately suspended from duties. I made the mistake of telling them how I felt. My sick leave ran out and we ended up making ends meet by living off our savings for three months, which, when you have got a house mortgage and so on, can be quite challenging. But thanks to help from my union and some friends I lodged a WorkCover claim, and I have to say that WorkCover has been excellent. You probably do not hear that very often. They accepted my claim almost immediately, which I was told would take months, which says something I think about the veracity of my employer's claims, and, with the assistance of key staff in our personnel area, have got back to work full time in a completely new team and environment.

I also got back all my lost pay. But most importantly of all I now have access to a psychiatrist whom I see fortnightly, and I can assure you that would be hard for me to meet the cost of. He has been wonderful, and I do not know how I ever got on without him. He treats me for depression and, as I said, I have suffered that all my life. Incidentally, I suffer from exactly the same discrimination that young Ella Ingram faced, and I made reference to that in my submission about how she faced issues in relation to insurance.

My psychiatrist also told me that I am ASD. I hasten to say I have not had a formal diagnosis. He said, 'You don't need one; I can tell you right now', and that I should be proud of what I have achieved almost completely without assistance. I can tell you that was probably one of the most powerful moments of my life. It made sense of a whole lot of things that have happened to me and a whole lot of discrimination and misunderstanding.

As a result of this discovery we now have had our son tested, and he is also on the spectrum — surprise, surprise — which, I might add, my parents still do not get. But at 85 I do not think they need to. Fortunately, he is high functioning, so with the help of my psychiatrist I can now deal with people and a world that I do not fully understand. Most importantly, I now advocate much more effectively for our son. In fact I have a lot of discussions with my psychiatrist about how to deal with issues for him. But I am one of the lucky ones, and I truly believe that I am one of the lucky ones. People with ASD are as different from each other as they are from everyone else. We put our son, without really understanding why, in a school — not a special school — which has very low class sizes and very good teachers. We pay through the nose for it — and we can afford to — and he gets the kind of help he needs.

There is no cure for ASD — not now. There may be a pill one day; scientists are now working on it. They are working on everything. They are going to send us to the moon and Mars. And one person with ASD has quite different needs from any other person with ASD. Some of us need a great deal of help, and some of us just need a place to feel safe. Many of us need an advocate just to deal with the world, let alone with something as complex as the NDIS. It seems very strange to me that you could say to somebody, 'You just go to this person and tell them all your needs and advocate for yourself and they will solve it', when your biggest problem is communicating and advocating for yourself. But we all have something to offer. Einstein was ASD. He did not fit into the world. Thank God he was so smart that the world had to take him as he was. Most of us are not that lucky. That concludes my statement today. Thank you for your time, and I welcome questions.

The CHAIR — Thanks very much, James, and thank you for sharing your story with us, and thank you also for your public submission which was very valuable to the committee. Thank you for sharing your age and your child's experience and your experience at your workplace, which is something I am quite interested in, because clearly you have had a journey through your workplace. Many people with ASD are not diagnosed and therefore may have issues around bullying and all sorts of other issues in the workplace, so I guess my question is — you are in the public service — how can a government encourage employers to support people with ASD? When you look back what do you think might have assisted you to be supported in your workplace?

Mr TUCKER — I do not think it is the government's role to create jobs. I am an economist by training.

The CHAIR — No, I am talking about public service.

Mr TUCKER — No, I know. I am an economist by training, and even in the public service the government can have a role. There are two areas. One is that for a lot of us on the spectrum we are very focused. We need a position where — basically we are not good at politics. A lot of the jobs, all the research jobs and those sorts of things, have disappeared. Every single position statement in the public service says, 'High-level communication and social skills'. I do not have them. I have always got into trouble with people when I told them what I believe to be the truth because I do not know how to sugar-coat things. When I first started in the public service, there were jobs where that was okay; you were technical-minded. So one of the challenges for the public service is are there even places still there, because I have trouble fitting into a policy environment where I have to write a brief which says to the minister, 'Yes, you're right, Minister, for all these reasons', when I know all the evidence says no, it is not. I just cannot do that.

You also need support and understanding from supervisors and training so that they can recognise when someone is not fitting in. I have had lots of little hints and indications; people have seen something but they do not know what to do with that information and I have always been told that it is a communication skill or a social skill. Nobody has ever hit on the issue. I do not quite know how that works but one would hope that in a sophisticated, modern organisation, if that was something that kept coming up, people might start to say, 'Well, maybe there's something here that we can look to' and maybe HR can advise supervisors on 'Here's some things to look out for. If this person is exhibiting these traits, then maybe they have this kind of issue'. So there are a couple of aspects to that. One is the kind of work, or is it the kind of work?

If I had my druthers, I probably would not even think about the public service. I am certainly not looking at it for my son. I am looking at creative sort of areas where he works in computing, and it certainly will not involve the public service. It will involve the private sector; it will involve people who really like thinking outside the square. I applied for a job in a commonwealth department where they were looking for someone who was a lateral thinker, and after the interview they rang me up and said, ‘You would have got the job, but you actually are a lateral thinker and we’re too scared to take you on’. So I really do not know if there is a place in the public service for me. That is my first point.

The second point is if there is, then there needs to be some adjustments for us. That is hard, and I understand that is hard. I am not saying this is easy. We found a very good school for our son. We found some excellent teachers. I went in one day and they invite you into the staff room and sitting on their desk is this book about teaching children with autism. But when I talk to my teachers about how my son feels and that he is actually feeling depressed and suicidal, they say, ‘Oh, he needs help’, and I say, ‘Well, he’s getting it. That’s why I’m talking with you’. They do not understand what they can do about it, and these are people who do this for a living.

I do not know how you are going to get this message through. People are starting to be aware of autism but they do not understand what it means, they do not get the signs, and it needs a lot of training. It took a psychiatrist who has colleagues who work with people on the spectrum to recognise it. So I think it is finding ways of alerting people to characteristics, particularly for adults. There is better recognition now at schools where children are picked up, but for those of us who are way past school it is all the medical profession, employers, trying to get the message through. ‘If you have an employee with these sorts of issues, maybe you should contact us, maybe you should encourage them to contact us, maybe that is an issue’. Which is what is being done for violence against women in the workforce. There are excellent programs now. I have been to the training on it. That is about seeing someone with some issues. If you feel you can talk with them, you encourage them to get help. If you do not, where do you go? Maybe something like that, but that means that you have got to recognise it, of course.

The CHAIR — That is right. Thank you, James.

Ms McLEISH — Thank you, James, for coming in. I just want to clarify: you were diagnosed and then you had your son diagnosed?

Mr TUCKER — Correct.

Ms McLEISH — Since you have had him diagnosed, because that was quite late — —

Mr TUCKER — Yes.

Ms McLEISH — What did you do then in terms of his life and school? Did you go and talk to all the people around him?

Mr TUCKER — Yes. There is no more government help; he was past the age where there was government help of any kind. It turns out that some of things that we did with him as a child were probably the right things — by accident, mainly because I had been there and I know what he needed. We do spend a lot of time talking with other parents. I joined Amaze. This is the Victorian arm of Autism Australia. I glean a lot of information from them and I glean information from the web. Of course we all know that you need to sift through it.

I talk to my psychiatrist. He is one of my main sources of advice. I talk to his counsellor — we got him a counsellor. The counsellor is prepared to organise. I have talked with his doctors — if necessary, if we can get him antidepressants. I live on antidepressants. I would prefer not to, but if necessary, we can. And we try to talk with his teachers about adjusting his workload. He goes to a school where they will be moving to the International Baccalaureate. We went to a session on that. The International Baccalaureate makes adjustments for children taking their years 11 and 12. We have already started to talk about when shall we talk with them about the kinds of adjustments he will need and the sorts of things he will need, because he has trouble with his fine motor skills, quite a lot of trouble. He is like me; he cannot handwrite to save himself, but he can type fast. So we are talking about having him being able to type his essays up in an exam.

There was an article just last week about New South Wales, saying, ‘We won’t allow students to type up their English essays’ — even after a government commitment of some years ago. I am not sure what the reason for that is. So obviously for a child to be able to do that, they are going to need to make some adjustments. They are prepared to, but you need to be able to identify and come up with a solution and then promote it. My thesis —

and my submission — is that not everybody can do that without support. I have a psychiatrist who, if I need to, I discuss it with.

Ms McLEISH — Do you think you lucked in with your psychiatrist?

Mr TUCKER — Absolutely, and I had to go through hell to get there, absolute hell to get there, but he is the best thing. There is a silver lining.

Ms McLEISH — He was skilled up about ASD too?

Mr TUCKER — I do not think he is. I do not want to talk too much about him, but I know that he has children who are ASD, so he is obviously very aware. He also has friends in the profession who work on it, so he is very tuned in.

Ms McLEISH — Networking.

Mr TUCKER — Yes. So I was very lucky. Most psychiatrists are not trained like that. I was perhaps lucky that my GP recognised some issues and sent me to someone who they thought might be able to — without knowing what the issue was. So it was a stroke of luck. Being bullied was probably the best that ever happened to me.

The CHAIR — You are probably the only person I have ever heard say that, James.

Mr TUCKER — I have had all sorts of bullying and physical abuse and so on. This was less worse than that. At least in the workplace they do not hit you.

Ms COUZENS — Thanks, James, and thanks for coming in today. We really appreciate it. From your experience, what kind of support is most important in terms of where we go from here in developing services, do you think?

Mr TUCKER — It is a little along the lines of what the Chairperson mentioned and we discussed a little bit. There is first of all, awareness, but not just awareness but an ability to pick the issue. They are people with issues. That is difficult and that involves training for all the relevant people — professionals, teachers, a lot of other people and more broadly, because of adults with the issue, beyond just the school.

Advocacy is the single most important thing. I need someone who can tell me how other people think, what their reactions to me are, what they mean and what I should do about it. I do not understand. I see people react and I go, 'Hmm. Should I smile? Are they smiling?'. I do not get it and I need help with that. Some of that is about maybe people around me and some of that is about having almost a mentor of some kind. If I was to deal with the NDIS, if there was something available, I would need help dealing with it if I did not have my doctor. So I think that that is the single most important thing.

For example, my son goes to a group called Inside the Brick. It is a Lego club. It was specifically set up by a fellow who is on the spectrum for children who are on the spectrum. My son absolutely loves it. There is no judgement; he just plays. He really gets on and it is a safe environment where he can de-stress, let his tape run down, quieten down, calm down — and everybody is like him. I have to say there is only one girl there — and she runs the place. She is fantastic. She is so smart.

Ms COUZENS — So would you see that as maybe something that could be implemented in the workplace, for example, with other colleagues?

Mr TUCKER — Absolutely. The government is the prime place to do it, because the government has the money. Large corporations are the prime place to do it. For other areas it would have to be a community person. But it costs money. I understand that. But I think it is money that is very wisely spent because of what people have to offer if they do not fall through the cracks in the system.

Mr FINN — James, I want to thank you for coming in today because your story is one that should be told far more often. I am just wondering if you see a place for yourself and people such as yourself travelling around telling the story of your life, what you have experienced, how you have been treated and how you have clearly come out well the other end? Do you see that as a means of perhaps inspiring people to get through their difficult times and end up as well as you have?

Mr TUCKER — The short answer is yes, and putting any flattery aside, it does not have to be me. I know that there is a woman in America who is an academic who speaks and who has ASD. She has two academic circuits. One is her academic circuit, the other is the autism circuit. She is a massive inspiration. She has children, she has survived and she has come through, and she says, ‘I am here because I am so smart they couldn’t ignore me’.

Mr FINN — Nobody has ever accused me of that.

Mr TUCKER — But I think people like that do need to stand up and talk, and I take my hat off to her that she does. I once had a lecturer who was extremely bright. He was considered eccentric, and he would have to have been on the spectrum. He was one of the world’s best economists, and he was caught urinating out of the window of his office because he did not want to go to the toilet. Anywhere else in the workplace that would have been a significant issue, but no doubt because he was so good, they ignored it. Ninety-nine per cent of us on the spectrum are not like that, fortunately. So the thing is that there is room for people, not like him, perhaps, but like this lady, to go around and inspire people and say, ‘There is a place’, maybe to champion those people you spoke of, those mentors and those groups in organisations. Yes, I agree with you.

Mr FINN — I thank you for that, because that is, I think, something that we really should have a good hard look at. I also thank you for giving us another topic for a committee to investigate, and that is the culture of the public service.

Mr TUCKER — You solve that.

The CHAIR — That would be a very complicated equation.

Mr FINN — When one is persecuted for telling the truth, you have got to wonder what the hell is going on.

The CHAIR — Thank you very much.

Mr TUCKER — I am afraid I will have to leave. I would love to stay, but I have to get back to the public service.

The CHAIR — Thanks, James.

Witness withdrew.