

# TRANSCRIPT

## FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

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

Melbourne — 10 October 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

#### Witness

Ms Karen Burgess, disability support worker.

**The CHAIR** — I welcome today Ms Karen Burgess. Thank you for attending our public hearing 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.

Please note that the committee will be following the practice of earlier parliamentary inquiries in relation to the naming of alleged criminal offenders. The committee will not hear evidence referring to individuals by name in relation to their alleged criminal acts unless the persons and acts have already been publicly disclosed. If you wish to inform the committee about specific allegations of this kind, the committee will close the public hearing, clear the gallery and reconvene the hearing in camera. Could you please advise the committee if you wish to do so. We would like to invite you, Karen, to now make a 15-minute statement, and then we will spend about 15 minutes asking questions, if you are comfortable with that.

**Ms BURGESS** — Yes. I did not actually prepare a statement. I just wanted to come today and answer any questions that you may have, because I feel like my submission was fairly lengthy and documented what I needed, or what I felt was very important for me to say. I am actually doing my testimony today in front of people from Autism Spectrum Australia. I just want to note that. I find that very compelling that that is the case, but it adds to the types of pressure that I have been put under to talk about the issues and the concerns that I have, especially around the abuse of people with autism who are attending these services.

**The CHAIR** — Okay, that is fine. Thank you, Karen; it was a very comprehensive submission that you gave to us. I note that you have also had some publicity on the TV channels. You would be aware that this committee has previously done an inquiry into abuse in disability services and that we have made 49 recommendations in relation to that inquiry, and those recommendations will be responded to by the government very soon. A lot of your submission related to abuse.

**Ms BURGESS** — Right.

**The CHAIR** — It was about your child who has autism, and I understand why you presented to this particular inquiry. Do you have a view on the recommendations the committee made?

**Ms BURGESS** — I do not think they went deep enough to address the current issues that are occurring in a lot of the disability services. I guess the difference in my testimony is that I am talking from behind the curtain a little bit, and in that I guess it is a little bit of a different perspective because I am kind of revealing organisational secrets to which clearly there is great opposition to me doing so.

**The CHAIR** — So you were in fact a whistleblower.

**Ms BURGESS** — Yes.

**The CHAIR** — And we did make quite a few recommendations around protecting whistleblowers within the system.

**Ms BURGESS** — Yes. Some of the recommendations confused me because of the fact that I believed that there are already protections in place, especially around the protection for whistleblowers. An example in my case and what I have been through: 126 of the Disability Act talks about how no harm should be brought to complainants, and yet I can detail a number of events where harm has been directly brought to me — as a direct result of being a complainant of what has been happening at the workplace.

I am surprised, after my meeting with the disability commissioner's office, that in the 10 years that the act has actually been operational for that, I am the first person to ask them to investigate under 126 of the Disability Act, when there is story after story of staff who do make complaints and their employment is scrutinised and often they lose their employment for doing so. I understand why people do not take the measure that I have taken, because there is an extreme amount of pressure that comes to those people. But nonetheless, I do not understand how it is that people have not been able to get this part of the act exercised.

**The CHAIR** — I think it was probably an interpretation of the act by the disability services commissioner, which we have made recommendations on, around own motion inquiries so that he can actually instigate investigations — or he or she, depending on who it might be.

Just a quick question about people on the spectrum, people with ASD. Do you think that, from your experience, they are more vulnerable to abuse?

**Ms BURGESS** — Especially in the environments that I have worked in in the past 19 years I have predominantly worked with people who are at the lower end of the spectrum, who often have complex communication needs and who also present with behaviours of concern. I think this particular group, where families are not engaged or advocacy groups are not engaged, are especially vulnerable to some very serious human rights violations. We need to consider additional protections for this particular group.

**The CHAIR** — Do you have in mind what those protections might look like?

**Ms BURGESS** — I would like to see a better auditing system for quality measures and quality care over auditing the business — an accreditation system like what you see in children's services or in aged care. I believe we should have a framework of quality disability services, a measurable outcome and an accreditation that goes in and audits these services. You also have the opportunity for staff to provide their feedback, just like in a childcare system, where staff are able to provide their feedback on what is happening within the system and to have an independent auditor reflect on those comments. I think at least having an accreditation system where you are measuring the quality of the service against a set of national standards and then you are getting independent people to review the quality of what that organisation is saying against the standard is something that needs to be implemented with the NDIS.

**Ms McLEISH** — Karen, I just want to focus a little bit on your role as a disability support worker and some of the training that people — the staff like yourself — have and the requirements to continue training or further on-the-job work. Do you want to talk to me about that?

**Ms BURGESS** — My role is predominantly and has been historically in management and frontline management — —

**Ms McLEISH** — I mean generally, not just your role.

**Ms BURGESS** — Okay. I am a qualified trainer and assessor, and I am a trainer and assessor for community services and disability qualifications up to the advanced diploma. I have had a lot to do with the training packages. Over the years each training package that has come out — and I have been training since 2007 or 2008 — has been slowly getting whittled away with regard to the level of expectation and the quality of expectation of the staff to perform more basic care rather than focusing on human rights, ethics, legal, social programs and behaviour management. This has happened even as recently as the last package. Originally most training organisations were expected to have about 200 hours in practice hours. Now that has gone down to a minimum of 120 practice hours for an average certificate IV disability worker. That is not sufficient, given the types of responsibilities we are expecting of our disability workers.

The fact that we do not even have a minimum qualification is also inadequate. We need to set a minimum standard, especially for people who have complex communication or behaviour concerns. I would see a need for a minimum diploma qualification for working with people of this nature, because you need to be able to assess the environment very quickly and make good legal and ethical decisions for yourself and other people in that environment on the go. You need people to have an understanding of the framework that they are working in to make good decisions as things are happening. You are dealing with people, not robots. A plan is great, but people, especially those on the spectrum, are always going to work outside of those plans. You are going to need to put people in who know and understand and can respond in a way that is ethical and that is going to meet their legal obligations.

**Ms McLEISH** — What sorts of training differences would you see that people might undergo if they are working with either end of the spectrum?

**Ms BURGESS** — I guess if you were working with people who had a number of skills, you would be looking at employment options, improved socialisation, skill development, being able to attend a TAFE or

being able to attend classes and pursue a vocation. At the other end of the spectrum we would be looking at people being able to engage for a time and to have meaningful contact with people or being able to — —

**Ms McLEISH** — What is the best way to have that training?

**Ms BURGESS** — In disability services we focus more on skill development and maintenance in people. Some people are not going to be able to complete the tying your shoelace program for the rest of their life, and yet they are put in these programs to tie their shoelaces year in and year out, and they are getting terribly frustrated. I think we need to be focusing more on the welfare. We need to be focusing more on a holistic approach, which includes music therapy, engagement, eye gazing and being able to sit with someone and be okay with someone holding your hand. That is a skill.

I do not believe the myths around autism that state that people with autism do not want to be part of the community or do not want relationships with people. I really get the sense that people do, but we need to make sure that we are engaging the right people that understand how to work with people sensitively to be able to pick up on other people's social cues themselves and respond based on what that person is communicating, not because the program has dictated the terms — for example, 'This is the program, and these are the objectives'. There needs to be more of a focus on welfare and health the other end.

**Mr FINN** — Karen, thank you for coming in, and thank you for your ongoing crusade against abuse. I may have misunderstood this, and please correct me if I have, but my understanding is that you said that there were some people from Aspect in the gallery and that you felt pressured by them.

**Ms BURGESS** — Yes, I do.

**Mr FINN** — You feel that that has been an ongoing pressure.

**Ms BURGESS** — Correct, yes.

**Mr FINN** — In what other ways has that pressure been shown?

**Ms BURGESS** — I have actually detailed the events that have been happening, and I have put that information together in a document along with some other recent things that have happened. Can I submit these other documents that highlight — —

**The CHAIR** — Yes. We will look at them before we decide to publish, though, if that is okay.

**Ms BURGESS** — Of course. There are a number of incidents where I have had legal letters sent to me asking me to get rid of information. I have been called a criminal. I have been told that I have been breaching a number of contractual agreements where there were no contractual agreements in place. I feel that, because I do not have the finances to be able to get the legal assistance that I need, that type of inequity is very intimidating. My understanding is that there have been many other people that have been saying the same thing, but as soon as the pressure, the letter, the threat or the inference about their character or what it could mean for their future employment happens, they just fall away. I think historically many of these organisations that are engaging like this have been quite routine in taking these types of approaches to ensure that people like me do not sit before a committee and tell you what I know.

**Mr FINN** — So are you suggesting that sort of intimidation is pretty widespread?

**Ms BURGESS** — Right. I believe it is.

**Mr FINN** — How widespread is the abuse itself, do you think? You have seen, as you have testified, instances. Do you think it was just a one-off or two or three, or is it something that is rife across the sector?

**Ms BURGESS** — Yes, it is rife across the sector. In 2000 I began working for the Department of Human Services. In 2002 I became a house manager and managing houses. It is very interesting from a workers perspective, because you work in these environments and you become desensitised to the abuse yourself, and I understand that because I got myself to a level of almost accepting the abuse. I was never happy with it, I was never content with it and I always raised it. I love doing what I do, I am a good worker and people with disabilities love me being with them. To even work in that environment I had to accept abuse. These are stories

that are not just coming from me; these are stories also coming from other people as well that have dared to speak up.

What had the greatest impact on me — the final straw with my last employment — was seeing that box and hearing what it was for. I just could not fathom how that could even have been created in 2016. But on top of all of that, when raising it, when trying to get it addressed, when trying to deal with all the surrounding issues that went into creating it, there was something bigger going on there. It is not just at this service; it is at other services. I had gotten used to it, and I think I have decided I do not want to be used to it anymore.

**Ms KEALY** — Thank you very, very much for your time today, Karen. I just wanted to ask you about the education and support that is provided to people, particularly younger people with ASD, in terms of what is okay behaviour, what is not okay on how to be treated and how they should report that. You are a whistleblower who has come forward, and so you are speaking on behalf of other people that say, ‘This isn’t okay’. I am just trying to get some sort of insight. From what you have seen, is there any education at all out there for younger people in reporting abuse?

**Ms BURGESS** — In relation to workers reporting abuse, do you mean?

**Ms KEALY** — People with disability, people with ASD.

**Ms BURGESS** — I think they are; I really think they are. In the short amount of time that I have come out and been talking about these stories I have heard so many more stories, and people just volunteering their stories to me. I believe they are; I believe they are making the reports. I believe staff are making the reports. I believe if you had a look at all the reports that were going in, either through the national disability abuse call centre through to the Department of Health and Human Services, I think they are all going through. What is not happening is the next step in effectively being able to deal with it.

You know, what really worries me is that people with disabilities and their families are getting used to it and having to account for the abuse. They are having to kind of factor it into their daily life to combat it, and we should not be in a position where that is acceptable. We need to start addressing that. We need to start really looking at the zero tolerance to this, which I think came out in the report, which is really saying no is no. Because someone is having behaviours of concern, that is not the reason why staff should then be locking people in classrooms. That is not the reason why we should be isolating people. This is not the reason for the types of strategies that are being applied.

We need to start calling it out and saying it is abuse and start giving people feedback on that, and start responding to people in that line and not giving them the, ‘Oh, it’s okay, you must have been having a bad day; you didn’t know’. They do know. They have gone to training; they have had the discussions. They know. Ten years we have had the Disability Act in place. They know.

**Ms KEALY** — So, Karen, in your opinion, if you believe that abuse is being reported, that means that you believe it is not being dealt with appropriately. Do you think it is a lack of an investigation? Do you think it is a lack of further follow-up and, as you mentioned in your summary from the beginning, that there should be national standards and an ongoing monitoring system? Where do you think the system is falling down if the reports are being made?

**Ms BURGESS** — I think it is the people who are investigating. People who are involved in these environments have relationships with each other, and I guess with those relationships, if you start tackling it, you are actually starting to encroach on some of those relationships that are already established. I think it is hard for people because they do not want to impact on that working relationship or that partnership that people are developing. We need to start putting the person with the disability and their families first over these professional relationships or fearing that there will be embarrassment out of dealing with it. At the end of the day, we are going to start identifying who it is, and there are going to have to be consequences. I do not think anyone wants to start tugging at that string, but someone is going to have to.

**Ms COUZENS** — Thanks, Karen. Just getting back to the training and education side of things, and given what you were saying earlier, do you think the training should be targeting specific skills in an area of, say, autism or disability generally, but in this case autism, but that they are specifically targeted to work with autistic people?

**Ms BURGESS** — I think there is room for disability workers to become specialised certainly — so you become maybe a specialised practitioner in working with behaviours of concern and you develop your skills as a practitioner working in that capacity — because some of these areas are very big and trying to have a disability service that can cover all of these specialties I think is putting too much pressure on the staff. There certainly is room to develop those autism speciality high-support needs — high communication, complex communication — so we are all working together as a multifaceted team for the outcomes of people with a disability and families.

**Ms COUZENS** — So would that be in all settings or just accommodation settings, education settings, or just across the board, do you think?

**Ms BURGESS** — I think we need a multifaceted approach to disability services. We need to remember welfare and mental health, because I think in disability services it is either one or the other. We need to be incorporating informed trauma care because so many people have been traumatised by their experiences at these services. I think we need to be providing more informed trauma care for people who are reacting to the trauma they have had. That is a specialty as well. I think we have got room to specialise, but we need to improve the quality of that training and education. We need to set those minimum standards.

**The CHAIR** — Thanks very much, Karen. I just want to thank you again for your submission and for your comments particularly around people with autism, which is what this inquiry is particularly working on, as you know. I just want to reiterate a couple of the things that you mentioned during the conversation with the committee today, particularly in relation to our previous inquiry. We have recommended zero tolerance. We have recommended mandatory reporting. We have recommended penalties for those who do not do the right thing, in particular service providers. We have recommended better investigation and oversight for abuse. I think that these recommendations that we have made should not be taken lightly. I think that we as a committee have sent a very clear message to everyone in the sector, whether it is autism or other disabilities, that abuse will not be tolerated. I just wanted to reiterate that, because I think that it is really important that both you, service providers and others who work within the disability sector have a clear understanding that our recommendations were not made lightly, and we anticipate that they will make a difference. So thank you very much.

**Ms BURGESS** — Thank you.

**Witness withdrew.**