

# TRANSCRIPT

## FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

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

Geelong — 19 September 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

Mr Geoff Barber, acting coordinator, care services, aged and disability, Greater Geelong City Council.

**The CHAIR** — Welcome, Mr Geoff Barber, the acting coordinator, care services, aged and disability, from the City of Greater Geelong. Thank you very much for your attendance this afternoon. I am glad you did not have to walk very far to come and meet with us. 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 to make a presentation to the committee.

**Mr BARBER** — What I did provide in writing I guess is relatively brief and I have not got a lot to add, I suppose. But just to quickly summarise: my feeling is that advocacy is important for perhaps all participants in my experience, particularly from the start of the trial period when there are a lot of unknowns. Now as we are coming into some time here in Geelong there is a lot more comfort around the system and what to do. But definitely for the first six months to a year I would say that even the most intelligent, articulate people would have benefited from advocacy.

On another point, my experience in terms of people working with NDIA and getting the plans that they feel that they need for their children did seem to have a bit of a relation to the parents' levels of education and their understanding of the system, their comfort in dealing with bureaucracy and their being able to be comfortable doing appeals and things like that and being able to interact in that environment. People who are more comfortable with that just seem to move through the system so much more easily, and a lot of people who were not comfortable just chose to disengage or delay their involvement.

I guess in terms of the hours and supports that were in plans that I had seen for young people with ASD, most parents indicated that they were getting a little bit more than maybe they had got before. However, it did seem to lean towards the therapeutic services more than the direct service hours, and a lot of people complained about that. Given that we were one of the providers of those direct hours, I guess they were hoping they could get more of that and they wondered I suppose why they were easily able to get a lot of OT and physio or other therapeutic supports but could not get additional hours when they were pleading for them.

I guess in terms of my last point there in my letter, the HACC program for younger people is currently still in operation and is a safety net of types for people who are deemed ineligible for NDIA services, but also for those people who have intermittent health needs or some health incident that occurs, such as a fall or something else that is not related to their disability, so they can fall back on that HACC program for younger people. Probably the awareness of that might not be so consistent across all referrers, GPs and other places like that. I was recently at a forum held by Deakin in relation to the interface between health and NDIA services and I used that opportunity to share with the group there that that HACC program for younger people is in existence and is a bit of a safety net at the moment for people who are falling through the grey areas or cracks. But apart from that, what I have written covers what I know.

I guess with the money one, we are one point of call in relation to the NDIA's interaction. We have had about 220 clients overall of which I am not sure how many were autism, but possibly 30 or 40, I suppose, in terms of children. A lot of those are transitioning to other providers, because at the moment in terms of our council services we are withdrawing from those supports. We are in the process at the moment of withdrawing from NDIA-funded supports, apart from delivered meals and home maintenance, based on a unit cost issue.

**The CHAIR** — That is disappointing.

**Mr BARBER** — Yes, disappointing for the clients as well, because we have provided a consistent, reliable service for a long time and some people have had their children with us for maybe 20 years, sometimes with the same carer.

**The CHAIR** — What are the reasons for that?

**Ms COUZENS** — Financial.

**Mr BARBER** — Financial. Unfortunately we are not able to charge a top-up fee. The NDIA unit cost is set; you cannot change it. We were not able to meet that cost, we were not able to breakeven, so we had to present

that financial position to the administrators and they made a decision on 16 August that it was not something that we could continue in so we decided we had to transition those people to other providers. I think that reflects what other local governments are considering and looking at. Some of them have already chosen not to go into this space, but even the private providers, as you would know, have been having some difficulties trying to make ends meet, given those costs, particularly around the direct support worker costs where it is at what they would call the low end. But for many people it is the one thing that they want to keep and what is most important to them is that person that might come in in the afternoon and help after school or that sort of thing.

**The CHAIR** — Thanks very much, Geoff. This inquiry is very broad and encompasses a lot of areas of life for people with ASD. I am interested to find out a little bit more about community participation for people with ASD in Geelong and whether there are sporting, recreation or cultural activities available across the city.

**Mr BARBER** — Yes. It is not something that we deliver in terms of my department. However, the swim, sport and leisure and other aspects of council have programs that incorporate people from all backgrounds and disabilities. I am aware of a few children and adults with autism who have taken advantage of local sporting groups and swimming centres, but I probably could not comment much more beyond that.

**The CHAIR** — Does the council offer respite?

**Mr BARBER** — Yes. Our department has offered respite but not overnight respite. Generally the type of respite that we are offering is for people on school holidays who might need extra support through the day or into the evenings. Mum and dad might want to go out and have the only time in the month when they are actually together without kids and things like that, so that time of respite as carer support.

**The CHAIR** — How many hours a week would that average out at?

**Mr BARBER** — The thing is that I do not know in terms of hours a week. It was intermittent depending on when people requested it and it was funded under the HACC program for respite. But once someone became an NDIA participant, they could only get what they could get in their plan. So previously we had some flexibility to provide respite under a respite budget for those people, but then when they shifted to a different funding stream it was different. They had to have that line item in their plan, whatever that was. In fact respite was never actually initially put down in black-and-white. In fact they really did not want to go anywhere near that word and that term.

Part of what I had to do early on — not had to do but felt was the best thing to do — was to speak to parents who were dealing with the initial conversation with NDIA and explain that because everything now is an individual client focus, goal-driven kind of framework, which I am comfortable with and work in, but that is as a professional, they had to try and frame their needs based on what that child actually needs from their point of view. I tried to help them word as best they could or talk to their planner in a way that achieved the family's needs by speaking about it in a way that was individual client goal-based. That might be they could get help with their homework and some reading activities. If that happens on a Thursday night, well, that is fine and mum and dad can go out shopping, or mum can go out with one of the other children who maybe has not got much attention because of the autistic sibling attention issues. They are trying to resolve family-centred kind of issues based on the fact that the NDIA needed everything as individual client-specific goals. They did not have a respite line item. I am not sure if that has changed now.

**The CHAIR** — So you were in effect being an advocate?

**Mr BARBER** — Yes. I was doing my best to do that, but yes, very client focused. I always referred people to advocates, and especially in the first 12 months I was doing that a lot. Because we are at the end now of the rollout and most people have had their plans and have worked through that, it has not be needed as much. Very much initially I was referring to advocacy and there was some waiting time to start with, but I think after the first year it became more manageable for advocacy groups here in Geelong.

**The CHAIR** — Does the council offer any support groups for families and carers of people with ASD?

**Mr BARBER** — No. We have a referral network, so we would refer to carers' respite quite frequently. If we could not provide respite, or if it was not in the NDIA plan and we could not do anything about that, then we

would refer on to carers' respite or ask them to engage with their own networks, because most families with children with ASD would have had some networks, not all, but in relation to autism related networks — —

**The CHAIR** — Would you say there is a good network operating in Geelong?

**Mr BARBER** — I think it is comparable to anywhere else. My personal view is that I see an increasing role for advocacy and I think that, given the insurance model and the kind of combative nature of trying to get what you want, it is very helpful for people to have advocacy because it is just not the kind of environment that they are used to. Also, people have been very much strength-based, as in the mental health sphere, not so much about my disability but what can I do. Then they have to go to NDIA and only speak about what they cannot do, especially when that is the worse situation. It is quite a different mindset to have, and I think that is where an advocate comes in really handy and probably will always do so in that insurance-based model, from my perspective anyway.

**Ms COUZENS** — Thanks, Geoff, for coming along today.

**Mr BARBER** — That is all right.

**Ms COUZENS** — Just in terms of the council's decision to pull out of disability services, and I know that is a costing thing, from your perspective do you think that is going to have an impact on the clients that you have traditionally dealt with, particularly the long-term clients?

**Mr BARBER** — It is definitely going to have a short-term impact. Of the large number we have transitioned there is a good-sized group — 25 per cent — that have been so distraught that they have either been angry, crying or silent on the phone in relation to this decision. For most of them actually — probably 90 per cent of people — the thing they value the most is the reliability, the safety and the security of a known care worker and that relationship. It was always frustrating to me as well as to the clients themselves that that was something that was never articulated, spoken about or written down in any NDIA plan or document. So there is definitely some initial trauma, and it is hard to say how long that lasts. I always say to people that we cannot promise the carer. They might retire anyway, so there is no continuity that is guaranteed. But many people have had that continuity, so that is what they are used to and that is what they value.

**Ms McLEISH** — Sorry, when you say they have had that continuity, do you mean — —

**Mr BARBER** — With us.

**The CHAIR** — With the council.

**Ms McLEISH** — But when they have left, that person has not continued with them.

**Mr BARBER** — No. We have encouraged that as a possible pathway. Because we were losing some hours for our staff, and a lot of those staff had relationships that some of them were keen to continue, we have made sure that we have been very flexible to say, 'Look, if you want to work for another provider, go ahead. We will work with you on your roster here'. But that is a decision that each care worker needs to make. Every other provider is going to have not quite as good an EBA as we have here, which is why we have had such a reliable and consistent workforce, very low staff leaving and very high staff retention. I guess in the short term it is hard to know too whether they will get a lot of inconsistency from staffing other providers, but that is probably my guess.

**Ms COUZENS** — We heard from the NDIS earlier that there are 39 new providers in the Barwon region. I agree with you about the safety that people feel being connected to the council.

**Mr BARBER** — Yes.

**The CHAIR** — Especially if they have got ASD.

**Ms COUZENS** — That is right, and I would imagine that there will be a significant impact for some of those people. Have you got any idea how many would be people with autism from the council service?

**Mr BARBER** — I think there would be perhaps 40 to 50. It is hard to know, but it is a fair chunk. Most of the children that we support would have been with autism. Maybe one-third would have other physical disabilities in terms of hoisting and things like that, but quite a few with autism. And quite a few in the teenager-coming-into-adult spot, because they have been with us for a long time. Those transitions are difficult for people with autism, so I think there is a lot of anxiety around that. It is one thing to change providers, but if it does not go smoothly for a year or two when someone is 15, 16, 17, things can go really pear shaped for some people.

In terms of the short term there is definitely going to be some trauma. But in the long term possibly I would think there are going to be some ongoing issues because providers are not going to have the staff retention that we have had, given the kind of wage that they have got. A lot of people will choose other careers that have got better prospects, so there are going to be a lot more people moving in and out of the system. My personal view has always been that it has not been valued highly enough in terms of what has happened. If it is just the same money to go into Woolies and work in the fruit section, then why would you put yourself through all those challenging behaviours and trying to manage all that? It just does not seem fair.

I think there is probably going to be some ongoing disquiet from parents. I guess it is just wait and see. My hope would be that as the rollout goes out nationally there will be some bigger lessons that will be heard. Even though we have been saying some things at the trial site, I realise that it will take sometimes more people across more sites for the message to be received.

**Ms COUZENS** — I think I am hearing what you are saying, which is that there will be an issue around the quality of service, given the lack of a good EBA, for example, or that rates of pay will impact on the quality of service that is provided to people with autism or disabilities generally too.

**Mr BARBER** — I think the quality of service is going to suffer. That would be my assessment. If you have a lower wage, you have less supervision, you have less meetings, you have less capacity for internal training and you have less quality staff in the end and more changeability of staff. People with disabilities, but particularly people with autism, have difficulty with change. It is one thing to say that there will be lots of different players in the market, but they do not want lots of different players; they just want someone that is secure. It is a shame that that was not valued or written down in terms of NDIA's framework. I have always tried to explain that when I have spoken to planners, but it is just not something that is in their paradigm, I suppose.

**Ms McLEISH** — What are the numbers, do you think, of those on the spectrum with autism in the Geelong region?

**Mr BARBER** — I would not know. I guess I have only been dealing with our client group. Outside of that I would only be guessing.

**Ms McLEISH** — Would you say that you pick up 1 per cent or that you pick up 60 per cent?

**Mr BARBER** — I think we would pick up a very small number.

**Ms McLEISH** — Because I look at a lot of carers who are absolutely devoted to the work that they do and the care that they do, and that is not necessarily linked to the dollar. They stay with families for a very, very long time. They grow to be part of that family. I know of a couple of examples where they have attended 21sts and other milestones. These people are not linked to EBAs either, those who have this dedication. When the administrators made their decision, which has impacted clearly, going by what you have presented, you have moved the clients on. If the families get the choice, do they not ask for the same carer so that they do have that continuity?

**Mr BARBER** — They can ask for the same carer, but if they work for us, that might not be possible.

**Ms McLEISH** — Have you not had to downsize as a result? You have passed off the client work —

**Mr BARBER** — We have lost about 13 per cent of our business, but we are in the process of losing it. The decision was only made recently, and we have probably only transitioned one-third of the people. We were aiming for the end of this month. The decision was only just made, and we could not do anything until that happened. I am expecting by the end of October to have transitioned most people, but there are going to be a

few of the more difficult ones that I am just not sure of. We have made sure to let people know that we would not leave them without supports and that we will be very cooperative in the transition. It is just a bit hard to know how many we will be left with as we come to the end of October.

We have always kept the door open and tried to explain the options for carers to continue to work with that person, but carers have got to make their own decision. Every second job has different tax implications. I cannot comment on whether another organisation is a good employer from their perspective for what they need et cetera, but I do agree that the people who work in this industry are not doing it for the money, so they are dedicated to the people they work for, I suppose. But I guess in this case they would have loved to have kept working with those clients if we were able to stay in the business.

Also, leading up to this, probably we have got less of a percentage of autistic children than maybe other providers because it is not our core focus. We are age and disability, but our focus is more on the older clientele. So if someone needs a bit more disability-specific support, particularly around behaviours, then we are not really the best place for that. So we did end up with more of the low-end-type children or young adults with autism who just might need a bit of mentoring and guidance but might not have a lot of other behaviours that are beyond our scope.

**Ms McLEISH** — Thinking about the clients you have had that are on the autism spectrum, you talked earlier about therapeutic services compared to direct hours and that you had lots of complaints. Can you tell me about the nature of those complaints related to autism?

**Mr BARBER** — It would be more about parents' frustration that they could easily get the OT, physio or speech needs met that therapists or doctors would say are useful. They would be easily signed off on, but if they were trying to argue for more direct time, be it around attending football or something on the weekends —

**Ms McLEISH** — So it would be a bit like a carer going out with someone to the footy on the weekend?

**Mr BARBER** — Yes, taking them, or maybe them playing footy. They can support them so that if there is some sort of emotional situation, they can jump in on the sideline and help them stay centred so they can get back out and play footy or soccer or do dance classes or whatever it is that they are doing, anything that is different. Scouts was another one. It is one thing to be able to go to scouts, but they really wanted someone to be able to go to scouts with that person, bring them back, deal with issues that might arise and help the parents feel that child was safe when they are at the scout hall. The people who are there would maybe not be able to manage behavioural issues, which are just often around emotional regulation and things like that and being able to understand that that person does not like me today and why that is, and just working through that, because they take more time than other kids. It is that kind of one-on-one direct work to help them through their community, social and sport activities. They were expressing to me as parents that they wanted more in that area.

**Ms McLEISH** — I thought that would be something that they would be able to negotiate through the NDIA, saying, 'These are the sorts of things we are looking to purchase'.

**Mr BARBER** — Yes, and I think they did get those things. I guess they felt that there was pressure on those hours. They had to keep justifying it. They were not sure if they were going to keep it.

**Ms McLEISH** — So they did not really have much of a choice. Others were trying to direct them rather than letting them choose. Is that what you are saying?

**Mr BARBER** — Yes, although from their perspective — and I have not got a child with a disability that has gone through that — they have only got a certain amount. They cannot just get someone supporting them every afternoon. There are some limits to that, so they have got to make decisions about that. I guess one of their queries would have been more about the amount of money. An amount of money might go to an OT or a physio, and they would see that next to the money for the support worker and would be trying to argue for an additional few hours here or there a week. They would look at the other hours from the therapeutic services and think, 'But why don't you just cut some of that back and give us some of this?'. Maybe with an advocate they could achieve some of that. Maybe it is just about how to be able to argue that and how to present the right evidence. I have helped a few people myself where I could.

**Ms McLEISH** — Where is the blocker? At what point is that being blocked so that they have to have that fight rather than saying, ‘This is what we want’.

**Mr BARBER** — It appeared to be at the planner with the family level. There must be some kind of direction from a planner’s level that they need to consolidate supports around direct support and make sure that it is all justified and that there are clear goals, and if they are not reaching an outcome, find out why they are not reaching an outcome. I think they found that whole discussion quite stressful and onerous and perhaps impossible without an advocate who could remove themselves from the emotion and say logically, ‘Here are the black and white objective points about it’. Sometimes it is just about someone re-digesting what they say. For me, I might hear something from Mum and go, ‘This is probably what I would say. This is how I would say it. This is the kind of evidence that I would use’, and just help them align themselves with the kind of language that the NDIA needs in terms of justifying that support.

**The CHAIR** — Thank you very much for your time this afternoon, Geoff. It was much appreciated.

**Mr BARBER** — Thank you.

**Witness withdrew.**