TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Shepparton — 15 November 2016

Members

Ms Maree Edwards — Chair	Mr Paul Edbrooke
Ms Cindy McLeish — Deputy Chair	Mr Bernie Finn
Ms Chris Couzens	Ms Emma Kealy

Staff

Executive officer: Dr Greg Gardiner

Witnesses

Mr David Tennant, CEO, and

Ms Karen Goodger, practice manager, disability support services, FamilyCare.

The CHAIR — Good morning, everyone. Welcome to our public hearing in Shepparton today for the Family and Community Development Committee inquiry into services for people with autism spectrum disorder. This is the seventh public hearing to be held by the committee in a series of hearings that will continue through to the end of the year and indeed into next year. In addition to hearings in Melbourne the committee has already travelled to Geelong and Bendigo to meet with stakeholders and hold public hearings, and we are delighted to be here today in Shepparton. The committee is thankful for the ongoing support this inquiry is receiving from the public, particularly from people with ASD and their families who have participated in each of our public hearings to date. These proceedings today are covered by parliamentary privilege and as such nothing that is said here today can be the subject of any action by any court or of any proceedings for defamation. If you have any special needs today, please see the committee staff, who will assist you. I acknowledge the presence at the hearing today of a former member of this committee, the local member for Shepparton, Suzanna Sheed.

I would like to now call our first witnesses, from FamilyCare, Mr David Tennant and Ms Karen Goodger. Thank you for attending here 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. I would like to invite you now to make a 15-minute presentation to the committee.

Mr TENNANT — Thank you. I am not sure that we will take the full 15 minutes for the intro statement.

The CHAIR — That is fine.

Mr TENNANT — We are very grateful for the opportunity to talk to the committee this morning, but we are also particularly appreciative that you have come to Shepparton. The opportunity for local people to participate in an inquiry like this in their community is a terrific one, so we appreciate the investment of time that that represents. As I said, the opening comments that we will make will be brief, and our written submission was also brief. For my own part, that recognises that the role that I play and my perspective are far less useful to the committee than those with current lived experiences. I do not have those and I do not claim them. I am also not a subject matter expert, but I acknowledge my colleague Karen, who is the manager of our disability support services and who is here today, will be able to answer the questions where I look dumb and blank — which is not put on; it is because I do not know.

But there are a couple of themes I would like to pick up on from our evidence and observations that I see the committee has already received some commentary on. The themes are around three broad areas: the challenges that people in rural and regional areas face in obtaining practical access to the supports that they require; the mounting pressures on low-income households generally, but particularly families who are facing multiple challenges or vulnerabilities, particularly where they require ongoing support; and the limitations of market-based solutions.

On the first of those, location, there is a common feature in submissions and evidence that the committee has heard so far regarding rural and regional access to services and the challenges that that creates for people. The supports that people need are often harder to find and to physically access when they live in regional areas, and for service providers as well the cost of providing services — exactly what is required when and where it is needed — is also higher than it might be in a metropolitan area and not something that our current funding and support system is particularly good at recognising. We are keen always to produce systems that make sense centrally, but we have long said that funding systems that recognise there are locational issues that sometimes require loadings to recognise them are important if you are going to be able to design services fit for purpose in regional areas.

Where it is not practical to ensure sustainable local delivery and people are required to travel to access specialist services — it is often the case that travel is required — for the people of Shepparton travel can sometimes be difficult, especially so if you are reliant on public transport. I acknowledge that the local member has been a particularly vocal critic of our transport situation in Shepparton, but as one who has used occasionally the train system to and from Shepparton, it is woefully inadequate and makes life very difficult for people who are reliant on it.

On the second general issue, financial pressures, FamilyCare's main service platform is child and family services. In the provision of disability support services there is often overlap, and the service platforms that we provide have a common feature across our client groups where people experience financial pressures, and that is part and parcel of living in a low-to-moderate-income family. Shepparton was selected by the commonwealth as a trail site for a series of welfare reform measures in May 2011. Those are current and live now, and we are one of only two sites in Victoria that has those current welfare reform measures and the only site in Victoria that also has a trial of income management. The precise detail of those reform measures has changed in the years since, as has the government overseeing them, but there are some common features. At a very general level families in receipt of benefit incomes are generally subject to more stringent participation rules, and increasingly there are consequences or penalties for not complying with those rules. For families where there are multiple levels of vulnerability, that creates additional difficulty for them.

A current example of that would be the ParentsNext trial in Shepparton, which requires parents with children between the ages of six months and six years and who have been unemployed for a period of six months or more to have compulsory participation plans or put at risk their parenting payments. Six months of age for a child is very, very young, and my understanding is it would be well before the question of diagnosis was being dealt with in any definitive way. From FamilyCare's perspective these developments are making it harder for families with children, particularly single parents. Multiply the vulnerabilities and those challenges increase.

The final general observation I would make is the limitation of market-based responses. Like the overwhelming majority of service providers around Australia, FamilyCare is very welcoming of the rollout of a national disability insurance scheme and the fact that it recognises access to resources as a right for people with disabilities. There are, however, limitations to market-based responses generally and those limitations are more likely to play out in rural and regional communities. The Goulburn Valley is one of the last areas in Victoria to fully transition to the NDIS, and we are hopeful that that will provide us with some think music and perhaps a better opportunity to make sure we do not end up with less access than we have now on the other side of transition to the services that the community needs.

It is a bit more than that though. The question that we need to ask is: how do we ensure that rural and regional consumers end up with the same or better access to the same or better-quality services? My personal experience of commercial responses to vulnerability and disadvantage suggests that exploitation is a more likely outcome than increased access and better service because commercial opportunities sometimes find vulnerability and then seek to exploit it rather than to support it.

The additional challenge for regional community service providers is that the transition to the NDIS is not the only major reform activity that is going on. In fact it is pretty hard for a not-for-profit service provider like ours, where we provide a series of services across a variety of areas, to find any single area of our service provision that is not subject to major change at the moment. All of those changes are significant. The most important of all is the Productivity Commission's human services inquiry, which will report to the commonwealth in late 2017. I do not believe it overstates things to say that another wave of increased competition and contestability in the human services sector places not-for-profit service delivery in regional communities at a far greater risk than it would in a metropolitan setting. That is probably enough of my general opening statement, and we are happy to try and respond to questions if the committee has any.

The CHAIR — Thanks very much, David, and thank you for your written submission to the inquiry. I note that you mentioned the NDIS, and of course that is part of what the inquiry is looking at addressing, particularly as we have seen it roll out across Barwon already. You mentioned your concerns about the NDIS, so I guess my question is: how do you think that those concerns can be addressed?

Mr TENNANT — Perhaps if I respond generally first and then throw to Karen. The first issue is that in a regional setting there is already a situation where people do not necessarily have choices available to them. There are either services available or there are there are no services available and so the transition of a market-based system to a community like this has that context already as a significant challenge to overcome. How do you encourage a sufficient range of players to provide the range of services that would be required, and how do you switch to a new model away from block funding to one reliant on funding by people selecting and then paying for services themselves in ways that for smaller organisations that transition is a safe and sustainable one to make.

There is a very real prospect that we could end up with fewer services as result of making that transition if agencies like ours decide that we are no longer able to afford to offer the service platforms that we do. In a multidisciplinary agency like FamilyCare it is rare that all segments of our service delivery are comfortably operating at budget or in modest surplus, and you frequently juggle finances to make sure that one area supports another when it is going through stress or pressure. If all are under pressure at the same time, it often is not possible to continue as normal.

The CHAIR — So in terms of transitional services, do you see a role for your organisation in that transition?

Ms GOODGER — I think we can support the families, which we are already beginning to do. Families are confused. They hear things, for example, 12 months ago from the trial site and from some of the other news that is filtering through regarding the NDIS. I think we can support families and try and make their transition to the NDIS as simple as possible, just keeping in mind that they have a lot of other pressures happening. Thinking about what David said, a lot of our families are also child and family services families so they are experiencing family crisis and a range of other issues that the NDIS, in all that transitioning and that change, will be another confusing area for them, so we will try and help them as much as we can.

The CHAIR — So there has been no information sessions held up here yet?

Ms GOODGER — We have had some for service providers and initially about two years ago there were some for families, but things change. The way that it was explained two years ago is very different to how it is actually working in areas that have rolled out. It is really just a matter of wait and see.

The CHAIR — Your submission noted a significant increase in clients presenting to your service with ASD. How has that impacted on your service?

Ms GOODGER — Probably the needs of the clients accessing our services are very different now to what they were 10 years ago. We used to have an equal mix of people with physical disabilities and intellectual disabilities and autism. Now I would say that 90 per cent of our current clients would be on the autism spectrum.

Ms McLEISH — Diagnosed?

Ms GOODGER — Yes. Because we are funded by DHHS, all our clients have to be diagnosed under the Disability Act. It just means that the range of services offered has changed. We have to cater for a group of young people that have significant behaviours, so it increases our staffing, but unfortunately the funding has not increased. We can take probably less clients. If there is a mix in a group of 10, for example, with behavioural issues, it might mean that they are one on one. Rather than having 10 in a group with four staff we might be having 10 in a group with six staff. It just means that the whole dynamic of the group is changed. We have to make sure we are mixing the young people that get along with their friends and that sort of thing, so it has changed and it is very different to what it was years ago.

The CHAIR — Obviously there are challenges for all people who are on the spectrum. You mentioned in your submission some people not wanting to seek a diagnosis of ASD. Can you perhaps talk a little bit to that and why you see that as important?

Ms GOODGER — We have many families come to us often for referral or just for information regarding disability. Many of the families that come to us with young children where there has been something raised at kinder or at primary school about the child possibly having autism are quite upset. They do not want the child labelled as having a disability, knowing that that would stay with them for the rest of their life. It is difficult to explain to them that with the limited funding opportunities that are out there, they really need that diagnosis. Even to access services such as ours you really need a diagnosis to get in the door, basically.

The CHAIR — And there are no diagnostic services in Shepparton?

Ms GOODGER — The public hospital has child and adult mental health services that do diagnosis. They have in the past had a significant waiting list — I could not tell you what that is today — and there is a private medical clinic that will do diagnosis. But the majority of the families that we see try and get enough money together to go to Melbourne. It is much quicker and there is less waiting time.

Ms McLEISH — Thank you for coming in. I just want to continue on the line that we were just following about the autism services that are available within the Goulburn Valley in particular. You have mentioned the hospital and some private things. At that medical service, what do they offer?

Ms GOODGER — There would be psychologists. There are physiotherapists and speech therapists available privately, and I believe there is a diagnostic team that will do autism diagnosis, but again I would imagine there would be a significant waiting list.

Ms McLEISH — You imagine; we need to find out. Can you tell me how many speech pathologists there are that work in this field or psychologists that work in this field?

Ms GOODGER — There are several psychologists that work through the hospital. A lot of families generally go to Melbourne to the Royal Children's Hospital, the families that we are involved with, because their child might have other issues such as toileting delay or health issues. They seem to get the full package through the children's hospital.

Ms McLEISH — One of the things that you mentioned, when David was actually talking, were about Shepparton, and I noticed that you have services in Mitchell, Strathbogie, Murrindindi and Moira. Can you reflect on the services there?

Ms GOODGER — We run disability services in the Goulburn Valley, and we have the school holiday program that we run from Lower Hume. We do not run services in Kinglake or Cobram or those places.

Ms McLEISH — So you cannot comment on the availability of services for those people down there?

Ms GOODGER — I know that Wallan has just been a recent addition to our services. We run holiday programs that pick up clients from Wallan. But we find that many of the families are families that have moved from Melbourne so they have already been accessing metropolitan services. They have remained with those services because they are involved; they get more services. They are very limited services in places such as Seymour and Wallan.

Ms McLEISH — Can you tell me when you support the families, and particularly families with children on the spectrum, what does it look like? What do your levels of support look like? Can you walk me through it?

Ms GOODGER — We often have a referral from a doctor or a school. We will contact the family and do a brief assessment over the phone just to see whether they have got a diagnosis and whether they are eligible for our service. Then we meet with them, either in their home or they come into our office. One of the coordinators will sit down with them and find out what they are actually after, whether they want respite, which is what we offer, or whether they perhaps want information or referral to another service, or whether they just want to talk about what is happening with them. If we are looking at respite, for example, we can help them with school holiday programs, after-school care, camps — that type of thing. We can refer them to our carer support program that has brokerage to offer other respite services, whether it is one on one, in the home or a weekend in a facility, for example.

Ms McLEISH — What do they ask for most?

Ms GOODGER — A lot of them want after-school care. They are often parents that have to have both parents working or it might be a single parent working, so we have an after-school program that is available every day of the school term, so we can pick up the children from the local special school or we can have carers or something drop them off, and we just provide after-school care like any other after-school care facility, any mainstream facility.

Ms McLEISH — Has there ever been any talk of the special school doing after-school care?

Ms GOODGER — I think they started it for a while, but the issue with them is some of their children come from quite far away. For example, if they lived in Cobram or Numurkah, there is no transport available at 6 o'clock when it finished, so that was a bit of an issue; they could not go home on the school bus.

Ms McLEISH — So those kids are not going to come to you either?

Ms GOODGER — No, not unless we were picking them up, but I do believe some of the local state schools offer after-school care, and if they have an issue with their child with behaviours, for example, we can recommend someone that might be able to go in and be an aide for that child in those couple of hours after school.

Ms McLEISH — You were mentioning people always going to Melbourne, and particularly the children's hospital, to access services. What do you need in Shepparton?

Ms GOODGER — I think we probably need a system where children can be diagnosed in a timely manner rather than waiting two years or having to travel to Melbourne or having to find the money to pay for it privately. Often children need services immediately. They do not have two years to wait to get that diagnosis and access services or funding. The funding available cuts off at seven, I believe, so if you have got a child diagnosed at five and you are waiting two years for assessment, then you have missed out on that funding that could significantly assist.

Ms McLEISH — If you wanted to do it privately you could get it done quickly, but if you do not do it privately you cannot; is that what you are saying?

Ms GOODGER — Yes.

Ms McLEISH — So private is quick.

The CHAIR — And expensive.

Ms McLEISH — Yes.

Ms GOODGER — And expensive, yes. Many of our families have multiple children in the family with autism, so that is also another issue. If you have to pay for services, you are paying it for three children, so it does get very expensive.

Ms COUZENS — Thanks for coming along today, and it is a pleasure to be here in Shepparton. Qualified staff in ASD for after-school care — do you have that?

Ms GOODGER — All our staff are qualified. The minimum standard of qualification would be a certificate IV in disability. Most of them have a diploma or equivalent. They also do a lot of extra training. We have been lucky until this year; we were HACC funded, so HACC had a great range of training available to people working in their funded programs. They do get specific autism training. If we had a child with needs that meant we were not sure anyone was able to work with them, we would get some workers trained to suit that individual's needs. We have a range of children with medical conditions, so all our staff are trained according to the clients that they are working with.

Mr TENNANT — There was an observation, I think, that Fiona Sharkie from Amaze made in her evidence to the committee about the general challenges with workforce, and for an agency like ours where we have so much reform activity all at the same time, some of which requires adding to your workforce very quickly, and each agency in a regional community is required to do something similar at the same time, it is a small pool to start with, and we are all essentially competing for people in that pool. Some longer term investment in bringing people through would be great so that there is a broader range of people to support in that transition; and there are some local efforts being made, particularly by La Trobe University, to do that. I guess the flip side of that in a community like Shepparton is that if your most significant growth area in employment is in social services, that says some other things about your community, so you need balance in those things as well.

Ms COUZENS — From your experience, what are the key things that need to be improved in ASD? If you have got a vision of 'This is what we would love to see happen', is it staffing, is it resources, is it assessments?

Ms GOODGER — From the feedback we get from families it would be the specialised services that can go into schools and assist children with autism in making relationships and making friends and that sort of social awareness. Psychology services are probably highly used by children with autism, or young people with autism, just because of the anxiety and some of the other mental health conditions that can happen as they age and have to get into the real world. Most families will come to us and say their child has been bullied at some stage, so I think better training for teachers and those people working with people with autism would be good, whether it is in the workplace or in school or university or anything. But I would say early intervention services here, while they are good, they could probably be better, and coming into an NDIS where people will be given funding to support their young person or young adult with an autism spectrum disorder, it is great having that money but if you have not got the services to spend that money you are not going to get any services.

Ms McLEISH — Do you think that will bring services here — that it will open up opportunities?

Ms GOODGER — I really could not say. It is difficult to get health professionals to country areas anyway, so I cannot imagine it will be any easier just because the NDIS comes about.

Ms COUZENS — Given that regional and rural areas are having much more difficulty in even accessing assessments and the expertise that is required — —

Ms GOODGER — Yes. Even just getting a child into a GP sometimes is difficult, so getting other services is pretty hard, and I cannot imagine it is going to get that much better just because the NDIS rolls out here.

Ms COUZENS — How can it be made much better? What do you think are the things that we should be looking at as a committee to ensure that those issues are being addressed, particularly for regional and rural communities?

Ms GOODGER — I think better training for some of our local GPs and medical practitioners. While they may be highly skilled in some areas, a lot of them have issues with understanding autism and actually knowing how families cope with that. Just for the medical people that do see people with autism, they need a bit more information and maybe some training on carer stress and the types of things that the families go through — not just dealing with the child having a disability but dealing with school and all the other pressures that come with parenting a child that has additional needs.

Ms COUZENS — Yes. I know in Geelong that the assessments are up to 12 months, if not longer, and we have one agency that does them there. In your view, how can we improve that? Because what they are trying to do is assess children before they start school, which is pushing back a lot of the other children on the waiting list.

Ms GOODGER — That is right.

Ms COUZENS — Do you think it is just a matter of putting those resources into regional and rural communities?

Ms GOODGER — I do not know how it will work when the NDIS comes to Shepparton. That is not for another couple of years. I am not 100 per cent sure how it is working in the areas that have rolled out, like Geelong.

Ms COUZENS — Well, the assessments still have to be done by somebody.

Ms GOODGER — I would consider a waiting list of 12 months inappropriate for families. The pressure and stress waiting for that 12 months before they can access the service would be enormous. Even children pick up on the stress of families and that type of thing. I do not know why they would not have more people doing that assessment. I am guessing that is done through the NDIA.

Ms COUZENS — No, it is not.

Ms GOODGER — No. I would imagine that that would be an area to begin — perhaps putting more funding into that, because once you can get children assessed at least they can start accessing some services, even if they do have to travel for them.

The CHAIR — Apart from the public hospital and one private provider you mentioned in Shepparton, you said ‘early intervention services’. Are there any outside of that?

Ms GOODGER — DHHS have early intervention services that work with preschool-aged children and, depending on the needs of the child and their issues, we will also support children in schools.

The CHAIR — Do you know what that early intervention consists of?

Ms GOODGER — Speech therapy, and they have physiotherapists and —

The CHAIR — Is that one-on-one with the child?

Ms GOODGER — occupational therapists. Yes. But it depends on the needs of the child. Not all children with autism require speech therapy or occupational therapy, so if they just want assistance with learning social skills or settling into the classroom and being able to study the way that they need to study, there is not a lot of help for that.

The CHAIR — So you have been around Shepparton for a while?

Ms GOODGER — Yes.

The CHAIR — And you have seen this all unfolding. Would you say it is a successful early intervention program that is being put out there by DHHS?

Ms GOODGER — It is probably better than in some areas. There was a time, probably 15 years ago, when it was difficult for them to get speech therapists. There were not any here, but that has changed and there are some good speech therapists now able to work with the children. The public hospital also has paediatric speech therapists that do work with children with autism, and there is also Mansfield Autism Statewide Services that will come over and work. They have a travelling teacher who will come over and work with the schools and the families in assessing what the child needs and who is able to support them in getting those services. But unfortunately they are no longer funded, so that is a user-pays system. So it can be difficult to get that funding for the family to pay for that person to come over.

The CHAIR — Yes, we visited them yesterday. They do actually still receive state funding.

Ms GOODGER — Do they? I know it is difficult for families.

The CHAIR — Yes. And also there is a very limited number of children who can access the service as well. In terms of the community — the Shepparton community — do you have a sense that people with ASD in your community are able to access the community sporting events, sporting clubs or recreational activities? What is the access like, and what is the acceptance like across your community?

Ms GOODGER — From the feedback we get from families, especially for children — I could not comment on how it is for adults — certainly a lot of our young people are involved in sporting clubs. A lot of them do come from smaller communities where everyone knows everyone else, so it is easier for them to access the local cricket club or whatever because everybody knows who they are and what their needs are. A lot of the young people access things like Auskick and Milo cricket. Because it is done within the school community, generally the support is there. I cannot comment on how it would be if they were to at 16 or 17 go and try and access the local football club, for example. But generally the feedback is good on getting them out into the community and accessing places like sporting clubs.

The CHAIR — Do you have any particular sporting clubs that acknowledge and make an effort to welcome kids with ASD?

Ms GOODGER — I know we have had one client that is part of the Mooroopna Football Club and the Mooroopna Cricket Club. He has had a really good experience there and everyone likes him, and he has been involved for probably 10 or more years. So that has always been good feedback, and we have recommended that people who live in that area, if they are looking for something for their child, speak to the people there because they seem to be very supportive of this young person.

The CHAIR — I just have one last question in terms of employment. Do you have a sense that there are opportunities for employment for people with ASD in this community?

Ms GOODGER — We are funded to support people up to the age of 18, so they are generally just finishing school. I could not comment on employment opportunities.

Ms McLEISH — But there are no transition programs that you are involved with?

Ms GOODGER — We are not, no. The special school has a transition program that they engage their young people in as they get towards the final years of school. I could not comment on what the other state schools or the private schools do.

The CHAIR — So once a child reaches 18 they leave your service?

Ms GOODGER — They generally sort of drift away from about the age of 16. Especially young people with autism want to be seen as doing things that their peers would be doing, so it is a bit of a stigma to come to a disability service as such. Often if they are involved with a day program and doing a transition there, they can access their services, so they would rather be with people the same age as them and not children with significant disabilities.

The CHAIR — Do you track their progression after they leave your service?

Ms GOODGER — Because it is a smallish country town I guess we hear about what they are up to, and they often will tell us if we meet them in the street, but we do not have any way of tracking otherwise, no.

The CHAIR — Is there a percentage of those who leave your service who are floundering, who do not have the support that they need, who do not have access to other services or who find themselves in financial hardship?

Ms GOODGER — Sometimes. Often those young people are the ones who come from families where there is some stress or financial hardship anyway, and perhaps the parents have their own issues or even disabilities and they have not been able to support them in that transition to work or study or services.

Ms McLEISH — Just a very quick one: of the 25 per cent of your clients who have ASD, what percentage of those would be Aboriginal?

Ms GOODGER — A very small percentage. We do have some. I would say perhaps maybe 5 per cent, but the local Aboriginal co-op here also is funded for respite services, so some of them access that.

Ms COUZENS — Is FamilyCare doing any work or support with adults with ASD?

Ms GOODGER — No.

Ms COUZENS — None at all?

Mr TENNANT — We have, however, built an emerging cooperative network with a series of other community service providers locally. It is called Shepparton Community Share. We received a small amount of funding from the Helen Macpherson Smith Trust that gave us an authorising environment to try that and, if it did not work, to fail, without having too many adverse consequences. But we have included one of the main adult disability service providers, ConnectGV, in that network, and as we get better at learning how to communicate with each other as a network and more as a community, then we are finding ways that we can swap information and perhaps help some of those transition points.

Ms COUZENS — So is that more or less a support group?

Mr TENNANT — It is a few things. It helps us as providers recognise that there are some things that each of us do that cost us a lot of money but that if we were clever and perhaps cooperated more, we might do once and share between us. But it also allows us to form a view about our community based on the interactions we have with our different client segments and then join those forces together. We have recently put in submissions to that Productivity Commission review that I referred to earlier, and that would not have happened if we had not have had that network.

The CHAIR — Great. Thank you, David and Karen — much appreciated. Thank you for sharing your service with us today. It has been very informative.

Mr TENNANT — Thank you.

Ms GOODGER — Thanks.

Witnesses withdrew.