

# TRANSCRIPT

## FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

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

Morwell — 5 December 2016

#### Members

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Mr Paul Edbrooke

Ms Cindy McLeish — Deputy Chair

Mr Bernie Finn

Ms Chris Couzens

Ms Emma Kealy

#### Staff

Executive officer: Dr Greg Gardiner

#### Witness

Ms Denise Bromiley, Manager Disability and Carer Program, Latrobe Community Health Service

**The CHAIR** — Welcome everyone to the public hearing for the Family and Community Development Committee's Inquiry into People with Autism Spectrum Disorder. This is the ninth public hearing to be held by the Committee in a series of hearings that will continue into early next year. In addition to hearings in Melbourne, the Committee has already travelled to Geelong, Bendigo and Shepparton to meet with stakeholders and hold public hearings. The Committee is delighted to be here in Morwell today.

The Committee is thankful for the ongoing support this inquiry is receiving from the public, particularly from people with ASD and their families. 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 to any proceedings for defamation. If you have any special needs today, please see the Committee staff and we will assist you.

I would now like to call our first witness from Latrobe Community Health Service, Denise Bromiley.

Welcome to our public hearing today, Denise, Manager Disability and Carer Program at Latrobe Community Health Services. Thank you very much for attending today.

All evidence at this hearing taken by the Committee is protected by parliamentary privilege as provided by the Constitution Act 1975 and is subject to the provisions of the Parliamentary Committees Act 2003 and other relevant legislation. Any comments you make outside the hearing will not be afforded such privilege.

It is a contempt of Parliament to provide false evidence. Recording of the proceedings will commence today and you will be sent a proof copy of the transcript and be able to make factual or grammatical corrections if necessary.

Thank you very much for your submission that you made to the inquiry and I invite you now to make a 15 minute presentation. Thank you.

**Ms BROMILEY** — Thank you for having me here today. I represent the Latrobe Community Health Service. As you note, I am the manager of the disability and carer program team at Latrobe Community Health Service and unfortunately Petra Spencer, who is the manager of primary intervention, wasn't able to be with us here today so hence you have me. I can speak to some of Petra's information but I will cover myself first.

The Latrobe Community Health Service is a not-for-profit organisation and was formed in February 1995 with the amalgamation of the Moe, Morwell, Traralgon and Churchill Community Health Centres. Our vision is better health, better lifestyles, stronger communities and our organisational purpose is to enable people to live healthier, better lives and longer. We have close to 500 staff at our work at Latrobe Community Health Service. I think it is probably the largest stand-alone community health service in the state. It has a long and successful history of providing high quality; community-based services to improve and support the health and wellbeing of our communities and a broad range of services are available.

We cover the whole of the Gippsland region and certainly the disability and carer programs. It covers the whole of Gippsland from Phillip Island through to the New South Wales border whereas the Primary Intervention Team largely focuses on the Gippsland — inner Gippsland, particularly the Latrobe Valley — area. So, we have got a foot in both camps today.

Regional areas such as Latrobe face the additional challenges of large geographical areas, scattered client bases, extreme weather and some difficult road variances. The bushfires of 2009 and the Hazelwood mine fire, for example, have had significant impact on the ability to provide services to clients in some areas. The percentage of individuals with low household incomes is above average in Latrobe compared to the Victorian average and around the same as the Gippsland region.

In 2011 the then Department of Health Victoria Gippsland provided funds to resource the Gippsland service planning for paediatric allied health. It is a project funded under the auspices of the Gippsland Health Services Partnership and a consultant was engaged to investigate the objective of the project and make recommendations. As a result of these recommendations in 2012, Latrobe Community Health Service developed a paediatric allied health service for children with undiagnosed developmental delay. The Paediatric Allied Health Service was developed within the existing funding although short-term additional funding was allowed for.

The paediatric project provided early intervention allied health programs for children with mild to moderate delay and who didn't meet the guidelines for the Early Childhood Intervention Service. So this includes those

who already had a definitive diagnosis of autism. So the landscape for families with children with difficulties remains complex to navigate and early criteria to the various services, at times, has been very difficult. Linkages to the right service at the right time are further compromised when barriers of poor health and low socio-economic status and financial hardship are co-existing.

Through the Disability Services Team we do have some funded early childhood intervention packages. We have 12 in total which, following an agreement with the Department of Education and Training, are located in the outer Gippsland region. So that's in the Wellington and East Gippsland area. There are other service providers in the inner Gippsland area that hold their early childhood intervention and services packages.

So in relation to the availability and adequacy of the services provided by the Commonwealth, state and local Governments, families often report multiple assessments with multiple providers, many who are deemed not to be particularly specialised in autism. I think part of this was the reason for developing the Children's Services Project as it was. It's also been their experience there is an under supply of skilled health professionals for early intervention services. Families are often assessed at multiple points by multiple health professionals but at times receive little actual intervention. So from the point of view of the Children's Services Program they've given me some brief information about the number of children that they're seeing and that one of the main issues is access to the paediatrician and assisting families with a diagnosis.

From the Disability Services Program we have a number of different funding streams. Some of it is through the State Government linkages program, HACC funding. So that's our age group from 0-64 for that cohort and basically people need to be just eligible for a HACC program and have perhaps multiple and complex needs and needs that can't be met within the current HACC system. We also receive some flexible support funding from the Department of Human Services, part of DHHS, and that funding covers across the Gippsland region. So again, those packages cover from Phillip Island through to the New South Wales border. We also receive funding to provide specific support for older carers caring for someone with a disability as well as just disability respite, and those funds can be used flexibly so can either be provided to provide direct support, respite support, but also respite in kind in terms of supporting access to something that will improve the life of the person with a disability, whether that be support for behavioural intervention, such as perhaps funding assistance to attend something like the Mansfield School or it could be used to provide support to access communication devices as well as personal care supports and those other things.

I asked our reporting team to run some figures for me and we find that over the last two years we've supported, of the clients that we've supported through the Disability Services Programs, it's been around 20% of people with a diagnosis of autism, which is not too dissimilar to what the percentage has been through the National Disability Insurance Scheme. And certainly our experience with clients is that people, by the time they come to the program, are often fraught and tired and really seeking some immediate assistance. So we function on what we call a wait-list-free model. So we take a referral, we talk to people about what their unmet need is and then work in partnership with them to try and provide some reasonably immediate support to them, depending on what the main issue is for them at the moment. That way we find we support more people, certainly with some short-term or interim supports, and then often where the need is we can allocate planning so we can work with families and people with disability, people with autism, and see what else we can do to support them.

**The CHAIR** — Thank you. So the referrals come from where to your service?

**Ms BROMILEY** — So people can self-refer or we can take referrals from any professional, facilitated referrals, GP, families and certainly the Early Childhood Intervention Service. The referrals are all managed by the Department and they allocate out.

**The CHAIR** — How many referrals would you get approximately in a month?

**Ms BROMILEY** — In a month we process anywhere from 35 to 50 people through our e-register. Again, as I say, that would be for a variety of reasons.

**The CHAIR** — Not necessarily...

**Ms BROMILEY** — Autism. No. No, I haven't been able to separate those.

**The CHAIR** — In the submission that your organisation made to the committee, there was a mention about the hub-and-spoke model and Telehealth. We have had a bit to do with the hub-and-spoke model and I was just wondering how do you think that these models of service delivery support health professionals and families, particularly in regional and rural areas?

**Ms BROMILEY** — When I spoke to Petra before she left on leave, she certainly talked about Telehealth and the access to support for the therapists and access to families, and even treating GPs, with a specialist paediatrician or autism specialist because often the ability of the families to get to a specialist located in the township can be really challenging, particularly with the possible requirements of the disability and the family and we often find there is more than one child in the family that may be requiring support. But certainly in the further east, just through my own program, access to therapists and the tyranny of distance is a real problem for people. Certainly the Telehealth model is seen, I think, as a means of support in terms of both diagnosis and management for follow up but also support for the therapists in gaining that, I guess, collegiate support and peer support through access to other therapists with specialty training in autism.

**The CHAIR** — How many paediatricians and other therapists would there be in this region?

**Ms BROMILEY** — That's a very good question. I can't give you the specifics of that. However, I do know that there are few paediatricians and then even fewer of those paediatricians with speciality in autism.

**The CHAIR** — Are they visiting paediatricians?

**Ms BROMILEY** — Some do visit. I know that just from the Sale region that one of the paediatricians there who had some experience has recently relocated to Geelong and now only visits Sale again two days a month or something like that. So it is very challenging for them.

**The CHAIR** — Yes. Apart from the tyranny of distance what other challenges do you think the families in your region face?

**Ms BROMILEY** — Access to support.

**The CHAIR** — Particularly for children with autism?

**Ms BROMILEY** — Yes, access to support. So it is that behaviour intervention support, the management strategies, the cost of therapy and often — we, in some of our ongoing support through disability services to children with autism, we'll fund some — if there is a need, fund some access to the therapy because of the cost. The families find it prohibitive.

**The CHAIR** — So given the cost and the roll out of the NDIS in the Gippsland region, which is 2017 and in the outer region in 2019...

**Ms BROMILEY** — Outer Gippsland, that's correct.

**The CHAIR** — Do you think that will make a difference? Do you think there will be better access and do you think people will find it a better system?

**Ms BROMILEY** — I think there is going to be a delay. I think there will be a gap in terms of that. I would, I suppose, have some concern about market failure in the initial stages. I think even though we're seeing some service providers and some other therapists move into the inner Gippsland region it is still pretty slow given we are looking at a roll out date of 1 October. So 10 months away. Certainly, I think, the challenges for outer Gippsland, because of — I keep referring back to it but that distance issue, it will be challenging but I think the market will take time to pick up the gap and I think in the interim time I would see that families are not going to be a whole lot better off to start with. I think even if they've had a plan done and those plans include access to supports, the actual physical ability to access those supports is still going to be challenged until the market picks that up and I don't see the market doing that, being ready to go, as soon as the roll out comes out.

**The CHAIR** — You mentioned that you provide a service to children that don't have a diagnosis?

**Ms BROMILEY** — Yes.

**The CHAIR** — But may have developmental delay or intellectual disability; is that correct?

**Ms BROMILEY** — Yes.

**The CHAIR** — Are you the only service that provides that sort of support in this region?

**Ms BROMILEY** — There is the flexible support funding that sits with the Gippsland Lakes Community Health Service — that is 0-6 years — and I think most of those would probably have to be eligible for the Early Childhood Intervention Service because it is flexible support dollars attached to that. I think we would be one of the only service providers that actually funds regions. Our flexible support dollars go from 0-64 years. So a lot of the FSP holders are in the 7-64 age group but ours aren't so we can be a little bit flexible and it depends very much on what the need of the family is and the child.

**The CHAIR** — So, apart from respite and paediatric services that you support, for older children and adults, what sort of support do you offer?

**Ms BROMILEY** — Again some of it is the access. There are some children that we have worked with over the age of 7 and supported access to specialist counselling through a psychologist to help the child and the family. We have provided support to attend the Secret Agents Society training as well as access to the Mansfield Autism Camp

**The CHAIR** — Do you offer any financial support for those, for the secret agents...?

**Ms BROMILEY** — We can. Where there's a need and the family are able to demonstrate the financial disadvantage then we can actually — we do a contribution and work in partnership with the families.

**The CHAIR** — How many do you think you would normally refer to the Mansfield Autism Services?

**Ms BROMILEY** — Probably only two or three a year. They are somewhat expensive.

**The CHAIR** — We have been there. Great program but very limited provision.

**Ms BROMILEY** — It certainly depends on how we are travelling. We have strict KPIs to meet for the department in terms of that funding and depending on, I guess, anyone's need at any given point in time we sometimes are in a position with funds to be able to support where there's been a direct need — demonstrated need — and that's been fairly costly for the families, but we have done some big contributions, on occasion. But largely to say it would be under the \$5,000 but we have, at times, funded a bit more than that where we could.

**Ms COUZENS** — Thanks for coming along today. Just from a regional perspective, how can the State Government improve access to services for children and adults with ASD in your regional area do you think?

**Ms BROMILEY** — Certainly, I think, providing — I come back to perhaps the Telehealth model. I think it is very difficult to provide incentives to specialists to relocate to regional areas. That would be good, and certainly specialist therapists as well as specialist paediatricians. Perhaps — certainly access to support for transport. Again, transport, we just keep coming back to transport but it is a major issue. A major issue even for the service evaluee. You can hop on a train and get to the city within a couple of hours but it is just complicated enormously when you might live in Lakes Entrance or something like that. It is just a whole day out. So, I guess, encouraging maybe not only use the Telehealth but even if specialists were to travel out to the regions and find some support that would certainly provide people with assistance. Finance is another issue. We find with the way that we function and the questions that we ask and because we are flexible, we can provide support financially to access things or we can provide support with other things where the actual requirement mightn't fit our eligibilities and we might have to find something that does to allow the family to shift their expenses and put to it what they need. We are lucky that we have some of that flexibility but I would see also that there is a financial need for people. There is no doubt that people with a disability probably have greater living expenses often and that can be related to communication aids, the respite, access to support, extra support for the children at school. I think that all does play a part in terms of people's ability to then actually get out the door and access somewhere.

**Ms COUZENS** — In some regions we have heard it is quite an ad hoc sort of approach?

**Ms BROMILEY** — It is, yes.

**Ms COUZENS** — Do you see there is a need for better coordination?

**Ms BROMILEY** — Oh, absolutely. Absolutely. The Latrobe Community Health Service is well-known across the region. People do come to us because we have such a range or suite of services. So people will often ring and ask us and we do find — we do do some planning episodes with families and it is around going through the whole system and trying to find where they need to be. It is very difficult for them to navigate and whilst we are allocated some planning episodes by the department we also may take those internally if we receive a referral, if we think that's what's actually needed, to sit down with a person with a disability and/or the family and help work out what it is. What the goals are, what the needs are and advocate where they need to be. We do work from a strengths-based approach. We try and build that capacity with the person or the family. However, it would be fair to say that we do support some clients where it is very difficult in terms of that capacity and lack of support. So we do take on some case management and provide support to those people. We will be in the transition post the new year of talking to our families and clients about transitioning. Because of our contract with the NDIA in the Central Highlands we won't be able to continue supporting those people but we do have a couple of clients who are older adults with autism that we've worked with for a very long period of time and it will be very difficult to transition those to another provider because of the established relationship.

**Ms COUZENS** — How do you think that is going to play out?

**Ms BROMILEY** — Not very well. I think, thankfully, we are in a position to be able to be a bit flexible and so as the manager of the program I wanted to start that work earlier rather than later so we can really work with participants and do a very, I suppose, staged, slow, approach because it is going to be in their interests, and at the end of the day my staff have been in the program for a long time and they've had long relationships with these people and feel it as much as the person with a disability. So we — it's going to be, I think, a difficult time for all but, you know, in the long run I'm expecting that it should be better, that these people have, support than we are currently able to provide.

**Ms COUZENS** — How can allied health practitioners be better supported in their work with children with ASD?

**Ms BROMILEY** — I think access to supports and information for them and training and upskilling, access to peer support. I think this is one of the things that they struggle with and I think certainly Petra's comments about Telehealth would be about providing an avenue for some of that training and peer support.

**Ms COUZENS** — How can the State Government improve access to services for children and adults with ASD in your regional area, do you think?

**Ms BROMILEY** — I think it would be probably a more coordinated approach. Something like the model we use. We have a centralised point of intake. So all phone calls to our 1800 service go to front reception and our service access and anyone who's seeking information or support of our service gets to speak to a service access officer. So a model something like that where there's a centralised phone number for people to ring and they can be provided with that.

**Ms COUZENS** — Is there anything that you can't provide at the moment that you think...?

**Ms BROMILEY** — At LCHS?

**Ms COUZENS** — Yes, that could be put in place?

**Ms BROMILEY** — Certainly access to children's services in Latrobe. I can't speak outside of Latrobe. They do have a waiting list, so do have limited staff and funds. So further funding to support that and to build that model further across the region would be certainly relevant.

**The CHAIR** — Do you have any interaction with the schools in your region? Is there a referral system in place from the schools for children with ASD?

**Ms BROMILEY** — Not necessarily. My staff do have relationships with schools, depending on clients that go to the school. Certainly we do work closely with schools but we don't have a network where we talk to schools across the region from the Latrobe Community Health Service.

**The CHAIR** — Do you think that would be beneficial?

**Ms BROMILEY** — Look, it probably would be. The workers, because we work on the Key Worker Model, have contact with the kindergartens and there are six-monthly meetings at the regional kindergartens where all kindergartens all get together and start the meeting but certainly that doesn't happen across the schools. We have staff going to the schools and talking when they do their expos and information and talking about particular futures for young adults and where to next, but in terms of working with the schools and encouraging referrals for children with autism, no, we don't. But it could well be useful.

**The CHAIR** — And similarly with maternal and child health nurses across the region, do you have interaction with them?

**Ms BROMILEY** — No.

**The CHAIR** — So no referrals from them?

**Ms BROMILEY** — No.

**The CHAIR** — So when families come to you and they have a child with ASD, what kind of therapies are they looking for? Do they know what therapies are out there? Is there a gap in the knowledge that is available to parents?

**Ms BROMILEY** — I think there is a gap in the knowledge. The children that come to us with developmental delay through the Early Childhood Intervention Service, all of those referrals are managed by the Department of Education and training. So they've had some discussion with their family prior to the referral about what the need might be. So often it would be for speech therapy, occupational therapy, it might be psychology even with younger children. It could be assistance for a communication device. So, yeah, those sorts of things.

**The CHAIR** — Is there anyone down this way who offers ABA therapy?

**Ms BROMILEY** — Not a lot, I don't believe. One of my staff, who actually relocated to New South Wales, which was a bit sad, was an ABA therapist. No, I think at this stage there is not a lot.

**The CHAIR** — Do you think there would be a demand if it were available?

**Ms BROMILEY** — I think so. Yes.

**The CHAIR** — I have no further questions. Thank you very much for coming along today. It is very much appreciated. We have gained a lot of information so thank you very much.

**Ms BROMILEY** — Thank you.

**Witness withdrew.**