TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Morwell — 5 December 2016

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Mr Shilo Wilson, Manager Respite and Support, Interchange Gippsland.

The CHAIR — We call Shilo Wilson. Welcome to our public hearing, Shilo, Manager Respite and Support from Interchange Gippsland. Thank you very much for coming along 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 invite you now to make a presentation to the Committee. Thank you.

Mr WILSON — Today I am here representing Interchange Gippsland. We are a local disability support agency and we provide services across the Gippsland region. The majority of our supports are provided in central Gippsland which is Latrobe, Baw Baw, Bass Coast and South Gippsland and we have a small number of supports extending to Wellington and East Gippsland.

In terms of the supports that we provide they're very diverse and varied, ranging from one-on-one paid support, where a worker is paid to support a child with a disability one-on-one, volunteer one-on-one support, where a volunteer cares for a child with a disability on a one-on-one basis. We have a number of group recreation programs running from the age of 10 years of age all the way up to 65. They are very much about getting those groups out and about in the community doing fun activities, things that you and I would like to do or the appropriate age group would like to do. It is getting them out and about doing fun things. We also provide adult day services. So we have an adult day program running from Wonthaggi which covers the Bass Coast region and we have recently commenced an adult day program in the Latrobe Valley and we also provide a number of family support options as well.

While our primary focus is providing respite for families we also run a number of activities that support the whole family. So throughout the year we hold a number of different events. We have a family camp each year where the whole family has an opportunity to go away together in a supported environment. We hold retreats for the mothers and fathers where we will take them away for a weekend and give them pampering or do something fun with those guys. We have a number of family days throughout the year, which is a great opportunity for families to get together and have a fun day out and we also run siblings’ camps as well which is an opportunity for brothers and sisters of a child with a disability to do something fun. We've had a lot of feedback from families that often the siblings without a disability miss out on a lot of opportunities because the parents' time is often consumed by the child with a disability or the child with a disability might have a variety of programs and supports in place for them but often the siblings miss out on that opportunity. So we feel that is a very important thing to offer to our families. The great thing about those programs, those activities, is any family that is registered with us, they have the ability to attend those activities. So you don't have to actively be receiving a support through us to access those family activities, which is really good.

So the participants involved with Interchange, they are diverse in many ways. Diverse in their age, their background, their socio-economic statuses, their disabilities. When we categorise the disabilities for those that are registered with us, autism has the highest prevalence. In terms of statistics we support 223 participants actively. So they are actively engaged in regular programs with us. Of those 223, 35% have a diagnosis of ASD. Of the 120 that are on the wait list, so these participants are currently not receiving a regular support through us, 56% are diagnosed with ASD. So the percentages are quite high. Often there is a diagnosis of ASD and other disabilities associated as well, so sometimes ASD is a primary disability, other times it is a secondary.

So what I'd like to do now, I would like to play a short 4-minute video which we recently produced with a handful of our participants that are involved in our group-based programs. Basically, it is an opportunity for you guys to hear what we do from the words of the participants and the families that we support. So, in the video there are three participants who are being interviewed by one of our local celebrities, Koco the Clown. Two of those participants do have a diagnosis of ASD. As I said, I think it provides a really good insight into what we do and the programs we run at Interchange. I will get that one going.

(VIDEO PLAYS)

Mr WILSON — Hopefully that video provides a good insight into some of the participants we support and an insight into the programs we run. Those three participants all attend recreation programs through Interchange which is an area that we probably specialise in in the Gippsland region. There are a lot of agencies that provide one-on-one support, where a paid worker is matched with an individual with a disability, but there is not a lot in terms of group support in the Gippsland region. The reason that these programs are running through Interchange is that we have had a lot of feedback from families that they want their kids to interact with other kids and do stuff that is fun in the community as opposed to the typical respite model where it is a worker providing support for a child on a one-on-one basis. Often the families do request younger workers because the majority of the children that we support are under the age of 18, a lot of families do like to have younger workers involved with their child. Just because there is more similar interests and I guess there is more similarities, more interests and that just helps get those close connections and close relationships forming, which is really positive.

In terms of the group-based supports, our group-based supports start from the age of 10 and in Latrobe we go up to the age of 65. Ideally, we would like to be able to offer that broad range of supports in every Gippsland region, but we can't at the present time due to funding limitations. Latrobe is quite well serviced in terms of going from 10-65, but we don't have that broad level of support in all the shires. Hopefully under NDIS that is something we can provide down the track and that is something that we are aiming to do, but it all comes down to the funding side of it at the present time. So that's an overview of what we do and who we are.

The CHAIR — Thank you very much. Thank you for the submission to the inquiry as well. What are the criteria for eligibility for your service?

Mr WILSON — Eligibility for our programs is the participant has to have a diagnosed disability and they have to live within the Gippsland region. That's the broad eligibility. In terms of the individual programs, often there are more specific eligibility requirements. A lot of our group programs are region specific, so the child and their family generally have to live in a particular area to be eligible for that. And in terms of support needs that also does have an impact on eligibility as well. Our group support programs, they are funded at a lower staffing ratio; depending on the program it is supported by two staff up to a maximum of six staff and they will support up to 16 participants on an activity. So, unfortunately, because of that staffing ratio we often don't have the capacity to support participants that require one-on-one support, those that have higher support needs often miss out on those group activities.

The CHAIR — So if you're — what would your service need then in order — you mentioned your waiting list?

Mr WILSON — Yes.

The CHAIR — What would your service need to support those people who are on the waiting list?

Mr WILSON — Unfortunately, again it comes down to the funding side of things. So if we had an unlimited bucket of money we wouldn't have a wait list. We would be able to provide a service to everyone that wanted to access the service through Interchange. At the moment, the majority of our funding is through block funding, so we receive X amount of dollars to provide a program and, often there's a cut off in how many people we can support on that program.

The CHAIR — So when someone comes to your service with ASD, what are they seeking? What sort of services are they seeking?

Mr WILSON — Often it is respite because we're primarily a respite service. Often it is respite and a lot of the times it is information as well. On quite a regular basis families will contact us and we will be the first organisation they have made contact with regarding supports and services for their child or for the family and often they want to know what else is out there, what are they eligible for, what supports are available in the community. We work quite hard to link families in with different supports as well. So in the big picture we are quite a small organisation. So, we work hard to link families in with the bigger organisations.

The CHAIR — What are the bigger organisations?

Mr WILSON — Latrobe Community Health that Denise was representing this morning. They are quite a large one across the region. The Department of Health and Human Services. HACC services through the local shires is often one that we link families in with and other disability providers as well. There is Yooralla, Scope, quite a broad range in the Gippsland region.

The CHAIR — You mentioned the recreational activities that you have available, what is the sense that you have of children and people with ASD accessing those recreation facilities in the community and what do you think the community response is to people with ASD out in the community?

Mr WILSON — It is quite diverse the response that we get. For example, we engage with a lot of smaller providers like local gymnastics, indoor play centres, a music group or a singing group, those sorts of things. We try linking with community-based activities and events and often if a provider or individual hasn't had any exposure to people with disabilities, including ASD, often we do find that they might be a bit reluctant to receive a group or have a group attend their venue, but then they see that these kids are just kids, they want to have a good time, they want to be involved in their local community and it is often a real eye opener for those that are in the community giving them a bit of exposure to people with disabilities and they are so encouraging. They often — they want our groups to come back again and again once we have been once, which is really positive.

We still hear of families and participants experiencing discrimination in the community, which is unfortunate, but I do believe that is shifting. I think there is a greater acceptance for people with disabilities now, which is obviously a great thing. So I think it's definitely improving but there are still people out there that have experienced discrimination because they have a disability.

The CHAIR — So would you have any advice for the Committee on how the Gippsland community spaces, activities, and events could be made more autism friendly?

Mr WILSON — Often — again, it depends on the individual, I think. When we are talking about autism we are talking about such a diverse range of people. I think it's really just about having the community — having an accepting community and a community that's open and welcoming to people with disabilities and ASD. We've got great facilities in the Latrobe region and other regions across Gippsland. There is accessible playgrounds in terms of accessible toilets and bathrooms and all that sort of thing are really, really good. There is obviously room for improvement in different areas but, I think, overall it is quite good. In terms of improving access for people with ASD, I think it’s really around the community's awareness of ASD. As I mentioned before a lot of people just haven't had exposure to people with disabilities and ASD, so just increasing those opportunities for those community members.

The CHAIR — So you mentioned your waiting list again, I'm just curious about — in your submission you gave us a case study, which was quite distressing I have to say. How many clients, would you think, based on your wait list, would be facing similar situations to the grandmother who was mentioned in your submission?

Mr WILSON — Okay. I would say percentage-wise it is probably a lower percentage. I would probably be talking; this would be at a guess, maybe 5% to 10% of families that are registered with us. We provide support to 223 families actively. A lot of those families are still waiting for more comprehensive support. So they might be accessing a program through us and maybe another small program through another agency but they could be sitting on the wait list for the Department of Health and Human Services for potentially an $80,000 or $100,000 package. So we are not fully meeting the needs of a lot of families that are actively accessing a support through us.

The CHAIR — How many of those clients you mentioned, including the ones in your submission, are likely to qualify for the NDIS?

Mr WILSON — I would say a very large percentage. I'm also hoping a very large percentage. I guess our concern is those that have lower support needs may miss out. So those, for example, that are high functioning autism, they may miss out on supports under NDIS. I guess that's our main concern. We're hoping that those with more severe disabilities and more higher support needs, that they will definitely be eligible under NDIS and they will get the supports that they need. It is those that are higher functioning and require less support that may miss out.

The CHAIR — Do you have a view on whether the service providers in Gippsland will be able to meet the needs of the NDIS-approved clients in this region?

Mr WILSON — I think they will. I think they will. I think the biggest struggle from what we are hearing is staffing, so it is getting the support staff on the ground, getting the coordinators, the assessment staff, it is getting them on board and into the disability sector that will be the biggest struggle. In terms of what Interchange is doing, we've been quite proactive in the lead-up to NDIS so we are communicating a lot with our families about what NDIS will look like for them, the changes that may take effect, and we are also working hard to engage with local training providers, universities, to get more staff on board.

The CHAIR — Schools, you involved with schools?

Mr WILSON — We are involved with schools. We are quite fortunate two of our group-based programs, which is for the 14-17-year olds, we utilise teenage volunteers on those programs.

The CHAIR — I was going to ask you about your volunteers, just while I'm thinking of it; do they have checks — police checks, working with children checks?

Mr WILSON — Yes.

The CHAIR — The age group of volunteers is clearly quite broad.

Mr WILSON — Yep, quite a broad age group. In terms of age range for our volunteers, our youngest volunteers start from the age of 14. So our teenage volunteers, basically they're there for peer support and to act as good role models on our activities. So they encourage involvement. They are there to be a supporting buddy.

The CHAIR — And they are recruited from the schools?

Mr WILSON — Recruited through the schools, yes. Our oldest volunteer at the present time, I believe she is in her mid-70s. Quite a broad age group. We have very comprehensive screening for all our volunteers. So, for example, every adult volunteer has to go through an interview process, three ref checks, they have to have a police check run, volunteer working with children's check. It is very comprehensive in terms of the screening and same for the teenage volunteers as well. We get them in for interview, comprehensive induction and reference checks.

The CHAIR — Fantastic.

Ms COUZENS — Thanks for coming today. Just on that, with the volunteers, what sort of qualifications do they have to have specific skills when they're selected to volunteer or do you develop those skills and do they go through a training program? Can you just expand on that a little bit?

Mr WILSON — The volunteers that are involved with Interchange don't have to have any particular skills. Basically, what we ask is that they're motivated and keen to give things a try. Anyone with the right personality, you can teach them the skills and knowledge they need to know to volunteer in the sector but they've got to have the right personality. They have to be willing to give things a try, be inclusive and be fun to be around as well. It's all about these guys having fun.

Ms COUZENS — If they don't meet that do you then say to them, "You can't continue."?

Mr WILSON — We have, on occasion, yes. In terms of our training programs, we have very comprehensive induction processes, ongoing support and training while volunteers continue to be involved with us as well. A lot of our volunteers do access accredited training, particularly with the one-on-one support which is our host program. That's where a volunteer volunteers to support a child with a disability one-on-one. Often if the child has a particular disability or a particular support that that volunteer needs to have awareness around we will make sure that volunteer gets appropriate training in that area.

Ms COUZENS — In terms of the recreational program, you mentioned earlier gymnastics and singing and those sorts things, I am just wondering whether you link into the sporting clubs like the footy club or the cricket club, performing arts, that sort of thing?

Mr WILSON — We definitely do. We have been really lucky to partner on a couple of occasions with GippSport. They have a very inclusive disability program that they run. So we have had guys involved in mixed netball, football, on occasions street soccer. We link in with the local clubs. A couple of the participants that we are involved with are very keen AFL supporters, both in the AFL league and locally with the local clubs and they are heavily involved in those clubs as well. That is really positive to see too.

Ms COUZENS — In your submission you talk about a high percentage of Aboriginal people, around 12%.

Mr WILSON — Yes.

Ms COUZENS— I suppose, how can people with ASD be supported, particularly the Aboriginal people that you refer to in your submission?

Mr WILSON — With the Aboriginal community what we have found, is it's slowly, slowly. You have to build relationships and trust with the community first before you can start to talk about services and put supports in place. So one way that we've been able to do that is each year we have an annual family camp for Aboriginal families that have a child with a disability. It is a chance for those families to get together for a fun weekend away and through that camp it is a great opportunity for us to build relationships with those families and towards the end of each of those camps we have an information session, we have a forum where we will have providers come in and talk about their supports and services and any family that wants to link in with appropriate supports and services, we will make those pathways for them. We will link them in where they need to be linked in.

Ms COUZENS — What do you think Government can do to improve that support?

Mr WILSON — I think it would probably come down to the appropriate allocation of funding for organisations to be able to dedicate their time to working with the Aboriginal community. Often with the mainstream community we can meet with a family, attend their house for an assessment meetings, discuss supports that can be offered in the community or that we can support with and we can link them in with those supports straightaway. Often with the Aboriginal community we might have to meet with a family three or four times to develop a relationship before we will even start talking about what supports and services that we can link them in with or that is available to them.

Ms COUZENS — Do you think it would be useful for the Aboriginal community to have their own skilled Aboriginal workers?

Mr WILSON — I think so. Look, I think so.

Ms COUZENS — Does that happen now? Are there any Aboriginal people working in that field?

Mr WILSON — Not specifically with us, unfortunately. We have tried engaging with the Aboriginal community to employ Aboriginal staff but haven't had any success yet. It is something that we will keep trying to do. There are a few Aboriginal-specific organisations in the region that do provide disability support services and often...

The CHAIR — Do you know what they are?

Mr WILSON — GEGAC, Gippsland and East Gippsland Aboriginal Co-Op. They primarily work across Wellington and East Gippsland shires, but they do cover the broader Gippsland region as well. Often we work very closely with GEGAC when working with the Aboriginal community as well. Often GEGAC already have an established relationship with a lot of the families we support so it might mean our worker will do a joint visit with a worker from GEGAC because then the family has got a familiar face coming in the door and it is a way to assist in building trust.

Ms COUZENS — Does that worker have any cultural awareness training?

Mr WILSON — Yes, definitely. All of our staff that work with the Aboriginal community have undergone Aboriginal cultural awareness training. It is something that we are very big on promoting and encouraging our staff to attend.

Ms COUZENS — Thank you.

The CHAIR — Do you think there are different needs within the Indigenous community when it comes to ASD?

Mr WILSON — I think there is. I think a lot of it does — it's probably — with the Aboriginal community we found a lot of families that we do support and work with, they're not aware of services that are available to them. Often they are not aware that they are entitled to particular services or supports.

The CHAIR — Do they understand autism and the co-morbidities that might go with that in terms of understanding...?

Mr WILSON — Some families yes, other families no. But I could probably make that statement for the mainstream community as well.

The CHAIR — Yes.

Mr WILSON — So it really comes down to individual family I would say. Yes.

The CHAIR — I have no more questions but thank you very much for your contribution to our hearing today. It is much appreciated.

Mr WILSON — Thank you for the opportunity.

Witness withdrew.