TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 21 November 2016

Members

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Witnesses

Ms Julie Langdon, chief executive officer, and

Ms Nga Do, family and volunteer match and program coordinator, Extended Families Australia.

The CHAIR — Can I welcome Julie Langdon, CEO, and Ms Nga Do, family and volunteer match and program coordinator, from Extended Families Australia. Thank you very much 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. Once again, thank you very much for coming along today. I will hand over to you for a 15-minute presentation.

Visual presentation.

Ms LANGDON — Thank you for the opportunity to come and present. It is good to be able to explore things in further detail. Extended Families is a not-for-profit organisation. We provide support, respite and significant social relationships and community participation for children with disabilities and their families, and we do that right across the broader Melbourne area. Our vision is for a society where children and young people with a disability experience full community inclusion and participation and their families are strong, resilient and connected.

You will have read in our submission that we support children and young people to feel valued, to develop their potential and to fully participate. We really focus on building strengths and skills and connections for children and families with the volunteers and with each other in the community. It really is about connecting people that is the biggest aspect of what we do.

In our programs we provide a range of services. We started off as the Foster Grandparent Scheme nearly 30 years ago in institutions where our volunteers were going into institutions and really would build connections and relationships. Obviously as social policies change, we are really supporting families at home in the community. So we started off with that volunteer program, and from there, whilst that is still the heart of it, we do have a range of other programs as well.

Obviously with the rollout of the NDIS we have been looking at what we do and how it gives us more flexibility about how we do it. We plan to take our key volunteer match program and do a similar thing with paid staff, called LinC. That is important because we actually have around 500 children waiting for a volunteer. I mean the sort of numbers that we can never manage, either with resources or perhaps even finding the volunteers. We want to take a successful community model, a relationship-based model, that can really help strengthen and support people to access the community and to build skills.

We have a range of recreation programs. We started doing some Come & Try days and we extended that into programs that we have named in different ways — Explorer days and Extendable. We also have some friendship groups. Friendship groups are particularly in the Vietnamese community and they have come out of a real response from that community about wanting time together in a supported environment. So we have one in the south and one in the west. Nga runs the one in the west.

We also run a series of playgroups. A number of years ago, probably about six years ago, we started looking at the parent support aspect and we were successful in getting a couple of MyTime groups. We always planned to have — I think at the same time with one of those Vietnamese — other non-culturally specific groups, that really just did not take off. It was really hard, with the amount of time needed to get people together and to build it up. So the Vietnamese community again have embraced the group model, so we have a MyTime group in the south and one in the west.

We are also funded under Play Connect for an autism-specific playgroup, which again has been highly successful. Unfortunately when the federal government reviewed their funding and decreased funding, our group was cut in terms of funding, despite having a particular audience. In fact it was probably why it was cut, because they felt that there were other groups nearby that people could go to. But the reality of having a language and culturally specific group is really paramount. We have continued to run that group and to integrate it into our other core services. And we have obviously started to roll out a series of NDIS programs and support coordination.

The ‘involve’ program that is down there is aspirational at this stage, and I was reflecting as I was listening to your last speaker that it is about helping people with a disability to be volunteers themselves and to have a meaningful volunteering role. I think that is really crucial. We sometimes get people with autism, as we have recently, approach us about being a volunteer, and we are quite flexible about who can be a volunteer, but it still is an alone, responsible role and as we move further into an economy with the NDIS it is difficult to match without there needing to be a number of supports to overcome barriers and to assist them in that role.

As I have said in our submission, children with autism make up about 60 per cent of our client base. So I really wanted to address a few things today that I thought would be useful to reflect on further. One of them is about useful service models. I want to bring to light perhaps the outcomes and issues for people with an ASD in services and bringing Nga along to highlight some of the culturally and linguistically diverse work and reflect on what is needed for these communities. I know that the committee was particularly interested in that. I also would like to just reflect briefly on the strengths and risks of the NDIS, which I think is paramount ahead of us.

I have talked a bit about our volunteer match model that has been really effective in helping people have relationships and in the context of those relationships developing skills, confidence and self-esteem. I thought I would just briefly tell you a little bit about Adam. It was back in 2010 that we had a pilot which we called Sporting Mates and we were trying to explore volunteers having a more active role in the linking, integration and participation of people in mainstream sport and recreation. Whilst this is an old story, and I have actually got a DVD of Adam's story I can give you too, I just thought it would be useful to reflect on that because we have had a long relationship with him.

Adam was matched to Jake, who was one of our volunteers. He did that when he was 13. Adam has autism and ADHD, so at the time of his involvement he was trying to adjust to a first year in a specialist high school for children with autism spectrum after his mainstream primary school advised that he would not do well academically and he should go to that school. He really found that difficult and that was reflected in his behaviour, which escalated, and his feelings about himself and his self-esteem. Under the project and being linked with Jake, he was able to develop his basketball skills so that his membership with local mainstream basketball was strengthened. Up until this time he had been spending minimal time on the court and was not fully included in the team he was assigned to.

Over a period of six months Jake really worked with him and the coach and things were really significantly achieved until he was shooting goals and doing well. So his physical abilities were achieved, but it was his social abilities that were also really strengthened through that. We helped the coach to understand his disability and how to give instructions. Adam's skills grew and he grew in confidence. He is a key player. He has gone on to win an award, which is hanging around his neck there. The formal relationship finished but continues to this day with a friendship about going to the footy and seeing Adam play basketball.

During this time he was transitioned to a mainstream school because of the issues with the specialist school, and one of the things that his increased basketball skills gave him was a point of contact with other children in the playground. Adam could play basketball. His mum speaks with tears in her eyes about the first invitation to a birthday party that she had had for Adam and which she puts down to what she calls the 'gold' of this relationship that is about his confidence and his skills. After some time Adam decided he wanted to help other children learn basketball, so we had what we called a small together group with another child and some older volunteer males. He did that for a while, and that group then continued as a friendship group. He won the all-abilities athlete of the year in 2011. Interestingly he has just continued to progress. He is now driving a car and has continued to progress, and that relationship remains important.

I wanted to move on and talk about our work with the culturally and linguistically diverse community. We do extensive work with both Vietnamese and Chinese communities, plus a range of other communities, but they are the communities we have employed specific workers for. We know that people feel under-confident in managing their child, especially when out in the community, and that often means that they do not go out alone; thus their interest in the group activities that we have.

I think the issues for CALD communities are the same as for everyone else, but I think they are just enhanced. It is plus plus. With ASD we already know that there are factors that create isolation. I think these are enhanced when you bring in the overlay of language and culture, and similarly finding supports around behaviour, self-worth and belonging. I have brought Nga along to gain further insight into the issues for our Vietnamese families. Certainly our anecdotal evidence suggests that there seems to be a high prevalence, but it is only our anecdotal evidence within the families that we are working with. In addition to her work with Extended Families, Nga has also been facilitating a group that is set up called the Vietnamese Families With Special

Needs Inc. We have had an ongoing relationship with them, but in the absence of them being able to find other funding, extended families has stepped up in terms of funding for Nga's role to continue to support that group, and we will build on our partnership. We have been helping them to try and source other funding for that group to continue.

Nga is a passionate advocate for her community, and particularly for children with disabilities and their families. I thought I would mention that she was also the recipient of the Excellence in Social and Cultural Access Award at the Victorian Disability Awards this year. So Nga, if you could tell us a little bit about what it is like for Vietnamese families who have a child with a disability. What is their experience?

Ms DO — I think the first thing is that when the parents just notice that their children have abnormal behaviour they are very worried, confused and lost. Then after they went to the doctor and then had been diagnosed with autism they feel very sad and hopeless. After that I know that the doctor refers them to go to the other services. But when they accept the services, they feel that it is very hard for them with the language barrier, and then it is uncomfortable for them to use the case letter because it is very difficult. It is something they talk about as very sensitive and upsetting, the case letter. I think the other thing that is very hard for the parents is their lack of knowledge about autism. They do not know how to handle the behaviour at home. It is very hard. Many mothers talk to me, crying and then they say, 'I don't know how to manage them'.

Also there is one family that had a boy who came to my playgroup when he was four years old. He seemed to me to be high functioning because he could talk and he understood very well all the instructions to do the activities. But after five years now he is nine years old, and I was assisting them one day and his mum said, 'Look at my house'. All the glasses were everywhere, broken, and then he broke the furniture and all the things, the lights and then the TV — everywhere. His mum said, 'I don't know that it may be one day coming I cannot handle it anymore. I think that maybe I put him in the institution'. When I heard that I feel very sad. Then at school, at her request, they send a psychologist to come to her house to observe and help him. But until now I do not think anything has improved. Then his behaviour was getting worse and worse. Mum said, 'Every day after school when I went to pick him up, I felt anxiety thinking about what could happen when he gets home. Every day is like this'.

Mum living with that, I am very worried about her mental health. The Vietnamese Families With Special Needs group comes every week. They meet and they share experiences. I think it is very good for them to get English language support from the group. The other thing is that they learn from the other mothers about how to manage at home. They share this with the other ladies. She came to the group and she said after, 'It made me feel better, because it is not only my child'. She hopes that her son will improve one day. I worry for the mothers, about their mental health. I think that if they get the right help — if the mother gets very good help for her wellbeing and can be happy, I think it has an effect on the child too. Those stories make me think that workers who work with children with autism must be specially trained to understand how to work with them.

With that boy the council sent a worker to help, to give the mother respite. But one day he stayed and met me, and he said, 'Can you help me with how to deal with him, because I have no idea?'. I asked him, 'What about your training?'. He said, 'I was trained to work in aged care'. That is why he had no idea, no understanding about this boy's behaviour. In this case I believe that people who are interested in working in this field must be trained in how to help them and understand them.

Ms LANGDON — I think coming out of Nga's story, I was asking about the family. They went to a playgroup some time ago and they are still going to the parents group on the Thursday. I said, 'So how did you come to visit Nga?'. It was that the mum had rung and was just so concerned. I think that is what happens. Nga is a leader in the Vietnamese community — an informal leader but a very good one, and people will turn to her. So Nga spends a lot of time on the phone at extended families doing all sorts of things that are not necessarily the volunteer match service or the playgroup that we are funded to do. Those links are so important for the future.

So one of the challenges under the NDIS, which will tighten up the financial aspects of providing services and a business model, will be how some of those things happen and how will they help fund it. On the other hand, it will create a lot of flexibility to create programs and services that are needed to fill those gaps, so that is the exciting thing as we move forward.

I probably need to finish. A few words about NDIS. Many families from a CALD background will need reassurance that the NDIS is a positive service that they can access and the assistance to do so. Our experience of other individualised funding packages, such as the Helping Children with Autism package is that most of our Vietnamese and other families were able to access the package, but what happened was that when something changed in the process, such as a speech therapist left or was not available, they did not end up spending their package or they did not end up getting linked back into the services.

So the good thing about the NDIS is the support coordination role, which will be there to manage crises and to actually help people keep linking in. But we want to make sure that the cultural diversity and language is recognised as one of the issues that triggers that. At first the NDIS was telling us that most people get some support coordination, because they have not got the time to be doing that sort of early work. But as it goes on it will be really important that there is someone to help with those linkages and ideally that that is someone with language and cultural skills — and obviously, good interpreters. One of our Chinese families had a very poor experience of interpreting in an attempt to try and build a plan.

Ms McLEISH — Was that a different dialect? What was the problem?

Ms LANGDON — No, it was just poor interpreting, I think. In the end she talked to our worker, Yoyo, who talked to the planner and we set up another one with a different interpreter. The family said, 'She didn't really say what I was saying or understand fully'. I have not explored the details of that. The mum just kept ringing our worker. I actually cannot tell you whether it was Mandarin or Cantonese that the mum spoke. Yoyo speaks both, and she kept on getting her to ring the planner to try and then explain. So it is good to have interpreters, but there is something there about making sure about the quality. Perhaps it is about not understanding the business or the process or the issues for disability; I am not sure.

Ms McLEISH — But they should translate exactly what is said, so it should not matter.

Ms LANGDON — Exactly. Certainly we embrace the NDIS and its flexibility towards some control for participants, but I think there are a number of significant risks, and one of those is potentially the loss of small organisations that may be the people who are trusted and the link for people within the CALD community, for example. Some service models may not fit well and certainly we are struggling a little to see how to fit our volunteer model, which has really been successful, into the NDIS. I found a pricing guide where it might fit, but it talks about establishing volunteers; it is not about maintaining them. I think the NDIS is seeing volunteers as informal support and does not recognise that there is a whole system of funded support that has to be around that to assess, train and support to ensure safety for very vulnerable people and children with a disability. There really needs to be a process there. So we are still exploring that.

I guess the other side of that is that is if it is not fitting, we are not yet sure how the state government will honour its commitment to continuity of service and whether there will be other ways for services to be funded. We have worked hard in talking to the ILC part of the NDIS and other people. People say it fits somewhere else or it is someone else's responsibility, and it is really not clear. I mean this is just our service but there will be others like that, and that is 200 children and young people matched with volunteers at any one time across the state, and a good percentage of those have autism.

In conclusion, I think there is a greater awareness of ASD in the community, and I think we are really going in the right direction. We need to continue helping the community understand about ASD and be more welcoming and accepting of difference and also to help people with ASD to be more active and valued. That is what we are about.

The CHAIR — Thank you very much, Julie, and thank you, Nga. I have a question about your volunteers. Thank you for the submission, by the way. Do your volunteers have police checks, working with children checks?

Ms LANGDON — Absolutely, yes.

The CHAIR — And they have a training period?

Ms LANGDON — Yes, they do. So we are funded currently under community-based respite from the Department of Health and Human Services, and so we are a registered disability organisation. As part of that we have the three-yearly quality cycle and the mid-year review, so we meet all of those — so certainly all of those checks and balances. I have to say that I think on the spectrum of volunteer assessment, accreditation and training we are right up one end, which is the very thorough end. That is also the other issue about people trying to cut costs to fit under a certain funding model. That will be a challenge in the future to do that. We have face-to-face training and we are now developing an e-learning model that we can continue to cover other things as well as ongoing training that they can come to.

The CHAIR — And is that specific training in special needs?

Ms LANGDON — Yes. And it is hard in one meeting, 4 hours, to cover everything. That is why we are looking at e-learning. But we do cover behavioural aspects and managing behaviour, and some of the ongoing training we always do every year is around developing social skills and managing behaviour and often that does have an ASD focus as we do it.

The CHAIR — So 60 per cent of your clients are on the spectrum?

Ms LANGDON — Yes.

The CHAIR — What percentage are high needs, what percentage are low needs and what percentage are in the middle?

Ms LANGDON — I am sorry. I have not done that analysis, but it would be quite a range.

The CHAIR — Across the spectrum?

Ms LANGDON — Across the spectrum.

The CHAIR — You mentioned the waiting list, 500 on your waiting list. They are from the region that you cover or from across Victoria?

Ms LANGDON — They are across Melbourne. We cover all of Melbourne and the Mornington Peninsula. That is our focus, so that is just within that.

The CHAIR — So that is just in Melbourne and the Mornington Peninsula?

Ms LANGDON — Yes.

The CHAIR — How do you recruit your volunteers?

Ms LANGDON — A range of mechanisms. Increasingly the internet is the no. 1 place that people are coming, so apart from our own website it is through the SEEK volunteering and GoVolunteer, and there are other websites. But also then the local volunteer resource centres, we liaise with them, as well as running particular campaigns. We used to do a lot of libraries and community things. It is very resource intensive and it is not as effective in terms of effort. But there are also a number of volunteer expos where people who are interested in volunteering might go and find out about services, so we do that.

The CHAIR — From your playgroup and from the other services that you offer, including your Vietnamese and Chinese groups, do you do referrals to service providers or support networks or therapists or ASD-specific supports?

Ms LANGDON — Absolutely. We are not funded as case managers, although we actually have started doing some case management, but that is a very specific role in our broad volunteer base role. We are not, but we are always picking up when we take a referral from a family about what services they have and what their needs are, and we would certainly be either referring or providing information to them.

The CHAIR — How do you get a referral from a family?

Ms LANGDON — Interestingly, a lot of our referrals have been self-referrals, so they are word of mouth or people looking up the website and finding that. We also get referrals from other disability service providers, maternal and child health nurses, schools — a range.

The CHAIR — Then you refer on?

Ms LANGDON — Then we would refer it on but try and make sure that they are linked in. Some of them may already be linked in with other services but many are not. Then it is also along the way, as we find needs and issues, that we would link in. I imagine now you would be referring people to other services?

Ms DO — Like health care or caring, yes.

The CHAIR — What about specific autism services like Amaze or any of the peak bodies? Do you refer to those?

Ms DO — Yes.

Ms LANGDON — We do have quite a relationship with them, and we would refer them on. In fact one of the key things we would make sure when families come on that generally they know that the Association for Children with a Disability have changed their name now, and also if they have autism that they know about Amaze and that they are linked there. So we would provide that information initially.

The CHAIR — You are the first group that has presented to the committee that has engaged with the CALD community, so I congratulate you on that. It is obviously a big gap in the system. Do you know of any other groups that work specifically with CALD communities with autism?

Ms LANGDON — Not in a specific sense. You have got ADEC, who obviously are working with multicultural groups and who are working with disability and multicultural aspects, so they are obviously doing something there. But in terms of particularly autism — —

The CHAIR — Your focus on Vietnamese and Chinese is because of the population down on the Mornington Peninsula and across that part of Melbourne?

Ms LANGDON — Yes. We did a project back in 2005 where we focused on the western region. I should say our volunteers are all ages now; they used to be grandparents. It was through the grandparent project. When we looked at the demographics, it changed things a lot for us. There was this population of high need with a high waiting list. But when you looked at the population in places like Melton, the older population was very low, so it changed our demographic for volunteers. But it also started us looking at the Vietnamese community, when we looked at the demographics, saying, ‘What are we doing to really be working and supporting this community?’. So we had a focus group that we set up with the Vietnamese association.

Out of that we then ran a pilot, and we have continued that work. Then, similarly, just through our network and liaison in the east, we were just aware of the Chinese community, and again — it is a bit about being responsive to the research and demographics but also what we are seeing in our day-to-day practice.

Ms McLEISH — I want to follow up on that same theme that Maree just finished on, with the different communities. You talked about the issues with the interpreters and then, Nga, you talked about somebody going to their doctor and trying to seek help. Do you think that within the allied health area there are enough people who speak multiple languages or is it something you always have to rely on, interpreters?

Ms DO — I think that the problem is that when they use translators they feel that they do not really convey their thinking. Yes, they translate, but you lose the feeling, something that you cannot understand. When you are the same culture and the same language, then you can sense that easily. That is why when they know they have an interpreter sometimes they ask me to go along with them, because they know that I understand them.

Ms McLEISH — Do the children tend to speak English?

Ms DO — Yes. It is very hard for the mother at home.

Ms McLEISH — The father and mother.

Ms DO — Yes. At school they speak English and then at home, mum says, ‘I don’t know how to talk with them at home’. They are very worried. They say to me, ‘I can’t speak English with them’. Then when I use Vietnamese with them, it looks like their children do not understand what it means. They feel that it is very hard at home.

Ms McLEISH — It is challenging anyway, when the kids go to school.

Ms DO — That is why usually the kids have challenging behaviour, because of that, mum did not understand.

Ms McLEISH — Have you got an idea about how many of the families that you deal with across your catchment are from culturally diverse backgrounds?

Ms LANGDON — I think I put that in my submission.

Ms McLEISH — It is in the submission. So there are Vietnamese and Chinese. Are there any others?

Ms LANGDON — There is a whole cross-section of cultures. We seem to be finding that there are more African families that we are working with in the outer south area, in Dandenong — out that way. We are very aware of the Turkish and other cultures in the north. As we move forward with our support coordination, our plan is to engage someone who can really work with that particular Muslim community, really. I think it does make a difference. We did quite a bit of work recently with the Hume-Moreland area, and DHHS gave us some additional funding to do that in the last financial year. One of the things we did was hold a family camp. We had 50 people at that camp, and it was fantastic just to see there was such a mix, such a mix of cultures who are engaging.

Ms McLEISH — Was that a sleepover camp?

Ms LANGDON — It was a sleepover camp.

Ms McLEISH — Whereabouts did you hold it?

Ms LANGDON — We held it at Lady Northcote lodge and we engaged the help of the YMCA to do that. It was only possible because we had that additional funding, but it was fantastic to see those relationships and support. It is one of the things that we really want to do, a fact I did not mention. Our southern Vietnamese groups, the friendship group and the MyTime playgroup, they have held a family camp the last couple of years that we have struggled to pull together. Again it is that sense of connection and belonging. For a number of years now the western-based group, the families with special needs, have held a camp. Nga has run that over a number of years and I have just been helping them get some funding for it. Do you want to say something about that?

Ms DO — Yes, I think it was 2003 when I started to work with the group, and then after that they asked, ‘Can you organise a camp for us?’, so for 10 years, every year, we have had a camp in January, and about 13 families participate.

Ms McLEISH — I guess it is an extension of the camps: what sort of activities do your volunteers do with people with ASD? And that would include probably being on the camps.

Ms LANGDON — Look, it is similar to our other programs. The thing about the volunteer program is that it is flexible enough to meet the child’s and the family’s needs, and it is about what the volunteer can do, so the matching is really crucial in that. Some would be meeting in the family home with the child just in terms of activities, reading and fun and games. The majority would be going out into the community, so they may be pursuing an interest; it may be as simple as going to the park; it may be like Adam, joining a basketball club; or it may be going to the football together, going to hear some music or assisting them at an art class. There is such a wide range of things. Then there are the events that we run, certainly in school holidays and at other times, that people come to to learn an activity, and they seem to embrace it.

The CHAIR — So the school holiday program?

Ms LANGDON — Yes. We run what we have called Come & Try days. It may be about dance or art. We had a fantastic baseball one recently in partnership with a local baseball club in Avondale Heights. It is about people having the opportunity to learn a skill, to break down the barriers that might stop them doing that in the hope that they might join a club or they might gain the confidence to be able to participate in the future. So they are very popular. They are very popular with the Vietnamese community and with children with autism.

Ms McLEISH — So what do clubs need to do to welcome and encourage people to join them?

Ms LANGDON — It is about focusing on inclusion, and you know there are some amazing clubs around. We have done a lot of work with the Lower Plenty Cricket Club; being inclusive is actually in their constitution, and it really comes through in everything they do. We have run special clinics for our children as an initial point. They would then be able to join other clinics and programs that they have. It was baseball, wasn't it?

Ms DO — Yes.

Ms LANGDON — Again, that club is taking a similar role, and they had this day for our children where they put on a sausage sizzle and they taught them the skills. They also had someone from the Paralympics come along and talk to them. There was this sense that people with disability can do sport and engage, so there are some really positive things. Others are not like that, and there is quite a lot of work that I know sport and recreation have tried to do. The Access for All Abilities program, which is no longer funded, was really trying to work with local clubs and groups to actually be inclusive of people with disabilities. So there has been some good work across the board. I am sure there is still a lot more that could be done.

Mr FINN — I too am concerned about the impact of the NDIS in a whole range of areas regarding autism. Have you been given any indication at all as to what those impacts might be? I noticed that in your submission you said that parents are generally confused about what the NDIS has to offer, and I think that is a more than fair observation. I am just wondering if you in your position have had any feedback from the NDIS or any education from people running the show up there in relation to what you can expect?

Ms LANGDON — I think the issues are really the same for everyone in terms of this rapid uptake of the service. I think that the biggest thing is the anxiety about having the supports that you need and being accepted. I think that has probably been higher for some of the families dealing with high-functioning autism — the fear would be that they would not be eligible or that they would not receive the supports that they have had. My understanding is that there are defined supports, so if you have Down syndrome or cerebral palsy, there is a sort of automatic pathway and a certain reasonable bundle that you are seen as being eligible for. I think that is less clear with people on the spectrum, particularly at the higher functioning end. The issue is about how well people advocate. We always know that those who are good advocates are often going to end up with more.

What I understand of the experience is that there has been more uptake in the scheme. I think that in the South Australian pilot, which I understand was for children, those numbers have really been much greater then they predicted, and they are seeing that as being the spectrum people coming into that. So it does seem that people are getting through, and our experience at this stage is still small. We are working in the north-east Melbourne area, and there are 130 people that we are working with in some way in the NEMA. Thirty five of those have had a volunteer match and the others come to the occasional social event. So there are quite a few coming through, and there is a mixed response about the package they have got. Some are really happy. From those, I have not got a sense of the autism — actually I do know that some of those do have autism, and the ones I know of are the ones who have chosen us to do their support coordination. They are certainly getting some therapy support as well as the social and community participation.

Mr FINN — Great. It was mentioned before that there were, I think, 500 on your waiting list.

Ms LANGDON — Yes.

Mr FINN — If you were properly resourced, what could you really do? Just let yourself go for a minute: if you had the resources that you would really like, what would you be able to do and what would those resources be? How much, in other words?

Ms LANGDON — Over 80 per cent of our budget — it is usually around 85 — is staffing costs. That is the biggest thing, because you are needing to put time into all of those recruitment mechanisms and the support mechanisms. My board keep asking me, with the funding we have got, what is the limit? What is the amount of matches we can do for that? It is really hard to define, because once you set up a match, a volunteer match, hopefully a lot of the work is in that set-up and in establishing it, and hopefully it is less as you go along. So it is hard to really define.

If this is what you are asking, if there were another $500 000, we could probably go a long way towards meeting half that waiting list, but there is still the issue of volunteers. I do not think we will ever find the volunteers for all of those on the waiting list. The other thing to say about that waiting list is that they want a service, and what we are trying to help the families who are waiting think through now is: do they really want a volunteer, and what is it about a volunteer that is about a genuine relationship? Someone is there; they are not a paid carer. It is about the genuineness and the authenticity that is really important to these families and to these kids. For some of the families, though, really, they just want a break, and they want someone to help their child to do skills. That is why we have set up the LinC program, because there will be families that will be happy to have a similar model with paid staff, but there will be others who really want that genuine relationship.

Mr FINN — That was my next question, and that is: if you had those resources and you were able to meet that demand, obviously you would continue with the volunteers, but given that you probably would not have the numbers of volunteers that you would like, would you go semiprofessional, as it were?

Ms LANGDON — I guess we have already made that decision to do both, because then we are at least offering a service that is meeting some of the needs, if not all. For some it may. Again, it is then about who the staff member is, what their commitment is to continuing and what their skill base is. That is the real challenge with the NDIS that was highlighted in our case: where are we going to find all these staff? But it is also about the training and support. So if a child's worker had an aged-care background, it is about making sure that there is the right training. So I think you need both. I think you need the paid staff that have had good training and skills but also the volunteers that we are bringing into that.

Mr FINN — Thanks, Julie. Nga, what is the prevalence of autism in the Vietnamese community in comparison to the rest of the community? Is it a greater rate of autism, or what is the general view there?

Ms DO — A little bit. In my group we have 70 member families, and I think 50 families have a child with autism. The rest are just with Down syndrome or cerebral palsy, but I think there are a few families. The parents ask me when they grew up in Vietnam they did not see many children with autism like this in Vietnam, so why are too many here? Because when they are out they see that around them.

Many families today know they have a child with autism too, but they do not want to disclose it because they are ashamed. Then I say at the moment I think in Vietnam they increased already; they know that. But it is just because of information — you know, here everybody can listen to the radio and can have much information to know that. But in Vietnam they did not know that. Why in here? The same, I think, that in Vietnam they have children with autism and in here too, and then some of the parents bring their child back to Vietnam and stay for a few months. They hope that their child can speak, because there is only one language around them everywhere, and the neighbours. Then after a few months, when their child starts to talk, yes, that is when they talk to the other mums and say it looks like the model, that when the child was still very young they went to stay in Vietnam for a while with the family around them, the relatives, and then when the child improved in the language, then they bring them back here.

Mr FINN — Are families in the Vietnamese community able to access easily early intervention services, and do they do so?

Ms DO — Yes, I think at the moment, yes. But before I started to work — I mean 10 years ago — when the migrant resource centre did the research they found out that many Vietnamese families who had children with a disability did not use any disability services, but very few — just a few families — and then they did this research.

Then I started to work on a one-year contract to help them to know about disability services around them to help them in their life to make it better. Then after 10 years now it ended up with this generation, the young mothers, they know and then they access the disability services easily if they can speak English, but with the others if they cannot speak English, when they ring up and they need to say something in English, they worry and they are scared and then they hang up the phone. Sometimes they ask me to phone on behalf of them to access the service. Then I think when I encourage them to use the service they say if there was not a Vietnamese worker, how could they talk with them about their children's needs or their children's behaviour or discuss with them something like this. That is why if they have a Vietnamese worker, they are happy, but not others. They say, 'I do not know how to help the children if I cannot discuss it with the staff'.

The CHAIR — Are many of your volunteers also acting as advocates, particularly with the NDIS rollout?

Ms LANGDON — No, not with the NDIS rollout. I think they are often a support to people and to parents, and often their relationship with the parents is as important to the family as the child. I am not aware of them taking that role, and we have not encouraged them to do that.

The CHAIR — So it is more about going out and doing different activities.

Ms LANGDON — Yes.

The CHAIR — Rather than actually assisting with paperwork or anything like that.

Ms LANGDON — I would not be surprised if some of that happened. We have certainly encouraged our volunteers to refer it back to us, but I think that for some they are certainly a support. You know, they are a debrief, someone who actually understands and cares for the child. I am not aware of them taking on that role, but it is a really important one. It is a role that we have talked about for the Vietnamese families, that is, having someone — whether it be a volunteer or a peer volunteer — who can help them with that. It is a really big issue, and I think that even within the group that Nga is talking about, some of that support happens. With the committee for that group we have talked about actually trying to set up a peer support program for new people coming into the group or with a new diagnosis so they can really help them do those sorts of things in terms of supporting them to access services.

The CHAIR — Do you find with the children who have been linked up with a support person volunteer from a younger age that they have more success? Like, is there a clear delineation between having that early support and perhaps finding work or employment later in life, or pursuing further education et cetera?

Ms LANGDON — It would be great to do some research on that. I have some anecdotal evidence up, but I know that a number of people that are no longer part of the program but still see their volunteers, so they still have that relationship as they go into life, and that is an important one. I have got case studies about people like Adam, who has certainly gained out of that, but it would be fantastic just to do some research to look at the impact or what has been important for these families.

The CHAIR — How long have you been running for?

Ms LANGDON — About 28 years.

The CHAIR — So quite a lot of young children would have gone through.

Ms LANGDON — And some of that was when they were in the institution, so we could start off there and then change. I think it is a really important piece of work. We did do some evaluation of our pilot Live Your Community program. We had a little pilot, which we did with Banyule council as a really small pilot, which we called Sporting Mates, and then through the group of local councils we managed to get some sport and recreation funding for this bigger pilot. We did evaluate that, but it was only really in the context of shortly after that, so we do not have the longitudinal studies around the impact; but certainly there is some impact around increases in confidence and skills.

The CHAIR — And similarly I would say that you probably do not have the information about how the benefits have assisted not just the people with autism specifically, who we are focused on, but how they have actually improved in terms of their capabilities within the community. So your volunteers who have a lot of experience over time would be able to perhaps give you that evidence, but clearly you have not got that.

Ms LANGDON — We get feedback. Again it is more case based, so we have feedback from people about outcomes for them and outcomes over time, but we have not done that yet or pulled that together, apart from looking at individual outcomes.

The CHAIR — Thank you very much. We have no more questions, so thank you for coming along today, and good luck with everything.

Ms LANGDON — Thank you.

Witnesses withdrew.