

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Geelong — 19 September 2016

Members

Ms Maree Edwards — Chair

Ms Cindy McLeish — Deputy Chair

Ms Chris Couzens

Mr Paul Edbrooke

Mr Bernie Finn

Ms Emma Kealy

Staff

Executive officer: Dr Greg Gardiner

Witnesses

Ms Lisa Hamling, facilitator, and

Ms Michelle Anderson, facilitator, Pink Musketeers, the Treehouse.

The CHAIR — I welcome both Lisa and Michelle to our public hearing this afternoon. You are representing Treehouse. 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. You would think that I would know that off by heart by now, but I do not. Can I invite you to make a presentation to the committee. Thank you.

Ms HAMLING — Sure. The Treehouse Geelong is a non-profit organisation group auspiced by YMCA Geelong. Treehouse was established in 2008 by parents wanting to acknowledge and act upon the need for a local whole-family friendship and support network for children with families with ASD. What makes us unique is all our groups are run by families living with autism for families with autism, so we understand the extreme loneliness, frustration and isolation that families can experience on a daily basis. The Treehouse offers support groups, social groups, family fun days, trampoline days and much more. We offer support, empathy and friendship for all family members. Friendships between like-minded parents can be invaluable, whether it be working through a diagnosis or issues that arise throughout the ASD journey.

We are a volunteer-run organisation, run by parents with children with Asperger's or people with Asperger's themselves. Our volunteers work thousands of unpaid hours to meet the needs of our 600-plus Geelong-based families. To fund our programs we rely on grants, donations and fundraisers to enable us to provide a service to all of these families. With better funding, the Treehouse would have a huge scope to expand its services not only for Geelong but to regional Victoria.

Being a small volunteer-run service, the Treehouse receives daily referrals directly from the NDIS, Gateways, headspace and various healthcare providers, such as paediatricians. This demonstrates our relevance and standing in the Geelong region, or more importantly, this demonstrates the need for what we are providing.

Our aim is to provide opportunities for people to talk to someone who gets it. When talking to a parent who is going through the same thing as you, it is a resource of knowledge you can only get from others who have been where you are going. We are not professionals; we are mums and dads.

The groups we have on offer are Pink Musketeers, which is a girls-only group — ASD diagnosis in mainstream school; Clubhouse Kids, which is boys and girls, primary-aged again, mainstream school, ASD diagnosis; Jellybeans, years 6 to 9, girls only; Aspyre, which is a high school group for boys and girls in mainstream; Young Adults, which is an 18-to-30 group for both boys and girls with ASD diagnosis; and Asperger Over 30s women-only group. We have a Lego club, which is open to all ages and all disabilities, a father's social group and a Tuesday morning catch-up — all are welcome to that.

All these groups hold monthly social events and are each run by a different facilitator who makes up their monthly events. Our groups are needs based but also limited by the time our fantastic facilitators can provide. There is much opportunity for growth, which is apparent in the emails received on the Treehouse page.

The Treehouse is in need of its own space. My mission is to lease a house to call home. This would allow us to run all our groups out of there as well as provide more groups. I would love it to be like a drop-in centre with a chill-out room, lending library, sensory toys, weighted blankets et cetera. There could be speech therapy, occupational therapy, psychology in some capacity, as well as training and guest speakers — somewhere for our kids to feel safe and comfortable, a place for friendships, a place of their own.

The two main themes coming from our parents in Geelong are aide funding in mainstream schooling and teacher training. For a child with an IQ under 70, the following services are available through the commonwealth, state and local governments: special schools; free therapy at special schools; if in mainstream schooling, subsidised or completely funded therapy; access to integration aides; and additional funding and support for a variety of aids and therapies, including respite. Although a child with an IQ over 70 does not have the same intellectual learning problems, they still require the same therapy and educational needs. IQ should not be the sole determinant as to whether a child is entitled to government funding and support.

When looking at schooling, all ASD parents are faced with questions for which the answers are more often difficult to answer. Where will my child fit in, and where will they be understood? Where will my child be truly

accepted and cared for? Will he or she be able to go to mainstream school, and will they cope? If they go to a mainstream school, will their needs be met? Which school has the most appropriate resources to best facilitate their learning?

I think the most important question is: can a mainstream school really endeavour to cater for students with ASD? In its current model, no. An ASD child often has a high IQ, but through slow processing speeds and executive functioning problems, when learning in a mainstream environment it is difficult, if not impossible, to reach their full potential.

The classroom environment should be such as to minimise sensory overload. The noise, colours, lighting and classroom configurations can be unbearable to an ASD student, compromising their learning potential and often leading to meltdown. This could lead to defiant behaviour, learning difficulties, being ostracised from their classmates, as well as creating a difficult environment for a teacher to control.

The reality is we are made to deal with a mainstream model catered for neurotypical children. Classrooms are social environments that rely heavily on being able to interact, socialise and communicate with others. This can intensify the anxiety students on the spectrum experience. Research shows the importance of understanding the link between academic and social and emotional wellbeing. Inclusion is about being proactive in identifying the barriers for our ASD kids and then removing those barriers. It is about meeting the needs of all children to ensure they get a quality education.

There are a number of barriers to providing better and appropriate support in the classroom for our ASD kids. These include funding, lack of knowledge and training, lack of specialist support staff and class sizes. It is not enough to give teachers professional development on autism; they need additional help from specialist staff to put adjustments in place in our classrooms.

Having an ASD supplementary curriculum built into the mainstream model would work on building their strengths and skills, communication, interpersonal and social skills, executive functioning, theory of mind, self-regulation, sensory needs and imagination and play.

The playground can be difficult for an ASD child. Lunchtime breaks can be socially confronting and uncomfortable for an ASD child. Having supervised lunchtime activities or access to a sensory room or a nurture room could help reduce anxiety. After coming in from a break, often an ASD child will find it difficult to focus and engage back in the classroom structure.

ASD children are getting excluded from school because of their behavioural needs, while other children refuse to go to school. Often ASD children are seen as poorly behaved or troublemakers. Better education would show that often the child is easily led or is acting out sensory overload.

Our ASD children have amazing skills and talents that need adequate nurturing. As parents, we can only hope for our child to grow up happy, confident and independent regardless of a diagnosis. With additional support, our kids will grow up to reach their full potential, being able to engage in society with meaningful relationships, raising a family and having employment options. Without this support they could be left behind. They may become isolated from society, be unable to interact with others and not be able to gain employment or care for themselves independently.

In our experience, the NDIS has a positive impact on encouraging and funding social activity and community participation options for people with autism. At present, it is difficult to access NDIS-funded therapy in school environments because of the separation of what is NDIS-funded and what is defined as state education responsibilities. Do you want to add a little bit there, Michelle?

Ms ANDERSON — Just briefly, why I am here: I am actually one of the facilitators. I run the Pink Musketeers, which is the group for primary school-aged girls, prep to grade 6. I really am concentrating at the moment — it is such a hot topic — on girls, and the real awareness that amazingly is coming out from lots of different people on how different girls are, how differently they are approached, how different their diagnoses are and where that is all going. That is why the Treehouse does see the need for having girl-specific groups as well, so we run the girl groups for the primary and for the teenagers too.

The CHAIR — Thank you very much. What are the ages that you cover? So that is primary right through to — —

Ms HAMLING — Right through to 30 plus.

Ms ANDERSON — I have four-year-olds in my group. We go from about 4 to 30.

The CHAIR — And what is the breakdown between the percentage of boys and girls?

Ms ANDERSON — In our groups?

The CHAIR — Across the groups over all?

Ms HAMLING — We have got our two girls only, but in our mixed ones — —

Ms ANDERSON — Which does change the dynamics.

Ms HAMLING — Yes, it does change the dynamics.

The CHAIR — So would there be more girls than boys within your whole Treehouse organisation?

Ms McLEISH — For 600 families?

Ms ANDERSON — If you look at the families that are a part of the Treehouse community, I would say no, there would not be more girls.

The CHAIR — There would not be?

Ms HAMLING — No, I do not think so. If you look at our family fun day — —

Ms ANDERSON — There would still probably be less girls than boys.

The CHAIR — Speaking of the girls in your groups — the Pink Musketeers and the Jellybeans I think you mentioned — we have heard a lot previously in other public hearings about the difficulty that girls diagnosed with autism or ASD have. What is your experience of the challenges that are faced by girls and women as opposed to boys and men?

Ms ANDERSON — They say that girls really present differently to boys, and because they present quite differently, they are generally diagnosed a lot later. They do not really fit within the guidelines of the diagnosis as it was created, because it was created so long ago in a time when it really was predominantly a male diagnosis.

The CHAIR — Is there any move to change that? Are the NDIS or the NDIA changing that?

Ms ANDERSON — Not on the high levels, but I think within. I know with my child's diagnosis that it was the speech therapist and the psychologist that did the joint diagnosis, and then that was taken to the paediatrician. I think that your speech therapists and your psychologists and the people further down the line that are actually diagnosing your child have a lot more information now, so they are actually applying their knowledge beyond what is on the paper and adding that in to give you that little bit of a leeway.

The CHAIR — But it is still not really encompassing girls and women?

Ms ANDERSON — No, I do not think so. It is really still largely down to what professional diagnosis your child has. I know especially with a lot of our girls that they have had to go down the diagnosis path two, three, four times before they got that final yes.

Ms HAMLING — And then you are missing that early intervention. A lot of them got it at 10, 11, 12 or 13.

Ms ANDERSON — It is still very common for them to not be diagnosed until they hit to the 10, 11 and 12 mark.

The CHAIR — And then post diagnosis are there challenges in terms of particular therapies that girls or young women might need as opposed to young men and boys?

Ms ANDERSON — I think in terms of the girls they have quite good social imitation skills. Quite often you will hear them being called chameleons, because they can kind of hide their difficulties and hide that they are not understanding and blend in with everything else.

Ms HAMLING — They leave all their behaviours for home.

Ms ANDERSON — Yes, leave all their behaviours for home. They do have a really strong desire, though, to interact and have social connections with other people. They want to be invited to the birthday parties. They want to sit around with friends and have gossip sessions. I think that because they are so socially aware, if they are diagnosed at that later age, they are really resilient. They do not want to have the therapies, and they do not really accept their diagnosis. We find a lot of the time if they are diagnosed at an older age, for a lot of them, a lot of the parents cannot get them into these therapies.

The CHAIR — So what can we do to fix that?

Ms ANDERSON — Earlier diagnosis I think is probably the main thing.

The CHAIR — Do we not need to change the diagnostic approach, though, first?

Ms ANDERSON — Yes, definitely, and then earlier diagnosis.

Ms HAMLING — There is a lot of awareness I think at the moment starting to come out — Tony Attwood and — —

Ms ANDERSON — Definitely. I think we are moving in the right directions of that with the awareness.

The CHAIR — What sort of challenges do they face when it comes to sexual education?

Ms ANDERSON — I am going to let Lisa do that one, because her daughter is approaching puberty.

Ms HAMLING — My daughter is going into high school next year. Can you repeat the question, sorry?

The CHAIR — I am thinking within the family violence realm, and particularly if someone with ASD also might have an intellectual disability or an associated comorbidity. What sort of challenges are out there to allow them to have the proper sexual education to understand respectful relationships and their own bodies?

Ms HAMLING — I know for me personally, going into high school next year with my daughter, I would never have thought of not going to a co-ed school, but we have chosen an all-girl school. I did not think we would be going down that path. It was purely because she is so vulnerable, naive and has very high sensory needs. I know I am very concerned when it comes to the opposite sex that she is going to be safe. I know that, being at an all-girls school, in school hours I am not going to have to worry about that, which was a big thing for me. Yes, they are just so vulnerable and naive, and with those sensory issues it concerns me.

Ms ANDERSON — There are a lot of books available for the girls and for the parents around this topic too, to help with educating them and educating them young. I know our OT suggested when our daughter turned eight that it was now time to start the education in all of those kinds of areas — one, because they are quite inquisitive and they are soaking up information, sometimes a lot earlier than a lot of children their own age. Once they decide they want to start learning about a topic, they need to know everything about that topic, so you can start getting into dangerous territory there.

There are the social skills groups working around the meanings behind people's words. I know for a lot of the girls that they will search out the boys based on, 'Any kind of attention that they are giving me must mean that they like me and I am doing the right thing'. They are very naive in that respect, so I think a lot of work does go in with specialists on teaching the girls what is expected behaviour.

The CHAIR — So you work a lot with teenagers, clearly, across the board?

Ms ANDERSON — Yes, there are a lot of teenagers.

The CHAIR — Social media. I saw you smile. Do you find that teenagers with ASD are engaging in social media? If so, what do we need to be aware of in that space? What are the dangers? Are the dangers the same as for any other teenager, or are there special things we should be considering in that space given the expansion of social media for teenagers in particular with ASD?

Ms ANDERSON — It is a great question.

Ms HAMLING — It is a great question.

Ms ANDERSON — It is something I have not really thought of before really.

Ms HAMLING — To be honest. I run a year 6 to year 9 group, which is only new this year. I do not run the older adults. I have got someone in the audience there behind us that has got one in the young adults; her daughter is 19. She would be great to answer that question.

The CHAIR — I guess the question comes from the fact that many people with ASD love technology.

Ms HAMLING — Hugely.

Ms ANDERSON — Massively.

Ms HAMLING — They live on it.

The CHAIR — And they absolutely spend a lot of time with technology. I am just conscious of the fact that this inquiry is to look at every aspect of life, and that is a big part of our life now and particularly a big part of young people's lives — and will continue to be in the future. I would be interested to hear from that person in the audience. If you would like to stay for our 4 o'clock session, I would love to hear your response.

Ms ANDERSON — Yes. It is definitely something for us to be aware of and to be thinking of too.

Ms HAMLING — Our children are not on Instagram or Facebook.

Ms ANDERSON — We are parents of children that have not hit that social media age yet.

Ms McLEISH — Not wishing to be discriminatory, but I will continue to focus on girls at the moment. You said that because of the different ways girls behave and present themselves and mimic, that their diagnosis does not often happen till later.

Ms HAMLING — Yes.

Ms McLEISH — Given that, with families with girls that get diagnosed at maybe 8 or 10 or 12, what types of early intervention services do they normally seek?

Ms ANDERSON — I know that there are a lot of speech therapists and psychologists that run group sessions with groups of girls, so they do their speech therapy or their psychologist's work with other groups of girls, which can be really helpful to then have other children to play off against.

Ms McLEISH — Other recently diagnosed girls?

Ms ANDERSON — Other recently diagnosed girls, yes. Really it comes down to if you are through the NDIS it is those core things that you have got your funding for — your OT, speech and your psychologist — so that is what you are doing. I know for a lot of the parents that what they are tapping into will be what they have been able to get in their plan. A lot of our girls do have social skills classes in their plan. I think all of them have attended at least a social skills class.

Ms McLEISH — Who would teach a social skills class?

Ms ANDERSON — There are private organisations that teach social skills classes, like Appleseeds. As well as that, they can be run through the therapists.

Ms HAMLING — And private psychologists.

Ms McLEISH — What would be the cost? How many girls would be in those classes, for example?

Ms ANDERSON — These are NDIS funded, but if the NDIS were not funding them, they run upwards of \$2000 or \$3000 for six sessions, so they are really out of reach for anyone who does not have that in their plan.

Ms McLEISH — So how many sessions would you get for that price?

Ms ANDERSON — About six usually, one a week.

Ms McLEISH — For an hour?

Ms ANDERSON — For an hour.

Ms McLEISH — That is rather pricey. You have told us about so many of the different programs that you run, but you do not have your own dedicated space and premises, which you would love to have. How do you do it now? Where do you do it?

Ms HAMLING — We did have a space for five years. It was in Ryrie Street above Bendigo Bank. We never knew who leased it. They just found out about us and gave us the space, and Bendigo Bank did not use it, so we had that for five years, which was fantastic. That has shut down, so it has only been in the last year we have not had a space. We use a lot of different places in the community.

Ms ANDERSON — The library.

Ms McLEISH — Because you are growing, by the sound of it, and you need more programs.

Ms HAMLING — We are. We cannot keep up with the need, to be honest, and it is huge. We also use Wild Rumpus. They are fantastic and let us use their rooms whenever possible. They have got a skills centre, which allows us to do — especially with the younger groups — some life skills things, so cooking, cupcake decorating.

Ms ANDERSON — But they are growing as well, so they have got more and more kids and more and more time slots that they need their space for, so it is a limited amount of time that we can use that space.

Ms HAMLING — That is how we try to work with all of our groups, because life skills are important.

Ms McLEISH — One other thing I want to just ask about: you said that many of the children and adults have got amazing skills and talents. I think those were your words. Do you want to describe some of those amazing skills and talents that you see within the 600 families?

Ms HAMLING — Creativity, definitely.

Ms ANDERSON — Definitely. I know, especially for our girls, it is usually along the lines of animals.

Ms HAMLING — Hugely animals.

Ms ANDERSON — Creativity involving anything art related. We have one young man in the treehouse, Liam, who is quite a prominent artist.

Ms HAMLING — Definitely computers and maths.

The CHAIR — Music?

Ms HAMLING — Yes, definitely. There are a lot of skills.

Ms McLEISH — Are they self-taught musicians, or do they pick up sheet music?

Ms HAMLING — Both.

Ms ANDERSON — I think a lot of the time they are self-taught.

Ms HAMLING — Self-taught by ear.

Ms COUZENS — Do you get any assistance from the council?

Ms HAMLING — No.

Ms COUZENS — Have you requested any assistance from the council?

Ms HAMLING — I have not, no.

Ms COUZENS — I am just thinking in terms of venues and that sort of thing, it might be worth pursuing.

The CHAIR — She is being an advocate for you. She is doing her job.

Ms COUZENS — That is right. I am more than happy to help. Just in terms of education, what is the experience of your members in finding schools that meet the specific needs of your children?

Ms HAMLING — Extremely hard.

Ms ANDERSON — It is really hard. We are dealing with children that are above that 70 IQ, so we have all got children that do not have aides at any point in time in the classroom. A lot of them do need that aide in the classroom. Especially, I think, the Musketeers — I have got the younger ones, our prep and grade 1 students — that have absconded and had quite violent outbreaks from sensory overload. That is all just left to the class teacher to manage alongside everything else that is going on in the classroom, which is quite difficult.

Ms HAMLING — You just see that they never finish tasks. They do not get their work done. They do not finish tasks, so they have not learnt that skill. Then the typical kids are moving on to the next skill, and that skill has not been taught because they did not even finish the task.

Ms ANDERSON — With our girls, they are quite often shy, they are passive and they will be sitting in the corner.

Ms HAMLING — They will not ask for help.

Ms ANDERSON — They will not ask for help. They will look like they are doing their work, but at the end of the session the teacher might go up and find that they have not done a single thing for the entire time, so quite often that leads to them really falling behind in their education too.

Ms COUZENS — Do you think there is a need for a specific school to cater for kids with autism, or do you think using and adapting mainstream schools to support children — —

Ms ANDERSON — That is a really good question. I think there is definitely a need for one if not both of those things. Depending on who you talk to you will get different opinions on the autism-specific schools. Some people will say that it is better off that they are still in the mainstream but supported in the mainstream because they are going to have to transition into mainstream at the end of their schooling and that makes that a little bit easier. What do you think?

Ms HAMLING — It is a tough one, exactly like you said. But then if you had a separate school, you had specifically trained staff, you had your sensory rooms, you did not do as much of the curriculum that did not need to be done, you had regular breaks and — —

Ms COUZENS — Could you see that in mainstream school, though?

Ms ANDERSON — No, and I think that is what it comes down to.

Ms COUZENS — That is where it gets tricky.

Ms ANDERSON — I cannot see every government school in Geelong being able to do that or how it would be policed.

Ms COUZENS — Do you think they could do it with the right resources and support though? Do you think it is possible? Let us say everything is there, whatever you want.

Ms ANDERSON — Yes, definitely. I think if every teacher was trained to be able to recognise and deal with all of the things that were going on in the classroom, if they all had support, if there was someone else in the classroom to support them and if these students had safe zones within the school that they could go to, then it would definitely work.

Ms HAMLING — And just keeping in touch with Mum and Dad. It is pretty important.

Ms ANDERSON — I would love to see speech therapists and occupational therapists being able to go into school. That is something that NDIS blocks, so that can be quite difficult.

Ms COUZENS — Yes, that has come up today and has been contradicted as well, but anyway.

Ms HAMLING — It is a massive issue. I have heard a couple of people say that when you are going in for your planning session it is important to know the right words to use. It can affect your outcome — how much you get, monetarily. They were saying that if you know the system, you will get a good plan. If you do not know the system — —

Ms ANDERSON — You have to be the kind of person that will go in and push and push and push, and so many parents are not like that.

Ms HAMLING — They are not able to do that, which is sad.

Ms ANDERSON — They are not comfortable going in and sitting in on their planning session and pushing for the most that they can get.

Ms HAMLING — I have had parents at our school say it is like going through a diagnosis again. They have gone and done it part way, and then they will not even go through the process because it is too taxing.

Ms COUZENS — We know in a number of schools that children with autism are often sent home for half the day. There are all those issues around that. Have you got any ideas on how we might address that? I suppose it comes back to resources and what support is there.

Ms HAMLING — That is really tough again. I do not know if Michelle has got a younger — —

Ms ANDERSON — Quite often the children are at that point because they have been so sensory overloaded in class that they cannot be there for longer than that period. A lot of the time that will be to do with how the classroom is set up. A lot of classrooms in our schools are open plan now, so there are no walls between the classes. That makes classrooms a lot noisier. Tony Attwood, one of the leading experts at the moment, says that the original system that we had where every child sat at their individual desk looking towards the front of the classroom is perfect for the ASD kids. Not so much for a lot of the NT kids.

The CHAIR — That is an interesting comment. We just visited a school this morning that had that very set-up because that is what the kids actually wanted.

Ms ANDERSON — It is what they need.

Ms HAMLING — Not group desks and open plan.

The CHAIR — They have just shifted from that.

Ms HAMLING — And how much they have got on the walls these days and hanging from the ceiling and all their artwork, whereas there is just nothing.

Ms ANDERSON — I know the junior classrooms are just covered in bits hanging and moving in the breeze, and colours. Just sitting in that classroom without even having to do any work for half a day is enough for a lot of them to have absolutely had it and not be able to be in there any longer. There are a few good schools in Geelong that do have sensory break rooms where students can go and have some downtime. Not all have them though. My daughter's school does not have anything like that. Something like that in all schools at the very least would be an amazing thing.

Ms COUZENS — One last question: what kinds of support do you think adult people with ASD need? That is a hard one.

Ms HAMLING — It is, because we are both at this end. Not that you do not think about that, but you are just not at that experience yet. Definitely Sarah, who has a 19-year-old, will be able to give some answers about that. One thing that I have talked about with her recently that I am sure she will expand on is to do with when they become an adult — and her daughter recently had an event at a hospital — they are put in an adult hospital ward and treated like an adult. There is definitely a lot more that needs to be done there.

The CHAIR — I am mindful of the time and that we actually have a person with ASD presenting to the committee next, so I might wind it up there and thank you again for your presentation this afternoon. I wish you had put in a submission. I am sure if you want to, we could perhaps make an exception for accepting a late submission. We have only really just touched the very tip of what you guys are doing, and it is really interesting and informative. Have a think about that. Thank you very much again.

Witnesses withdrew.