TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Morwell — 5 December 2016

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Witnesses

Ms Tona O'Connor,
Ms Michelle Hackett, and
Ms Natalie Owens, South Gippsland Autism Action Group

The CHAIR — The Committee calls Ms Tona O'Connor, Ms Michelle Hackett and Ms Natalie Owens. Welcome to our public hearing today Ms Tona O'Connor, Ms Michelle Hackett and Ms Natalie Owens from South Gippsland Autism Action Group. Thank you very much for attending today.

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

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

I invite you now to make a short presentation to the Committee.

Were you planning to read this?

Ms O'CONNOR — Yes.

The CHAIR — We only have 15 minutes of presentation.

Ms OWENS — We are grateful that you are hearing our cries for help today regarding our desperate need for our children's right to a fair and equitable education. We would just like to quickly introduce ourselves and tell you a bit about our situations.

I'm Natalie. I have a son, Caelan, who is struggling in school. He is increasingly becoming unable to cope at all. He lashes out and hurts others, swears, and throws things, because he is at such a loss. He needs constant breaks and spends a lot of time in his "calm down spot", which is placed under a teacher's desk because they are unable to provide him a sensory room or calming area. It has been a constant fight with the school on how to deal with this behaviour. Past reactions have been expulsions, behaviour contracts and punishments. Caelan is a target of bullies due to his "unusual" behaviour.

He is a danger to himself and others. He has threatened suicide in the school yard, surround by peers, by holding sticks to his neck. At home he has held knives to his throat. Upon psychologists' advice, we have had to remove all sharp objects from his reach. This is his way of saying how bad things are for him. He has no other way to express it.

We need to be available, as a parent, at all times to pick him up if the school feels he isn't coping or if he has severe meltdowns.

I am often approached by other parents who are disgusted by my child's behaviour as when he isn't coping he lashes out and can hurt others. The two most recent incidents involving Caelan are the stabbing a child with a pencil (requiring medical attention to remove the lead) and smashing a child's glasses. In both cases parents of these children made formal complaints. One of the relief teachers at Caelan's school will no longer take his class as she is fearful of him.

Caelan is on reduced hours and the school teacher and principal have both admitted they don't know what to do with him.

He hardly completes any work tasks despite being significantly modified. He doesn't cope at all with recess or lunchtime breaks as it is difficult for him to cope not knowing what rules are as they are often inferred.

His stress levels are so high; his OT compared them to a soldier going to war. To get through the day and to try to conform to the school's expectations is making him ill. He often has black bags under his eyes and he has tummy aches from his anxiety. It is so difficult to send him to school knowing that it is making him sick.

He is now on medication to help with anxiety. We were hesitant to medicate purely because he does not cope in the school environment. We believe in a more supportive and understanding environment, he would not need medication.

We have spent hours and hours and thousands of dollars on therapies and medications to help him.

He does not get invited to play dates or asked to parties. He is high-functioning enough to notice this too so it further affects his self-esteem. I am unable to have baby sitters, after school care or even get a friend to pick him up from school.

Caelan is a beautiful, very clever boy and generally a calm child at home when he is comfortable. Believe me, we have our moments, and he does need help with daily tasks, but he in no way displays the behaviour he does when he is in the school environment because they are unable to cater for his needs.

He feels a lot of empathy for others and is very loving. He feels terrible after his meltdowns when he has hurt people. In his words, "He doesn't want to be like this. Why would he choose to be like this?" I try to encourage the mindset that autism is a gift, but neither he nor I can believe this when everyday life is a struggle and there is no help in sight. Please help me to allow Caelan to reach his full potential. It breaks my heart to have to drop him off every day knowing that he isn't able to cope and is not supported the way he deserves to be.

Ms HACKETT — My name is Michelle Hackett and I have three children. My eldest son, James, is 10 years old and in grade 4. He has ASD.

We begin our school day with him screaming with anger that he doesn't want to go to school.

James calls all of us, myself and my two other daughters, stupid idiots and hurts us, constantly pinching, knocking us as we walk past or trying to talk to him.

I forcibly dress him — he is 45 kilos — once, twice, three times, depending on how many times he rips his clothes off.

I forcibly feed him his breakfast because if I don't he will be worse. If he won't eat, I pack in it his bag.

We drive to school and I park in a secluded car park behind the school where I ring the school and they send someone out to drag him in. This is one example of an extra strain on the school resources and the school day hasn't even begun. James hates going to school because, "The teachers are mean. The kids are mean and they hurt me and I got another detention for doing nothing." This is all his interpretation of social cues. He does not understand people's facial expressions. He does not know where the "stopping point" is for mild but typical aged-appropriate boy behaviour — wrestling, tests of strength and the like. He is nearly always the one who keeps on going and it turns into a full-on fight.

At school James continuously pokes and pinches other kids. He pushes and hits them. If he is angry at something, which we call the red zone, he will become very violent and dangerous. He has broken kids' bones before. I have to ring parents and apologise for James' behaviour often.

This term James has had detention every day for hurting kids. He does not see that he has done anything wrong at all. It is always someone else's fault. He recently picked up three kids separately by the neck and threw them on the ground. He proceeded to jump on the last one. He received two weeks' worth of detentions for that.

At the end of the school day, as soon as James sees me, he explodes — angry, crying, he does not want to go to school ever again. He hates everyone. So our afternoon and evening progresses into a fiery bliss.

I also have a daughter, Sam, who has Down syndrome and the pathway for her has been easy. She was accepted into early intervention programs because of her diagnosis. She has a low IQ and she has been accepted into the specialist school for next year. And because of the way she looks, everyone accepts when she hits them, pulls their hair or throws tomatoes at them and if she cracks it with a temper tantrum in the shopping centre it is lovely and cute and fine but if James does it...

People ask me how I cope with a child with Down syndrome and I just say, "It is actually a walk in the park compared to my son, James, with ASD."

I am also a primary and secondary school teacher. When I began teaching 19 years ago in secondary schools, I thought there was only about one autistic student in the whole school. Ten years later when I was leaving schools there was about one per year level. Now it seems there is one or two or three per class. It's very interesting. Kids with ASD have different needs, that are not being met in mainstream schools and that is why they have the meltdowns, hurt others or don't cope and make their homes a scary place to live in. Kids with

ASD are extremely difficult and emotionally draining for their families. Kids with ASD will gradually turn into adults with ASD and while they grow up and mature they will have a lifetime of dealing with having poor social awareness and lack of skills in dealing with others.

James is a great kid when he is calm and full of interesting facts and questions. He loves to be doing things and makes us laugh. He may not present with obsessive behaviours such as putting cars in a row or flapping or stimming but he has huge and violent meltdowns. Because he is so big at 10, I worry about what will happen as he grows older. I see a school specifically designed for ASD children with higher IQs as a positive way forward for so many kids like James.

Ms O'CONNOR — I'm Tona O'Connor. I have three children, a daughter 29, a son 28 and a 9-year-old son Leo in grade 3. Leo has autism, ADHD, OCD, anxiety and severe behaviour disorder. Despite the school doing the best that they can it has been a constant struggle and here is a brief outline of the challenges.

He has never attended full-time school hours.

He cannot attend without a one-on-one aide.

He has periods of only managing an hour a day in class.

His extreme behaviour issues at times require two staff members to deal with him.

He has a history of running off, hitting, kicking, scratching, throwing things, swearing, sexual innuendos, stripping off his clothes, urinating on the floor, trashing a room and students have needed to be evacuated from the classroom.

This unsafe behaviour has involved hurting students, staff and other parents.

Although the school has implemented many things, I have been told that some days he may as well not be at school as they are just "managing" him.

A behaviour plan was written up by the school stating that mum was to be on call to pick up from school whenever behaviour was extreme.

Although he has a one-on-one aide mum is also required to go on school excursions.

He has significant modification to his work-school requirements.

In class he sits quite separate to the other children.

Due to unpredictable and impulsive behaviour, he doesn't always participate in school activities and forward planning is always needed in anticipation of things going wrong.

His aide had time off on stress leave last year due to burn out so this year they had two aides to avoid this.

His behaviour and challenges are the same across all settings, at home, with respite workers, with therapists, at special needs events, anywhere we go. It is across the board.

So it is not just lack of poor management, the struggles are real and every day.

He had 12 months discretionary placement funding at the specialist school for severe behaviour but that ends at the end of this year. His IQ was above the criteria for the special school eligibility.

Three psychologists and the psychiatrists have said that his level of autism is moderate to severe and his IQ doesn't do him any favours. He is medicated and his family has spent countless hours and money on ongoing therapies, including fortnightly two-and-a-half hour trips for psychologists and OT which means taking him out of school for these appointments.

When Leo is not under stress he is a beautiful boy.

I'll end it there.

Ms OWENS — Our focus today is on the education of children with Autism Spectrum Disorder with an average-to-high IQ.

For some children in this category, they will receive a positive education in the form of a successful mainstream school experience, unfortunately for many others, they will not.

We don't believe the inclusion-at-all-costs philosophy of the current system is benefitting our children. One size does not fit all and sometimes even a school committed to inclusive practices struggles with the constraints of the current system.

The cohort of children like ours have such amazing potential yet their complex needs and extreme and even violent behaviours mean they need a separate school dedicated to their needs and to ensure a positive future. We want to be clear that we are not asking for a special school. We are asking for a school specific to children with Autism Spectrum Disorder and an average-to-high IQ that caters from prep to 12, with a flexible learning program including VCE and VCAL.

Data from a recent survey of 319 Victorian families with ASD found they had an average-to-high IQ. That was done by Spectrum School Parent Advocacy.

The Education Department/Government does not track mobility or current school situation of this cohort of children. They are no statistics and research on this.

School mobility — 56% of this cohort of children had moved schools at least once due to issues or difficulties. Of these, 21% that had moved schools, they had done this twice. Many who had not moved schools asked, "Where are we to move to?" Or, "My child is only in prep/grade 1 but moving is on the agenda."

The current school situation — 48% of children surveyed are not in Government mainstream schools. These children are scattered between independent schools, Catholic schools, community schools, home schooling, distance education programs, disengaged programs and school refusing. Those that remain in Government mainstream schools are jumping from one to another.

98% of children experience social or academic issues at school.

75% struggled academically despite an average-to-high IQ. 68% were bullied and 99 experienced behavioural issues and difficulties. 95% have anxiety, 71% experience school refusal and 56% experience some form of exclusion such as exclusion from camps, excursions, et cetera.

The results are alarming and have a huge impact financially on society. These kids have so much potential yet they are suffering in a system that does not meet their needs. The impact will have lasting negative effects on these children. The Australian Bureau of Statistics identify autism as having the lowest level of employment and further study as compared to all disabilities.

How would the school benefit our children? Class sizes would be smaller, educator-to-student ratio would be smaller. The teachers would want to teach our children and be trained in special needs education, therapists such as OTs, psychologists and speech therapists would be on hand for these therapies and for advice for teachers regarding the best way to teach each child, the physical environment would be sensory friendly, life skills and self-worth programs would be integrated into a flexible and responsive curriculum and the environment would be conducive to social interactions and making friends.

Currently there are special schools with an IQ cut off at below 50. Specialist school students need to be below 70. Where are our children meant to fit into the system? Our children cannot go to specialist school because of their IQ, but can't cope in mainstream. They have no choice but to attend mainstream schools and within mainstream schools many don't even receive a cent of funding. It needs to be understood that IQ does not determine the level of autism or the level of support needed. We feel that if our children's needs were being met at school then it would alleviate a significant amount of stress and burn out for us as parents. Having to travel long distances for therapies takes time away from school for children and time off work for the parents. This causes excessive strain on finances and the whole family.

Recently we wrote to the Minister of Education, James Merlino, and received this reply: "The Labor Government is committed to making Victoria the education state by ensuring that every community has access to great schools, supporting our teachers and principals to be their best in ensuring that every student experiences the chance to succeed, in learning and in life." We have attached this letter. Our children are not receiving a valuable education. They are struggling just to get through the day at school. Their mental health and wellbeing is declining as they are made to feel their behaviour is bad and that they are not understood. Other children in the class are also not receiving the education they deserve or are promised as so much time is taken out to deal with our children. We appreciate you listening to our concerns. We really hope it has made an impact as we are absolutely desperate to see these changes happen for the sake of our children and many others in this situation.

The CHAIR — Thank you all very much and thank you for sharing your personal stories. It is really important to the Committee to hear from parents like yourselves who are facing challenges every single day. Do you — are you okay with your children's names being used in the transcript of evidence?

Ms OWENS — Yes.

Ms O'CONNOR — Yes.

Ms HACKETT — Yes.

The CHAIR — How many members are in your group?

Ms OWENS — We have the three of us who are the main...

Ms O'CONNOR — Well, with the Autism Action Group, our main — the one that wrote the submission, Jacinta Cooke, has moved interstate.

The CHAIR — So you are a small group just coming together to support each other?

Ms OWENS — Yes.

The CHAIR — So your membership hasn't grown?

Ms OWENS — We just had our — we know of other situations. We were just the representatives.

The CHAIR — I was going to ask if you have any idea how many families there are with children who might be in similar situations.

Ms O'CONNOR — We are also involved in an autism support group in our area and there are 100 members in our...

The CHAIR — Just here in Morwell?

Ms O'CONNOR — That is Leongatha, Inverloch, through to Phillip Island, around that area. There are 100 in the support group there. Latrobe Valley, I think they have a support group here with around 300 people.

The CHAIR — Would you say that the ASD community is growing, that there are more diagnoses of children?

Ms O'CONNOR — My 28-year-old son has Asperger's Syndrome so in the 20 years — when he was at school, 20 years ago, I think I knew two other kids in our whole area with autism and now it's — I now know many, many more. I actually can't put an exact number on it but at his school alone there is probably — in his school of 200 —

The CHAIR — Which school is that?

Ms O'CONNOR — St Laurence's Leongatha.

The CHAIR — Is that a Catholic school?

Ms O'CONNOR — It is. Yes.

The CHAIR — Are your children all at Catholic schools?

Ms O'CONNOR — Yes. Apparently funding was better at Catholic schools. When I rang to approach schools when my funding was about to start...

Ms OWENS — So they are smaller as well. It is easier to cope. We were encouraged to go to Catholic schools.

The CHAIR — How many special schools are in the region?

Ms O'CONNOR — Leongatha and Wonthaggi.

The CHAIR — There are only two? Do you know what their enrolments are?

Ms O'CONNOR — The special school, I think for next year it will be 44 but they have a capacity of 70.

The CHAIR — Is that a new school?

Ms O'CONNOR — No.

Ms OWENS — The Wonthaggi one is three or four years, maybe.

The CHAIR — So what we have heard from you today we've heard many times across our public hearings, particularly in relation to the IQ test which is discriminatory, as we know. You wrote to the minister and did you have input into the Special Needs Plan? The state Special Needs Plan that was released?

Ms O'CONNOR — He referred us onto Tracey Walker.

The CHAIR — So you had discussions with the department about...?

Ms O'CONNOR — We did. We met with Tracey Walker and Heather Braden, principal of the special school, but then it just fizzled out.

The CHAIR — I guess I'm more familiar with the public school system, so being that your children are at Catholic schools it is a little different, I suppose. I do know — we visit a number of public schools that have really, really good integration models and the one at Fawkner, Moomba Primary, has been a pilot for the state in terms of integrating children with ASD to the mainstream classrooms because of the IQ being above 70. Are you aware of any schools in this region that do it well? I know you are at Catholic schools but in the public system?

Ms OWENS — No. We find that even in our support groups and Australia-wide Facebook page there are always people complaining of the same things that just — I know that our children are sort of a little bit different, I guess, in that — not different but I forgot to mention that my 12-year-old has Asperger's and, yeah, inclusion works really well for him. It just doesn't work for us.

The CHAIR — It's not one-size-fits-all. That is the thing about every system or anyone with ASD. So I guess it is about how — we are trying to look at how we can have different models, perhaps, that suit different children.

Ms OWENS — We have heard of some of the models in Melbourne or other states that do work.

The CHAIR — Did you qualify for the Behaviours of Concern funding from the state?

Ms O'CONNOR — Is that the 12-month funding?

The CHAIR — I think it goes longer than that but I'm not sure. You could be right but there is an assessment for difficult behaviour and funding?

Ms O'CONNOR — That was what my son — it was the 12-month discretionary funding for the specialist school.

The CHAIR — I think it is more than discretionary through the state system. What about secondary schools? What are the options?

Ms HACKETT — We have already gone to the Catholic secondary school in Leongatha and it doesn't seem promising. We thought we would start the process now because our boys would go there in two or three years and we just walked away going, "No, that doesn't sound promising at all." They are not going to change anything.

Ms OWENS — She did say, "Maybe you should try — maybe this school isn't suited for you. Try somewhere else." But that's the problem, there is nowhere else.

Ms O'CONNOR — From what we hear the funding even drops off even more once they hit secondary and the secondary college — our boys don't have that executive functioning to be able to navigate around the school or — I just know that we would not cope at all in the secondary college so Mary Mackillop was the secondary college, was the only real option because he can't go to the specialist school. When we approached them, and I told her exactly the story of how my son is, she said, "You may want to look at other schooling options." I said, "There are no other schooling options."

The CHAIR — What about post-secondary in terms of what next for your children?

Ms HACKETT — I believe my child — I believe, and hope, that he will go to university and get a job. I'm aiming really high, but he just can't cope.

The CHAIR — Will you need to move away from the regions to do that?

Ms HACKETT — Maybe.

Ms O'CONNOR — I can't say how my son will go. My son has very little awareness of social — he is nearly 10 and he will still strip off his clothes and says really inappropriate things to people that really scare me. I almost feel like I will have him home forever. I can't imagine him functioning.

Ms OWENS — I think my son would probably do something like — he is very clever. At the moment, his aim is to work for Disney Pixar.

The CHAIR — Aim high.

Ms OWENS — I think that will probably change over the years but he might be through distance — he wouldn't be able to go very far, I wouldn't think. I can't — I have high hopes for him but if he was similar to how he is now he would not be able to cope.

The CHAIR — Were all of your children diagnosed at an early age?

Ms O'CONNOR — He was three but four by the time we had the diagnosis.

Ms HACKETT — Eight.

The CHAIR — Early intervention therapies?

Ms O'CONNOR — Yes.

The CHAIR — Was ABA a part of that?

Ms OWENS — Not available where we are.

The CHAIR — So just psychologists, speech therapists, OT?

Ms OWENS — Yes. The local support services that pick you up.

The CHAIR — Do you know much about ABA? Do you think it would have been a benefit for you to access that for your son at an early age?

Ms OWENS — Oh, yes.

Ms O'CONNOR — Definitely.

Ms COUZENS — Thanks for coming along and sharing your experience. I think, Michelle, you mentioned as a suggestion a school for high-functioning children with ASD. How would you picture that? How do you think that could work?

Ms HACKETT — Because I'm a teacher I just have always dreamed of opening up my own school anyway because I think there is so much potential for kids.

The CHAIR — Do you think there are enough autism specialist teachers to work in a school?

Ms HACKETT — No. I just see it as — since I started teaching I always loved kids with disabilities and I did ask for them to come to me anyway and they have. So I just have always been drawn to them and they're honestly the ones when I started teaching and then there were more and I just loved it. I do think they need separate things. They need to be taken out and doing their engine room and they need to be taken out into the sensory room. They need to be shown things differently. My son should never write. It drives him crazy. But — I just think — other kids need to write, that's their sensory stimulation. He needs to be typing. I just see definitely small classes. I believe in physical activity for them and I would like to see some programs with that that set them up for life as well. And then some need VCAL and some need VCE.

Ms COUZENS — Would you see it as a mainstream school that has that integrated program in the education system or a very specific program for people with...?

Ms HACKETT — Specific program. Like cut some of those subjects out for those kids. Then use art therapy, music therapy. Rather than the music curriculum or the art curriculum that they are doing, use it as therapy to help their sensory needs and stimulate them. Same with PE, cut a lot of those things that they teach in PE, help with their health. My child is obsessed with food. We have so many issues. Things like that would be great and then the stimulation that the OTs do with them.

Ms COUZENS — Given they are all very individual and have different things, maybe cutting that in the mainstream education may not be the way to go, do you think? I wonder whether having mainstream subjects in there is beneficial for kids that want to go on to university.

Ms HACKETT — Totally is but, yeah, some of them, I think, that would be changed.

Ms O'CONNOR — I would like to see a model of a unit within the mainstream school with a Special Ed teacher and a small ratio that is basically what we have said in there, so that they could do foundation studies and then come back and do work that's more specific to their needs.

Ms COUZENS — Are you aware of the Dookie model?

Ms O'CONNOR — No.

Ms COUZENS — Very small classes of 12, is it?

The CHAIR — With individual learning plans.

Ms COUZENS — That's outside the mainstream school system but something like that. From what I'm hearing, you're saying something like that small program is actually operating within the mainstream school system; is that pretty much what you're saying?

Ms O'CONNOR — Yeah.

Ms COUZENS — What kind of support do you offer for other parents and carers in the local area that you represent?

Ms O'CONNOR — At the support group?

Ms COUZENS — Yes.

Ms O'CONNOR — We have a resources cupboard where we meet, where people can share sensory...

Ms COUZENS — Where do you meet? Is it a community centre somewhere?

Ms O'CONNOR — It is the hub at Inverloch. It is the community hub so we have a room booked there and meet once a month. The majority of it is just emotional support, ideas, sharing ideas and...

Ms OWENS — Learning about the different services. I think most of us have found that connecting with other parents is where you find the information and who — what therapists and things in the area because they are not all qualified to work with ASD and you do waste a lot of time going from person to person. If you go and speak to these, I think that is where we found — a lot of parents have found — our Facebook page is very active. There are always people asking questions on there and we can all help each out over that.

Ms O'CONNOR — Particularly parents with a new diagnosis. They get a diagnosis and it is where to from here?

Ms OWENS — Which hasn't changed from when our children were younger. It would have been great if it was around when ours were younger, this sort of service.

Ms O'CONNOR — We always said too our ideal thing would be — the thing you hear from parents all the time is they are trying to chase up a good psychologist that understands ASD or a speechy and we are travelling in this direction, that direction and it would be great if you have a central hub where the therapists, like specialists, come and visit once a month and they have a file on your child, that they're all on board and all working together because we are seeing different therapists that do different things.

The CHAIR — We have heard about the Telehealth model today as an option for regional and rural communities, would that work for you, do you think? So basically you access a specialist via a teleconference rather than face-to-face?

Ms O'CONNOR — I'm not sure — I don't think my son would respond very well to a teleconference meeting to be honest.

Ms OWENS — We did try that when he was very young with a speech therapist via Skype but it didn't work. He wouldn't sit in front of the screen. It would probably work for some very well. There are not many options where we are. There is a lot of travelling.

Ms COUZENS — You've come up with a couple of ideas around — within the school and community hub or professional hub for people accessing those professionals, are there any key things that you think the Government should be aware of that would benefit children like yours?

Ms O'CONNOR — Education is our main concern but I feel that we can do all the work, we can take them to therapists, we can access support through each other but we don't have any control over — we send them off to school and it is like sending them in front of a firing line every day. We don't have any control over how that works.

Ms OWENS — And we don't have a choice. I tell other parents and they say, "Why don't you put them..." It is not very well known that you need the cut offs. We have had the whole, "Why aren't you just putting them in another school?" But there is no other option.

Ms O'CONNOR — And the schools are just as frustrated as we are. I'm not criticising the school.

Ms OWENS — We're not blaming the school.

Ms O'CONNOR — The principal of our school, they're just as frustrated by not being able to manage things themselves.

Ms COUZENS — Thank you.

The CHAIR — I have been approached by many families whose children just fall outside of that IQ and have had to fight to get them into a special school. What do you think of the approach of having more therapists within the school system? Access to therapy, actually within the school system?

Ms O'CONNOR — That would work better.

The CHAIR — That is a model we have heard would be of enormous benefit, particularly in relation to behaviours of concern, and then, of course, we have already put in place teacher training around ASD. I'm not sure if you are aware of that, but a teacher can't register now unless they have done that training. So that is just a new thing that was introduced. Screening for preps, starts next year. So every child in prep will be screened for autism and dyslexia. I guess what I see as the big gap at the moment is that we don't have trained autism-specific — we do have them but they are spread very thinly across the ground. In terms of bringing therapists into the schools, there is a bit of a — confusion, I suppose, around how the NDIS will fit into all of that. Will your children qualify for the NDIS?

Ms OWENS — I imagine they will.

Ms O'CONNOR — Yes.

The CHAIR — Do you see that that will make a difference?

Ms OWENS — I guess so. We don't — it's not in our area yet so we don't know. It looks promising.

Ms O'CONNOR — I hope it will help my son to be able to better participate in the community.

The CHAIR — Do you think that the community here has enough available recreation activities and resources for kids with ASD? Given that you said, you know, the behaviours of concern mean that you don't go out a lot, what do you think is needed to make it a more inclusive community so that — I suppose, raising awareness?

Ms OWENS — And this having — maybe if a sporting thing does get set up, that there is someone there who is available, but if there is someone there who is trained or if there is access to — like, my son — my older son does scouts so my 10-year-old did try it and he didn't last because he needed — we had to stay with him all the time, which we couldn't do all the time. If there was someone there, you know, like, where at school you get — if there was an aide there that could help him through it. I know that our children are all the same in that they don't lose very well and they don't cope with losing. So I hardly ever put my son into any sort of sporting thing because I know it would just be a nightmare for him and the others.

Ms O'CONNOR — We don't do anything apart from disability services. My son can't play sport. He doesn't go to birthday parties, play dates. He is purely at home, at school or we do have once a month he goes for a social — small social group date with Scope for five hours but we has to have one-on-one and that is even a nightmare. They struggle to manage even that. With four children and three support workers and that is even difficult. We don't really go out to social things.

Ms HACKETT — And we do heaps of sports. James does swimming, Little Athletics and soccer. We just make him. We just make him. He hates it. We split up. So I go with the littlest with Down syndrome and he goes with the other two and you have to have an eye on him and an eye on Sam. So we are just basically separate all the time. That's our daily life anyway on weekends. But we make him. We make him do swimming one-and-a-half hours per session twice a week, Little Athletics.

Ms COUZENS — Does that help with his behaviour at all?

Ms HACKETT — Sometimes but we just think it is good for him. He does enjoy it. The other thing is he does like being social and he just doesn't understand and he can get very angry and he does have play dates but it is all on his terms and his level and we just have to be there all the time watching him. "Okay, it is done. It is up. Let's go." I do just pull him into that pool. We believe we are doing the right thing but who knows.

Ms OWENS — I did swimming lessons with my son and eventually they said they couldn't cope with him anymore. So even, I guess, when you do go — and there is, like, Tona does a program in Leongatha and I live in Inverloch, and I could travel over, which I probably will do, even though the pool were aware of his needs and accepted him, they then realised that they couldn't do it. So we are now not able to do it. They are all different, aren't they? Some will.

The CHAIR — In terms of before and after school care, is that not an option?

Ms O'CONNOR — No.

The CHAIR — School holiday programs?

Ms OWENS — Not available actually.

The CHAIR — No before and after school care?

Ms OWENS — No.

The CHAIR — School holiday programs?

Ms OWENS — I have seen the YMCA do it but there's no way that I can...

Ms O'CONNOR — We can't — I can't put my boy into anything where they are not trained to deal with him. That's the bottom line.

The CHAIR — Would that help you if there was a service that provided a school holiday program where there was one-on-one support, would that help?

Ms O'CONNOR — We do actually have two hours' respite with Interchange. Shilo was just here. I have two hours a fortnight respite that I can use. Again, that is someone that is trained.

Ms COUZENS — Have you heard about the Secret Agent Program?

Ms O'CONNOR — Yes.

Ms COUZENS — Have you participated in that?

Ms OWENS — It is a long waiting list.

Ms O'CONNOR — The psychologist that we are seeing runs the Secret Agent Program. She is in Traralgon and she is brilliant. We have been seeing her for over a year now and she sees Leo one on one and she says he is not even ready to go into that. She doesn't feel that he can even manage.

The CHAIR — How old is he?

Ms O'CONNOR — He is nine nearly 10. She wouldn't put him into a group yet. She says he is not ready. That is telling you something.

Ms OWENS — They are really great in Charlton Reaches where I also go. I am on the waiting list for both my sons to go on it. We are only able to get half an hour appointments because she is so busy and we are travelling an hour to be there for half an hour where it takes 15 minutes to get him to be quiet. That is how stretched it is. To find someone really good...

Ms COUZENS — So an expansion of that program would be really useful by the sounds of it?

Ms OWENS — Yeah. I even rang up somewhere in Frankston and they said it was a bit of a wait as well. I didn't put my name down there. It just seems to be a really good program.

The CHAIR — Thank you so much. Can I wish you well for the holiday period? It will be very challenging for you. It is challenging to take them to school but it is challenging when you don't have to take them to school as well. Thank you so much for sharing your stories today. It has been really, really helpful. Can I wish you all the best.

Ms O'CONNOR — It's hard to share personal things but we needed to do it. So, thank you.

The CHAIR — We will break for five minutes, thank you.

Witnesses withdrew.