TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 21 November 2016

Members

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Witness

Ms Lisa Carr.

The CHAIR — Welcome, Lisa. Thank you 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. We would like to invite you to make a short statement, and then we will ask some questions.

Ms CARR — Thank you. I did print out some notes. I only did five copies because I was told there would only be five people. I could obviously talk about the subject I am going to for a long time, so please help keep me on track. First of all I want to thank you for this opportunity. Basically we have had a hell of a year, and it has been about finding an appropriate secondary school for our twin boys. They are in grade 6. We have come to a decision on a school, and this really is a very nice way for me to end the year — to feel that I have been heard about some of the issues and rejections and things we have come across.

Anything that I put in quotes is actually verbatim. I will not read all of this, but I will read what I think are the main things. I am speaking specifically regarding our family's experiences with finding a suitable secondary school for our sons. They are identical twins. They were born at 29 and a half weeks. They were both diagnosed to be on the autism spectrum at age one and a half years. Despite some obvious traits such as stimming, delayed development and social awkwardness they are happy and very compliant children. Behaviour problems in my boys have never been apparent. In actual fact when one of my sons first said 'No' to me, I politely told him off but secretly I was going, 'Yay', so that is how pleasant they are.

Just a bit of background: I am a qualified secondary teacher and I have taught at multiple venues, including Echuca High School — country kids, government school — Lauriston Girls School in the residential Year 9 program, and also Williamstown High School in the trades program. I did teach for 14 years, and their father is a psychologist. I have included this information because it is relevant to a point I will make at the end.

Our optimum choice was for son 1 to attend Rossbourne School and son 2 to begin at mainstream school and then transfer to Rossbourne if required. This then would give each boy an opportunity to make their own friends and consolidate their own identity. Also we wanted them to be in a co-ed system. Two clear questions we asked ourselves of each boy were: was it better to be at the top of a group, like at Rossbourne, where particularly for son 2 he could sort of feel confident, or was it better to be part of the mainstream? What was in each boy's best interest?

Despite having aided time at primary school, son 1 does not qualify for aide time at secondary school. Son 2 does not, but he has since with recent testing been deemed to not be on the autism spectrum. That I credit to all the early intervention that we were able to experience.

What I want to tell you about, as well as my boys, is the kids for whom there is no adequate educational placement in Victoria — those children not accepted by private schools, those who do not qualify for special schools and specialised settings, those who are not behaviourally challenged so do not fit into alternative educational settings and those who do not qualify for aided funding in mainstream government schools. That is my boys, and I am sure we are not the only ones.

I will not go into Early Intervention at child care and kindergarten but will discuss primary school. They were in a bridging program in prep between St Paul's College (Villa Maria) and All Hallows Primary School. This was completely unsatisfactory and discriminatory. The principal claimed that any funding they might receive on the boys' behalf would not be spent on an aide for them but on school resources, and my boys were also deemed to be difficult. I truly believe this is because we were very open about their diagnosis. We had all the testing done; we had all the labels.

We then transferred them halfway through prep to Chatham Primary School. The principal's first comment was, 'This is the boys' school', and we were welcomed. They are currently succeeding at grade 6 level. Son 2 qualified at level 2 for an aide 10 hours a week, and son 1, level 3, 15 hours per week.

In the recent transition tests, son 2 now has been deemed not to be autistic; however, he has low IQ and has aspects of autism in terms of being socially awkward. He has suffered a six-month episode of severe depression already in grade 4, which dramatically affected his academic achievement, let alone his state of mind. Son 1 did

score on the autism spectrum, but he has high language skills and his IQ is of mixed scores. He does not have an intellectual disability, but he does display a processing disorder. Son 1 without help will not even be able to begin expected work unless he has an aide by his side — simplifying instructions, keeping him focused. He will not know what books or what materials to take to which classroom and will likely get distracted on the way or lost between classes. His lack of motivation occurs unless it has something to do with YouTube. Just an issue with transition testing: it was very difficult because some of the testing can only be done 12 months before year 7. That obviously then meant a great delay in us researching schools because we did not have that final data

In the next section I just wanted to identify everything that I and my husband have done in terms of trying to find a suitable secondary school. Both boys were placed on the waiting list at Rossbourne when they were initially diagnosed. That would have been about 2006. We were invited to apply this year. Since 2010 I have thoroughly researched everything on transition — what to ask schools about what they can do for you and everything. I have also done some in-services.

The next list on your handout — I will not go through them — is all the areas, all the departments, that I contacted seeking specific help regarding my boys, because at this stage I knew son 1 did not qualify for an aide. You can see there: Lyn Campbell, disability coordinator, DEET; Association for Children with a Disability; and so on. Basically all their responses were very sympathetic, but they could not offer any specific school. They were not allowed to tell us of a specific school that would suit my boys.

I just draw your attention to the second-last point. I have spoken to a few parents whose children have not succeeded in mainstream education and in essence have become school refusers. These children are now being homeschooled.

The information I have might not be very accurate, for this is all the information I have been working on. Independent schools receive a certain percentage of funding to cater to children with special needs, but from our experience independent schools do not take these children, so it is left to government schools to take them, but they do not receive adequate or proportionate funding. A fellow from Blackburn High said 60 per cent of kids with special needs end up in high schools because independent schools will not take them. I have evidence of that from our experience this year. This is just my knowledge of the funding.

There are independent special schools, but only one, Rossbourne, caters to social and emotional — and probably not academic — needs. All the others have behaviour issues as their focus. We do not qualify. Neither son 2 nor son 1 have behaviour problems. Son 1 has got angry a couple of times but once you know why his issues are solved.

I have listed those other specialised independent schools. I know that as part of re-registration each year Victorian teachers must complete a certain amount of PD directly related to students with special needs, and that refers to a response I had to an independent school.

We have seriously considered moving to the peninsula and even the Gold Coast, but we currently have very suitable activities now close to our current home, and that has taken years to find. In particular, we are at drama at St Martins Youth Theatre, which is just marvellous, and we will be there until we die, if we can.

I have learned that there is interim funding available in 2017 for those who do not qualify for PSD funding. This, however, is only to support transition from year 6 to 7, so it is not ongoing.

The next 17 schools are the schools that we have either visited or contacted, either with the boys or without them. Perhaps I will not go through all of them, but I have divided them, as you can see on your handout, into secondary special, private schools, state high schools and then Catholic schools. I would like to draw your attention to Rossbourne's response. Our boys spent two days in year 7 there, and they were separate days. Son I was also observed at his current classroom at Chatham Primary. As I said, they were already on the waiting list.

All of Rossbourne's literature suggested that they specialised in children who fall between special schools and mainstream. Rossbourne accepted son 2 immediately, even though he was not on the autism spectrum. They would not take son 1 because 'he was not an independent learner' and that he 'got out of his chair and flapped'. When we challenged them, their response was exactly this:

We are a private school and we can choose who we want.

Son 1 really wanted to attend Rossbourne as he identified with this cohort. He has only ever said about one school, 'I want to go there', and it was 'I want to go to Rossbourne'. This would have been fabulous. We asked what we could do to prepare son 1 to be accepted into Rossbourne and the response was:

He needs to enter without aided support.

We did try that. They did observe son 1 in his current classroom, as I said. They will not take him. To not accept son 1 into their classes of only 12 students is absolutely absurd. I will not tell you what I said on leaving that first meeting. They felt son 1 was not enough of an independent learner in a group of 12 students.

Ashwood School said they would love to have taken son 1, but his results did not qualify. He is above Ashwood's score. He is above the score for Bulleen Heights school. He does not qualify for a special school.

We have also investigated a range of private schools. The reason I put their responses in is that these are the responses we got without anyone saying directly, 'No, we won't take your son'. Yarra Valley Grammar said:

We query whether the boys would cope with the academic rigours required by the school.

Peninsula Grammar said:

Not sure whether this is the right school for the boys.

For Scotch College they had to sit a test, and as son 1 had not even sat the NAPLAN, we did not make them do that, so that now probably is not an option for us.

Knox School, Wantirna, I draw your attention to. The boys spent a day in grade 6 there separately. Their response:

We have a very VCE-focused program. This may not be where their future lies.

It might not be, possibly is not, but again I am sure they are not the only ones. This was said by the principal, and I quote — I wrote it in my diary as he spoke:

No school can refuse an enrolment; otherwise we would be held up for discrimination.

Our staff skill set is non-existent or rusty in the area of autism. To have expertise in this area takes time. We have not got that. It takes people with finesse and nuance to get the best out of kids, and our staff doesn't have that depth of experience with those who are different.

We investigated Donvale Christian College, which would have been perfect, but as we are not strictly practising Christians we, as parents, would not qualify.

We investigated a range of state high schools. Generally we had to look at the physicality. Son 1 gets lost and he has low tone, and if there are stairs he will never get to the class because he will be exhausted before he gets there. So that really eliminated Camberwell High, Kew High and even Balwyn High. Balwyn High does cope with special kids, but not at the IQ that my boys are at. As for Catholic schools, we were very much disheartened by our initial experience, but they tended to have no vacancy.

The boys have been accepted into Blackburn High. The vice-principal has kindly already come to Chatham Primary for a meeting one morning to learn all about the boys. I know they are worried, and we are very worried, but they are going to do their best. Blackburn's buildings are in a circle. At least someone can point son 1, 'Right, you just go to that building over there'. There is only one building with three storeys. They have a house tutor-mentor group. There are lots of aspects that are good, but it is not what we wanted.

My conclusion is that funding for aides in government secondary classrooms is absolutely essential. Someone does not have to have "nuance and finesse" to help son 1. Someone just has to sit beside him and say, 'Son 1, read this. What does it say? What do you have to do? Where are your pens? Where's your book? Your book's there, get it out'. That is all. They do not have to have "nuance and finesse".

I have learned that despite all my individual reading and all my reading on recommendations of what to ask schools and about transition and choosing a secondary school, it matters little, because I have learned that particularly with the private system it is just up to the individual principals who make the decision.

I believe Victoria needs more autism-inclusive secondary schools. I have listed the ones that are in existence: at Ballarat, Noble Park, Flemington and Geelong. As a teacher I know we are meant to teach across the varied learning needs and styles, but there is a limit — and I know that as a practising teacher. There is a limit to catering to someone with an IQ of 72, which son 1 has, to someone who is gifted if you have a class of 25, 27, or maybe even 23, without someone sitting beside my child.

I believe government and service agencies have Early Intervention down pat. I believe we do that very well. Primary schooling is a work in progress, so it has been quite successful for us and there are lots of resources and so forth. But there is not enough provision for inclusion of a child on the autism spectrum in a mainstream secondary school. My husband and I are hopeful but also quite fearful in the light of the reality that is a mainstream school trying to cater to children such as ours. Blackburn High has shown they will try their best, but we will see.

I believe you might have questions, but I will just finish. I would like to know, if there is time, how my experiences that I have shared here are to be used and where this goes from here?

I also have a point relevant to why I put in my qualifications. I do not know how people who do not have an educational background, who do not have English as a first language, who do not have access to resources, computers, the latest information, how they navigate the minefield of having a child on the spectrum. I do not know. I do not know where their children are ending up.

I want to know where my sons will go when school becomes too difficult for them, either socially or academically? What will we do if either boy becomes a school refuser because it has become all too hard? I am a teacher. Homeschooling is not an option! I will not homeschool my children! It is essential, particularly, that they are exposed continually to the social world that everybody else is exposed to in secondary education. Thank you very much. As I said, heartfelt thanks for listening to me.

The CHAIR — Thank you, Lisa. Thank you very much for coming along and sharing the journey of your sons through school. It is a very challenging time that transition period from primary to secondary and then again of course once they finish secondary school. We very much appreciate that this has been very difficult for you, so thank you very much.

Just to quickly answer your questions at the bottom there, we will be using your testimony today as part of our final report, which will be presented to the Parliament in June next year. We do have some concerns ourselves around people from CALD backgrounds, particularly those who have children with autism or who have not been diagnosed themselves. That certainly has been raised with the committee. Again, as I said, our terms of reference are in relation to the prevalence of autism spectrum disorder; the availability and adequacy of services across a whole range of different areas, including education and employment services; how this all fits in with the NDIS; and of course the economic and social cost of failing to provide adequate services and what the demand might be.

Now, I would suggest from what you have told us today that you are probably one of many who are fighting a battle with where your children fit in, particularly in relation to the education system. Can I ask you a couple of questions regarding the early days?

Ms CARR — Yes.

The CHAIR — How old were they when they were diagnosed?

Ms CARR — One and a half.

The CHAIR — And one has since been — —

Ms CARR — And then it was at age three, and then in the transition testing this year, son 2 was deemed to be not on the autism spectrum. Now, the reason given for that — all I know is that perhaps he was always on the borderline. He certainly does have autistic tendencies, which is reflected in his social skills; well, he does not have any friends. His friend is son 1, and that was another issue. We wanted an opportunity to — —

The CHAIR — So son 2 is — —

Ms CARR — Is not.

The CHAIR — He is not on the spectrum, but son 1 is.

Ms CARR — He is not deemed to be officially.

The CHAIR — And they both have intellectual disability?

Ms CARR — No. Son 2's IQ is 83, I think, and son 1's is 72 — something like that.

The CHAIR — Okay, so they are both over 70 in IQ?

Ms CARR — Yes, they are.

The CHAIR — Good. So once they were diagnosed, what sort of support did you get?

Ms CARR — I cannot remember her name, unfortunately — it was a fabulous speech therapist who watched me carry each child down those stairs one at a time, and we were put on to Villa Maria Early Intervention in Kew. We were there for — I cannot recall the number of years; it was three or four. That is where we were exposed to hydrotherapy and speech therapy. I also sought out music therapy, movement and dance. As I said, my boys were lovely, compliant. They did not walk until they were three, and I do not think they really talked until they were — you know, I had to learn a new language to speak to them. I am an English teacher. I always prided myself on speaking to them in adult language. It was never 'horsey' or anything like that. I had to go from, instead of saying, 'Do you want another biscuit?', to learning sign language. 'More, more?'. 'Happy boy?'. 'Clever boy!'. That got them toilet trained. 'Clever boy!' got my boys toilet trained. 'Clever boy, you'. It was not chocolate frogs or anything.

The CHAIR — So do the boys have any other co-occurring conditions?

Ms CARR — No.

The CHAIR — So no ADHD, no anxiety, no depression?

Ms CARR — Well, anxiety and depression — yes, I have mentioned that — with son 2. With son 1 it is not so evident. Certainly with son 2 there is extreme anxiety, as I said. In grade 4 there was a six-month series of things where he thought he had seen bushes moving. It was a combination of factors, and he would turn up to the kitchen table in the morning and say, 'Mum, I can't get these pictures out of my head'; he was in grade 4. He was about to get the top grade for maths. That would considerably — —

The CHAIR — So do you think either son 2 or son 1 will be eligible for the NDIS?

Ms CARR — I believe son 1 will be. I am not so familiar with the NDIS. I believe son 2 will be, but not under autism — under mental health issues. That is my understanding. That is about all I know.

The CHAIR — Do you currently receive support from the Department of Health and Human Services?

Ms CARR — I receive — which one is it? — carers funding.

The CHAIR — For both of them?

Ms CARR — Yes.

The CHAIR — And are you working still?

Ms CARR — No, personally I have not worked since before they were born. I have certainly suffered from severe depression myself since they were born, and I have been hospitalised three times for that.

The CHAIR — Blackburn High is the school they have been accepted into?

Ms CARR — Yes.

The CHAIR — How far away is that from your home?

Ms CARR — We live in Surrey Hills currently, so what is Blackburn? Four or 5 kilometres. We rent, so we could move there, but then as I said, their current activities are now actually — scouts is down the road.

The CHAIR — St Martins.

Ms CARR — So I do not know. Again, I could have looked at many more schools, but I also knew that I had to put a limit on it myself. As I said, my husband investigated a school in Queensland, and we were all ready to fly up there, but finally my husband realised that we have no support up there. I have one sister who can help me. That is it.

The CHAIR — What is your anticipation of what your children will need once they enter secondary school?

Ms CARR — An aide.

The CHAIR — Both of them?

Ms CARR — Son 2 would not like to admit that he will probably need an aide. For example, I was helping them with their homework last night, and son 2 cannot read instructions effectively. He cannot select the appropriate material for research. He will do something once, like most kids, and then that will be it, but his strategies for interpreting and reading are very limited.

The CHAIR — And what support have you had from the department of education?

Ms CARR — An aide for son 1.

The CHAIR — So son 1 has an aide?

Ms CARR — And son 2.

The CHAIR — So they have both got an aide?

Ms CARR — Yes, and it was — —

The CHAIR — So your issue is that an aide will not go with them to secondary school?

Ms CARR — No. I have been told that son 1 does not — —

The CHAIR — Have you been in touch with your local member?

Ms CARR — No. You can see I have been in touch with everybody else. Maybe that is my next task — all we need is an aide. Not even for all lessons.

The CHAIR — I can see you have done a lot of extensive research into the different schools around, and you probably know more about the secondary school system and its autism-specific programs than we do.

Ms CARR — Just another comment too: I did also look at schools like Preshil, a really alternative school. Son 2 wanted to go to a school where you wear a tux. My boys like structure; they like bells. We like blazers; we like formal. If they went to a school where they could choose what they wanted to do, well, son 1 would look at YouTube all day. Again, it just is not an answer. Our only answer, if it was not Rossbourne, which would have been perfect for son 1, is Blackburn with an aide.

Ms McLEISH — Thank you very much, Lisa, for that really detailed assessment of your struggle. It has been really valuable for us. Was one of them accepted into Rossbourne?

Ms CARR — Son 2.

Ms McLEISH — And is he going to Rossbourne?

Ms CARR — No.

Ms McLEISH — So they are both going to Blackburn?

Ms CARR — They are both going to Blackburn. That picture — and this is what I saw at Rossbourne — was absurd, the picture of Son 2 going to Rossbourne and son 1 at Blackburn High; it was bizarre. So son 1 could be at Blackburn on his own! Son 2 — he could have done Blackburn on his own with help, with guided help, and in a way we wanted him to be on his own to make his own friends. This is their final chance to have a real go at really making some friends. They are going to leave primary school behind. They are going to Blackburn. They are not going to Camberwell. They did not care about not going to Camberwell because they do not have any friends.

Ms McLEISH — Have they got siblings?

Ms CARR — They have half-sisters who are 34 and 31, and a dog called Pepper. That is their daughter.

Ms McLEISH — Can you tell me what St Martins do well?

Ms CARR — St Martins do not tell them off. They can be silly. They are, again, just happy to participate. There are a couple of kids in there who are different — a bit more extreme in their behaviour, a bit louder, a bit more demonstrative. One, we qualified for an inclusion scholarship, because we had both of them, which was just fabulous. That paid for 70 per cent of this year's fees, and that in itself was so welcoming because we had the two of them. That will change next year probably. They have a support teacher in there. They are all unique kids. I do not know if they are all on the spectrum. The teacher just draws them in. They include them all. They praise and are positive about their participation. I believe we have until they are 16 to be part of it, and again that was a factor in not moving away to the peninsula or Queensland because they love it; it is vital. Again, this is just an example of where Son 2 can feel a bit the top of. He is developing a bit of confidence, whereas he does not in the mainstream school. He does not play footy. He does not play cricket. He is not one of the cool kids. But in drama he is just one of, as son 1 is. I highly recommend it. They are brilliant.

Ms McLEISH — We have not heard of them.

Ms CARR — You have not? They are based in South Yarra.

Ms McLEISH — We have heard of St Martins but not this inclusive program that you are talking about now.

Ms CARR — It is not specifically for kids on the spectrum. It is just drama.

Ms McLEISH — They are doing a great job. They might be able to teach others how to do such a good job.

Ms CARR — They are. They also ran an in-service, for people who were interested, on "Autism and the Arts", which I attended. I cannot remember the name of the lady who works with Opera Australia as an autism consultant and somewhere else. I cannot think of her name. I cannot remember.

Mr FINN — Lisa, can I commend you on your extraordinary efforts to support and help your children.

Ms CARR — Thank you.

Mr FINN — It is just a remarkable story. One thing that has got me — I mean, there is quite a bit in here that has got me a little bit flummoxed, but there is one in particular, and that is when you say son 2 is no longer regarded as being on the spectrum. How did that happen? Was it a psychologist?

Ms CARR — Yes. They had the official testing by the school psychologist and the speech therapist — I actually have their results here. I think I have got nearly all of them. If you want to see them, I am happy to hand them over.

Mr FINN — No, I am just interested to know. I have not heard that before; that is all.

Ms CARR — No, I know. Autism is considered to be a lifelong disorder. Maybe it might be because I had the two of them and they were delayed development. They were born early. There were a lot of issues — the late walking, the late talking. I do not know. They were officially tested at the Royal Children's Hospital when they were three, so again, as I said, we had all the testing, all the labels. I was not trying to get around the system or anything.

Mr FINN — So the diagnosis was given when they were three?

Ms CARR — Yes, initially it was verbalised at one and a half when I expressed concerns, and my husband said, 'How dare you be so negative?'. I will not go into that. That is another presentation. I am sorry. I did not bring all that; I have not looked at that for a while. Son 2 was deemed to be mild on the autism spectrum. Son 1 was deemed to be on the autism spectrum plus an intellectual disability. I received that information in the post, and I opened those letters in my kitchen. I had no idea that son 1 was going to be deemed to have an intellectual disability.

Mr FINN — Yes, it is pretty rough to get that in the mail. How did it come about that Son 2 was deemed to no longer to be on the spectrum?

Ms CARR — Again, just through the transition testing. The results have come out — and I have those results — that he does not qualify to be labelled autistic, but I still believe he has a lot of autistic tendencies. Son 2 can rise to the occasion. He can be neurotypical. He can try and fit in. But as soon as he gets home, he just collapses into like behaviour with son 1, and that is where he is most comfortable. Son 1 is his best friend. Son 2 is most comfortable at son 1's level. But he works hard. He wants to be seen to be part of the group. He wants to achieve. He wants to please people, and I can see that he pushes himself.

The CHAIR — A bit of mimicking?

Ms CARR — I am sure he does. But with all the early intervention, they are both exceptional with adults. They will come and give you a joke and shake your hand and all of that. With children of their own age, they have little knowledge. The only other reason I can explain son 2's change of diagnosis was all of the early intervention experiences that were offered by Villa Maria, but also that I sought out. So, for example, the boys were only interested in — all we used to do — they did not play Lego. They sometimes lined things up. Son 1 sometimes spun things, but all they were really interested in doing was dressing up and dancing to music. You could not get them to colour in, so I took them to Art Therapy at Abbotsford Convent. We did Art Therapy there. We did dance and movement in Carlton. I just ensconced them in art. We have taken them to live stage shows. I have exposed them to as many experiences as I would if they were neurotypical, and son 2 has obviously gone with it. I do not know the scientific explanation for why he is not deemed to be autistic.

Mr FINN — And what was your reaction to this news that he no longer had autism?

Ms CARR — I honestly have never really paid a lot of attention to it, because our whole focus was the shock and exhaustion and efforts at trying to find the right school. It is sad in a way because I think he could still benefit from any help that son 1 gets. He has done the Secret Agent Society. They have done every program. Not that I wanted them to be normal; please do not misunderstand me. I have never wanted them cured and I have never wanted them to be normal. I want them to just have every opportunity that any other child could expect. I am not trying to ignore or wash away the diagnosis.

Mr FINN — Thank you. You have been extremely helpful to our deliberations.

The CHAIR — Thank you, Lisa. Are you okay for us to be using your sons' names, or do you want their names redacted?

Ms CARR — That was one issue. We never told them they were on the autism spectrum, which as it turns out for son 2 was probably a good thing. I do not mind my name being used, but perhaps not theirs, I think.

The CHAIR — Yes, we can do that. Not a problem. Thank you very much. That has been really informative. Thank you for coming in. I know it is not easy, but you have done a great job, so thank you very much.

Ms CARR — That is all right. I thought, as I said, that this was the end of the battle and we would just move on to Blackburn, but it looks like I am ringing the local member. Thank you very much again for the opportunity. It was the CEO of Amaze who informed me that I could have this opportunity.

The CHAIR — Excellent. Great. Thank you very much, Lisa, and good luck.

Ms CARR — Thank you.

Witness withdrew.