

LEGISLATIVE COUNCIL ECONOMY AND INFRASTRUCTURE COMMITTEE

Inquiry into the Multi Purpose Taxi Program (MPTP)

Melbourne—Thursday, 9 December 2021

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Ms Kaushaliya Vaghela

Ms Sheena Watt

WITNESSES (*via videoconference*)

Ms Sandy Kervin, General Manager,

Mr Lance Dale, Advocacy Officer, and

Ms Barb Watts, Community Representative, Save Our Sons Duchenne Foundation.

The CHAIR: The Legislative Council Economy and Infrastructure Committee hearing for the Inquiry into the Multi Purpose Taxi Program continues. Please ensure that mobile phones are switched to silent and that any background noise is minimised.

I would like to begin by acknowledging the traditional owners of the land, and I pay my respect to their elders past, present and emerging.

My name is Enver Erdogan, and I am Chair of the committee. I would like to introduce my fellow committee members that are here present today: Mr Rod Barton, Mr Lee Tarlamis and Mr Tim Quilty.

To all witnesses giving evidence, evidence taken is protected by parliamentary privilege as provided by the Victorian *Constitution Act 1975* and further subject to provisions of the Legislative Council standing orders. Therefore the information you provide during this hearing is protected by law. You are protected against any action for what you say during this hearing, but if you go elsewhere and repeat the same things those comments may not be protected by this privilege.

All evidence is being recorded, and you will be provided with a transcript following today's hearing. Ultimately transcripts will be made public and put on the committee website.

For the Hansard record can you all please state your names and whether you are appearing on behalf of an organisation or in a personal capacity. Over to the three of you.

Ms KERVIN: I have the honour to say hello from the very beginning. I am Sandy Kervin, the General Manger at Save Our Sons Duchenne Foundation, and I would also like to acknowledge the traditional owners of the land we meet on today. For me it is the Gadigal people of the Eora Nation. Respects to their elders past, present and emerging.

I would just like to introduce very briefly the Save Our Sons Duchenne Foundation as the peak body for the Duchenne and Becker muscular dystrophy communities. When I mention Duchenne, I actually speak of a spectrum that covers Becker muscular dystrophy as well. I appreciate the opportunity that we have got to talk to you today, which is fantastic. Thank you.

The overview I would like to give you is very brief. It is about how we started and why we are here and why we are having this conversation. So in 2008 Elie Eid, our founder, started Save Our Sons to try to find a cure for Duchenne muscular dystrophy. It remains at the heart of everything we do today, to actually work towards improving the quality of life and a cure, because we realise that our boys are living a lot longer and we want to actually give them opportunities to live a full and healthy life. That includes living independently, having access to transport, education and a life that we would want for any of our teenage boys.

Duchenne is a life-limiting illness. It is a muscle-wasting illness. Our boys, as they progress to being older, through medical advances are living longer, which is an amazing feat. So they have got those opportunities to do what other people can in the community, but it is restricted when they do not have access to safe transport that is actually cost effective and efficient and effective for their needs.

I am going to hand over to Lance, but we have got more information about what Duchenne is, if anyone on the panel wants to know more about that.

The CHAIR: I would like to hear more about it in general as well, so maybe afterwards we can also organise a meeting with the group.

Ms KERVIN: Fantastic. And from Lance. Then we will talk to Barbara. Barbara is a parent, so she will actually be able to give that insight into what it is to live with somebody and be part of the Duchenne community and have that day-to-day perspective.

The CHAIR: Thank you.

Ms KERVIN: Lance, I will hand over to you.

Mr DALE: Thanks, Sandy. Hi, everybody. I am Lance Dale. I am the Advocacy Officer for Save Our Sons. I would like to echo what Sandy said and really thank the committee for this opportunity today to present the view of our community to this very important inquiry. Our community is only small, but it is important. It is important that it is given a voice. More than anything today, we really appreciate that you have taken the time to invite us to be part of this important inquiry.

I have been watching the inquiry very closely, and I have actually been tuning into some of your broadcasts. I do not know that we will be saying anything particularly new today that you have not already heard, as I notice that you have been pretty thorough with your witnesses. I will not say that you have grilled some of them, but I did enjoy some of your questioning of some of the rideshare companies in particular.

I am going to assume you have read our submission. This submission was written following extensive discussion with our community in Victoria—people like Barbara, who is on the hook-up today—and what we are saying today is largely reflected in our submission. It has come through the consultation with our community. I just want to say how vital we see the Multi Purpose Taxi Program as being for a community where our boys and young men do not have mobility. Most are confined to wheelchairs. It is really critical that they have got this option available. Public transport is important, but it is often inefficient and very hard for our families to navigate.

The other thing is that some of our families do own wheelchair-accessible vehicles, but they are incredibly expensive. And this is an issue I think some of the companies that are part of the MPTP will have to wrestle with, because the cost of running and maintaining a WAV is very prohibitive for a lot of families, hence the reliance on the multipurpose taxi scheme.

We really want to see an increase in the number of WAVs. We are concerned that the expansion of the scheme to rideshare companies may not pick that up. I actually did have the opportunity to meet with a disability taxi provider at a disability expo in Sydney on the weekend. I will not mention the company's name, but he was following this inquiry very closely. He did indicate that he did not feel Uber and some of these other companies would be coming on board with wheelchair-accessible vehicles, because of their cost and the maintenance that is involved. He was very much of the view that these companies would cherrypick the more glamorous, or the more profitable, parts of the scheme at the expense I think of some of our community members.

In saying that, we do want to see an expansion of the scheme. A number of our families raised issues of time delays and inefficiencies, particularly in regional areas. I know there are studies that have gone into this previously. I actually had a look at the *State of the Industry Report 2019: Accessibility* this morning, and many of the issues I think that we are talking about today have been picked up in earlier reports such as that one.

A number of our community talked about the need to develop relationships with individual drivers to be sure that they were getting the right service at the time they needed it and also that they would have a driver that was cognisant of the needs of people with disabilities. We think that is unsustainable. We think all drivers, irrespective of which company, should have these skills and this sensitivity to people with disabilities. It is a multipurpose taxi provision scheme after all, and they need to be up with all of that. The other thing is while we want to see an expansion, we are also concerned about safety issues, and safety issues came through very loudly for us. We do not think that the two things are irreconcilable. We think we can have a thorough, comprehensive scheme and make it a safe one, and I think that is what, hopefully, we are all working towards.

So just quickly some of the key recommendations our community made were ensuring that all drivers had working with children checks and national police checks. I listened to one of the interviews—I think it was with Uber—and I was not 100 per cent certain that they were doing that sort of thing. The same safety standards should apply and cameras are in all providers, not just the traditional taxis and things like that, and I think that has been an issue, if I can say, that Mr Barton has been quite active on. We want to see a standardisation across

the board to ensure that the same safety regulations apply and the same things are across all providers. We want to see there be tighter regulation, monitoring and auditing of operators and a rigorous complaints process established. I think we are all aware of what has happened in New South Wales. There have been so many reports—and we are based in Sydney—about the failing of Uber to take action on things like sexual assaults and a whole range of safety issues. I think it is called the point-to-point transport commission or something of that nature, and there has been a very public discussion of that in New South Wales. I think we all want to see that being avoided in Victoria.

The last thing that I would probably say is the importance of training for drivers at an agreed standard, not something that is just pulled out of a cornflakes packet and is a tick-a-box exercise but real training in disability awareness and maybe something there on rare disease leading to disability, which is our community. But there is a need for us to have confidence that, irrespective of the provider and the drivers, they are going to be suitably trained and sensitive to our community's needs.

I think that is all I really wanted to say. I have heard a lot about price gouging and yes, that is an issue that really affects us as well, particularly if we cannot get vehicles, because it is just not seen as profitable to run a WAV at the time that we need it. I will finish at that point. Barbara, would you like to add anything at this stage?

Ms WATTS: I think you have summed up most of it, but would you like me to mention a little bit more about Duchenne muscular dystrophy from a parent's point of view? My son Lachie is 19. He was diagnosed with Duchenne muscular dystrophy at the age of two, and it is a progressive disease. You know, they go into a wheelchair at about 11, but it just does not finish there. It is every muscle, so it affects the heart, it affects all the upper body muscles, so in the end they cannot feed themselves. It also affects the respiratory muscles, and their life expectancy at the moment is only early 20s. Fortunately, as Lance mentioned, their life expectancies have increased due to the different steroids they are using now. But there is no cure, so we want to try and maintain their independence as much as possible. That is basically it, but please feel free to ask me any questions about it. But it is a devastating disease; it really is. And these young boys—you know, we try and give them the best quality of life, but they just lose the ability to do all the things that they learn to do as children, which is just heartbreaking.

The CHAIR: Thank you, Barbara, for sharing that and informing the committee of the challenges faced by families. I also want to thank Lance, and Sandy as well for your overview. Lance, yes, I have read the submission. It was very helpful. I like it when people come with actual recommendations. I know one of the points you talked about was a rigorous complaints process. It is great to get complaints or feedback about services, but it is even better when people make recommendations on the way forward. I enjoyed reading your submission, and I did note there were a few that really struck a chord with me about working with children checks and some of the other safety and training recommendations you made. I also enjoyed your contribution raising the aspect of, which has been touched on but we have not had as much evidence about, the costs of putting a wheelchair-accessible vehicle on the road. I am hearing it is \$100 000-plus, and usually you have higher maintenance costs in terms of running it than a family vehicle would normally have, so obviously with the nature of the sector the family concerns around the provision of those services is very real. Thank you for sharing that.

What I might do is go around committee members for them to ask questions. I know Mr Barton is eagerly waiting, so I will start off with Mr Barton, then we will go to Mr Quilty, then Mr Tarlamis and I might have the final questions if that is okay. Mr Barton, over to you.

Mr BARTON: Thank you all for coming in and sharing your views with us here. I have looked at your 10 recommendations and, for me, none of them scare me. I think they are all very valid. The only thing I would just make a comment about is the Victorian government working with other jurisdictions to harmonise the use of the Multi Purpose Taxi Program. I think we are going to end up with the feds running all this a few years down the track. I can only see tears further down the track as we try to push the costs down. That is a little view of mine. But if you had to pick the three most important things to help you right now out of all those recommendations, what are the things that you need?

Mr DALE: Could I just say, increasing the number of wheelchair-accessible vehicles I think would get us a long way. I did read, and tell me if I am wrong, that there used to be—is there a subsidy provided by the state

government to provide these? I just read it in that *State of the Industry Report* that I mentioned earlier. There seemed to be some generous subsidies for operators to actually provide these vehicles. I do not know if that is still in place. This is a 2019 report.

Mr BARTON: There has been some cutting back, but it depends on whether it is rural and regional or metropolitan, things like that. You know, that is one of the huge things that we would like to see, if I may speak on behalf of the industry. We would certainly like to see help, because whether you put on a \$30 000 taxi or you put on a \$100 000 vehicle, these vehicles both earn roughly the same amount of money.

Mr DALE: Yes.

Mr BARTON: So if we are going to put those wheelchairs out there, we need to give them a hand to get there.

Mr DALE: Yes.

Mr BARTON: So you will have no argument with me on that one—yes, I think we should.

Mr DALE: Look, I will defer to Sandy and Barbara on the other two—I have got my one in there.

Mr BARTON: Right.

Ms KERVIN: Barbara, would you like to go next?

Ms WATTS: Certainly I agree with Lance that we certainly need more vehicles. At the moment it is not a reliable service. If we really need to be somewhere at a particular time, we usually have to book it half an hour or an hour earlier than we need to just to ensure that we get there, because if it does not turn up, you know, we are in a lot of trouble because we cannot just hop on a tram. We really rely on this service, so that is essential. I think obviously safety has to be, as a parent, an incredibly important aspect. The good thing about Uber is at the moment there is a tracking system: I can look at my phone and see where the car is. If I put my son into a wheelchair-accessible vehicle, I do not know where it is at any time. So ideally if there was some sort of tracking system that could just give me and other parents peace of mind to know that they have arrived at their destination safely.

Mr BARTON: Now, I do not know off the top of my head, but I can tell you that 13CABS have an app—most of the taxi companies have an app that does exactly the same things as Uber, so you can track them. I just do not know who in the Multi Purpose Taxi Program, whether that is worked into the system, but I am going to find that out this afternoon.

Ms WATTS: Okay. Fantastic. And training of drivers needs to be really important. In my experience—I mean, do not get me wrong, I am not knocking them; they do a good job—I think training is probably lacking. I have been in situations where my son has been hoisted up and put into the van and then they are really fiddling around with the tie downs, they are not quite sure how to do it. And, you know, it worries me because obviously this is essential. I mean, this is like a seatbelt to these kids and everyone else in the van. So that has to be a prime consideration: training by the companies of their drivers not only in how they deal with disabled people but also that safety and if the equipment is maintained. Really, we put our kids into these vans and we do not know when the last lot of maintenance was done, when the hoist was last serviced et cetera. So the safety aspect is just a huge one as a parent, obviously.

The CHAIR: Sorry to cut across, Mr Barton, but, Barbara, just before that second question about driver training, you touched on wait times being half an hour to an hour and that sometimes they could not turn up and there are all sorts of delays. How long have wait times been an issue for you? Have you noticed it has got worse, or has it just been consistently around the same kind of period?

Ms WATTS: Look, you know, sometimes they are on time, but it is unreliable.

The CHAIR: Is it a new or just a longstanding issue?

Ms WATTS: A longstanding issue.

The CHAIR: So you would say even two, three, four years ago it was the same kind of issue?

Ms WATTS: Yes.

The CHAIR: Okay. Thank you. I just wanted to put it into a time line. So it is a longstanding issue. Thank you. Sorry, over to you, Mr Barton.

Ms WATTS: No, I understand. That is all right. Thank you.

Mr BARTON: Chair, I think we could probably say it was even worse years ago. They are better, but we have still got a long way to go. And one more—

Ms KERVIN: Lots of parents are reporting the same thing—that their young person with Duchenne muscular dystrophy cannot necessarily look over and make sure they are well clipped in, because of the muscle weakness they are experiencing. So they cannot actually check if someone has clipped them in properly. There were reports that there have been times when they have not been clipped in properly, and the wear and tear on the fittings and fixtures is questionable. If the carer is there or the parent is there to see them into the taxi, they often monitor that it is done correctly, but if the young person is coming home, calls a taxi and is fitted, they have to take their own life into their hands and hope that the person did not just end up with that taxi today, that they actually have been trained to use the disabled taxi and they did not just have it as the only taxi available when they got to the rank. The training for us is essential.

Working with children checks are a great step as well, and national police checks, because a lot of these children are using accessible vehicles to go to school if their parents do not have a vehicle. So we are entrusting really young kids who do not know the direction they are going in. They do not know how to inform the driver if they have gone the wrong way, and it is a stranger to them often. So building that relationship with parents is part of the comfort that they get, but if they knew that there were checks in place, I think that would help.

Mr BARTON: I absolutely agree.

The CHAIR: Excellent. I might pass over to Mr Quilty. Do you have a question?

Mr QUILTY: We talked about ridesharing services cherrypicking the cheaper or the more profitable work, and that is based on the idea that we should have more wheelchair-accessible vehicles and they should be providing services to people without wheelchairs as well as wheelchairs. Is that the case?

Mr DALE: Look, I cannot speak with any confidence on that, but I think more the issue is I guess around the price gouging and how that impacts on people that need the wheelchairs at certain times and the cost of travel. It is just that they are not going to be available, or if they are available for our community then they are going to be paying more to use vehicles. That is probably not sort of answering your question. I read it was the transport alliance or something that made a big statement around price gouging and the impacts of certain companies basically cherrypicking their way in the scheme and how that will affect other parts of the scheme for people that really need it. But I probably have not really—

Ms KERVIN: Lance, I think what we have been told is that with rideshare often you have surge pricing as well. So therefore if you have got a limited cap of \$50 per trip and somebody does surge pricing and you have gone with a rideshare provider, then you are not going to go very far with your 2½ times the fee and all the rest of it.

Mr DALE: Not in Melbourne on a Friday night.

Ms KERVIN: Let alone somebody who is regional or remote that needs access to this because there are not public transport options or alternatives.

Mr QUILTY: Yes. Okay. What I was trying to explore there was: is an increased subsidy per trip perhaps a better way of getting around this? And, I guess, could you talk a little bit more about the issues in rural and regional?

Mr DALE: Yes. Barbara is well placed to talk about the regional, but I will say that one of our recommendations was we feel the cap for individual trips is too low, that it could be improved. I also

understand there are certain groups that are exempt in terms of having to make payment for the scheme. Our community is certainly not one of those groups. But I think there are certain exemptions for certain groups in Victoria who are severely disabled, and I do not think there is a cap in place for those groups. I think I have made that point in the submission somewhere. But on the regional stuff Barbara is probably much better placed because she is—Barbara?

Ms WATTS: Well, we did live in Melbourne. We are spending most of our time down in Inverloch nowadays, and—

A member: Nice.

Ms WATTS: Yes, it is lovely. But we do not really use wheelchair-accessible vehicles, because there are not any around here, so it is as simple as that. But we are fortunate in that we do have a modified vehicle, purchased over 10 years ago at a cost of around \$65 000 back then—so even then incredibly expensive. But we just use the modified vehicle here because we just do not have the facilities here at all. So if we want to go out for a celebration or have a couple of glasses of wine, we do not—you know, we cannot—because it is just not available to us here. And this is just an example, but obviously in all regional areas I think they are facing the same problems. And there are a lot of kids, I know, from the Victorian Duchenne community who live regionally and so are impacted by this.

Ms KERVIN: One of the impacts as well is that the scheme does not go across state borders. So people want to visit Melbourne, and they want to use every bit of tourism they possibly can. But they cannot use what they have got from another state, and they do not have access in other states. So we need to be talking to the whole government about how people can move across Australia, can live their best life and can actually have experiences. But when we are restricting transport as one of those issues, that is really difficult for our families.

Mr BARTON: It would make a lot of sense, wouldn't it.

Mr QUILTY: Sorry, just talking about how it does not cross state boundaries, how does that work on the borders?

Ms KERVIN: That is exactly my question. I do not know how that works for the border towns. That is a real concern—that if they have to sit in, say, Mildura and send their kids to New South Wales schools, I am not sure how they are dealing with that—not just our community but all of the communities who use accessible vehicles.

Ms WATTS: Can I just add here, as a parent, I mean, obviously with a child in an electric wheelchair it is very limited as to what we can do with regard to travel. So really, being realistic, it has to be in Australia. He cannot go on a plane—my son, anyway—for long periods of time. So the fact is that then, if we go interstate, which they are encouraging us to try and do these days, we cannot use the taxi card at all, and the cost is fairly prohibitive if you are actually using one of these maxi taxis just with three of you in there and not having any subsidy at all. So, you know, it does make it incredibly difficult. I just do not understand the reasoning behind it.

Mr DALE: Our research suggests that most of these schemes are very similar in every state, even at the level of subsidisation. They are just going under different names, but they seem to be virtually mirrored. In every state jurisdiction there is no difference.

The CHAIR: I appreciate the input, and there seems to be consensus from your side in terms of the need for some sort of either cross-subsidisation across state borders—because we are one nation, at the end of the day, and one country—or we have a uniform scheme where each recognises each other, something along those lines. And it seems I understand from your community why that is important. And, Barbara, thank you for again putting to us your lived experience of how that affects your travel choices—and your family's travel choices, not just yours. Thank you for that. Mr Quilty, do you have any more questions? I might pass over to Mr Tarlamis. Over to you.

Mr TARLAMIS: Thank you, Chair; and thank you, Sandy, Barbara and Lance, for both your comprehensive submission and coming along and talking to us today and sharing your personal experiences as well. It has been really valuable for the inquiry and for our consideration. Because of what you have added

today but also your comprehensive submission, with the detailed recommendations, I do not actually have further questions. So thank you.

The CHAIR: Excellent, Mr Tarlamis. It has been a really good discussion, because the submission was quite comprehensive. I must admit when I turned up today for this hearing I said, ‘It’s a good discussion’, and some of those points that I wanted to discuss have already been raised. I notice that you are calling for, Lance, in the recommendation, a minimum I guess percentage of the commercial passenger vehicles being wheelchair accessible. Is that right?

Mr DALE: Yes. I think it is called the transport alliance—they have called for something very similar. The fundamental problem is that we are getting new operators but there does not seem to be any requirement to provide the sorts of vehicles that not just our community but a lot of people out there in wheelchairs would really benefit from. So yes, I think that is important to remember—that we are only one community amongst many rare disease and disability groups and that there is a much greater need out there. That seems to be reflected in the submissions that we have read as well.

The CHAIR: Now that Uber—and there might be other rideshare apps—are going to go online, I guess most of your community will not be able to use those services, because they do not have wheelchair-accessible vehicles. Are you concerned about that?

Ms KERVIN: I am, because more vehicles do not mean more access. I know we need more vehicles and we need to be able to allow people to use their devices in more ways, which is very innovative and great; however, it does not address any of the needs of the community. So yes, more vehicles for us are a bonus for somebody who may be hearing-impaired or vision-impaired or does not have a physical impairment of any sort, but once we get to that physical need, then it does not address the needs of our community.

The CHAIR: All right, thank you. On that note, most of the questions I had have been answered in your submission or your presentation today, so at this point I will ask if any other committee members have any additional questions. Mr Barton? I am just looking.

Mr BARTON: No. Their submission and their recommendations are very thorough and very good. Thank you.

The CHAIR: Thank you for appearing before the committee. Some of the issues—

Mr DALE: Sorry, can I just say: if there are any questions beyond today that you would like us to provide you with more information on, we are more than happy to go off and do that for you. If there is anything that you would like a response on that we might not have covered, then we will happily pursue that for you.

The CHAIR: Thank you very much for that offer, Lance. I was going to say we may have some questions on notice. We have got a couple of committee members who were not able to make today’s hearing, so they may have some questions also. So if you are able to do that, that would be of great assistance. Your submission and your presentation today will be helping us in our deliberations moving forward.

On a separate note, outside of this hearing I would love to reach out to the organisation and hear some of your broader concerns and of course issues, so I will reach out in due course, maybe in the new year. But in relation to these terms of reference, I want to thank you again—all of you: Barbara and Sandy as well as Lance. It has been a very, very informative session.

Mr DALE: Great. Thank you very much, and good luck.

Ms KERVIN: Thanks for your time. Thank you, Chair.

The CHAIR: Thank you. And that concludes our hearings today. Thank you.

Committee adjourned.