

TRANSCRIPT

LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

Inquiry into increasing the number of registered organ and tissue donors

Melbourne—Friday 23 June 2023

MEMBERS

Ella George—Chair

Annabelle Cleeland—Deputy Chair

Chris Couzens

Chris Crewther

Gary Maas

Cindy McLeish

Meng Heang Tak

WITNESS (*via videoconference and via Auslan interpreter*)

Mr Philip Waters, General Manager, Deaf Victoria.

The CHAIR: Good morning. My name is Ella George, and I am the Chair of the Legislative Assembly's Legal and Social Issues Committee. Today we are here to hear from public witnesses about our inquiry into increasing the rates of organ and tissue donation. I welcome from Deaf Victoria Philip Waters, General Manager, and I also welcome Marc Ethan. Thank you for joining us today. I invite you to make a brief opening statement, and then we will have some questions from Members.

Philip WATERS: Okay. All right. Hello, everyone, Members of the Committee. Thank you very much for inviting me here today. I just want to make a few comments in regard to organ donation for the Deaf and hard-of-hearing communities. I do not have any research or evidence of the percentage of deaf or hard-of-hearing people who have been providing donations, but from our lived experiences and also with the staff that work with the now organisation, I have had discussions with them, and we are aware of a lot of people who have registered as organ donors. A lot of people in the community are focusing more on surviving, and there is also a four times higher rate of mental health issues and things like that. Most of the deaf and hard-of-hearing people are not employed work in mainstream employment sectors, so the focus is mainly on short-term survival—basically just living rather than thinking about the future or the impacts of the future for them.

If you want to become an organ donor, that means that you need to have really good communication skills and also a really good relationship with your family. Deaf and hard-of-hearing people—with regard to the communication itself, it is a huge issue. There are many families who do not communicate well with their deaf or hard-of-hearing child or family member. There are often people who are deaf or hard of hearing who do not really have discussions with their family about vital things to do with their lives. If there is another person within the family that is an organ donor, for example, having discussions, deaf and hard-of-hearing people will often miss out on those discussions in the family because of the communication barriers.

Those few deaf and hard-of-hearing people who are successful at university and who are literate in English will probably consider organ donation. I think in general organ donation is not a priority for deaf members of the community. Personally, I am an organ donor. I have been since I was young, but, then again, I would like to see more. I would like to see something similar to the Aboriginal and Torres Strait Islander communities and the CALD communities—the culturally and linguistically diverse communities—in regard to the approach that they take to try and fit in with the mainstream sector in regard to organ donation so they can also understand what is actually involved in the organ donation process. It has to be unpacked. All of the concepts in organ donations have to be unpacked for those community members. I think that is probably a really good way to approach maybe the schools—year 11 and year 12 students—and work with them to try and educate the students so that they are aware of organ donation.

Also, the organ donation website—Auslan videos are okay, but it is difficult to find the video on the OTA website. A video itself is not enough. I think going back to the communities and speaking with the communities to raise awareness would probably be more beneficial.

The CHAIR: Thank you, Philip. That was a great opening statement. We will now move to questions from Members. Gary, would you like to start with a question?

Gary MAAS: Yes. Terrific. Thank you very much, and I really thank you, Philip, for your time today. I also would just like to say that at many times lived experiences say a lot more than looking at statistics on a sheet of paper. I think what you have given us this morning has really given us tremendous insight and was actually very, very powerful. Thank you so much.

Philip WATERS: That is okay.

Gary MAAS: I just wanted to say, the big question is: how? We have a community that has other obvious, more pressing needs and priorities. How can the Victorian government better inform our Deaf communities that this is an important issue, and how can we potentially sway the Deaf community to register to become organ donors?

Philip WATERS: Okay. I think we probably need to visit the schools. I think of education and maybe getting them at an early age—presenting there. It may even be having a deaf person presenting there who is an organ donor themselves, giving their life experience in regard to organ donation and what that means for them in regard to saving other people's lives, the treatment in regard to lungs and things like that—all of the impacts

it could have and the positive impacts for you if you are an organ donor. It is about just having those resources there and making sure that the language is available for deaf people. Maybe even at sporting groups or social groups we can give information that is relevant to them and make sure that they have adequate information through information sessions, even if it is written down on a piece of paper or you have the registration forms there at that time.

Gary MAAS: Thank you. This is my final question. I know when I was growing up conversation with family about becoming an organ donor was very important. If the conversation for something like this cannot take place with families—there are some of the barriers that you have identified—where else could potentially that conversation take place?

Philip WATERS: Okay. Well, within the community itself, I guess; in the schools, as I mentioned before; and probably just having role models, people who have previously been donors themselves. Often what happens in the deaf sector, I think, with things like this—for example, organ donation or other important things that are vital for their lives—is the deaf and hard-of-hearing people think that that is for hearing people. ‘It is for others, not for us. My issues are different right now; my barriers are really different.’ So they probably do not understand. I think it is really important to demonstrate to them that it is important for deaf and hard-of-hearing people and it does benefit them if they become organ donors, and they can also contribute to society and not feel like they are removed from society.

Gary MAAS: Your time and your insights are greatly appreciated. Thanks. I have no further questions.

Philip WATERS: Thank you.

The CHAIR: Thank you, Gary. Chris, would you like to ask some questions?

Chris CREWITHER: I will keep it short, but thank you very much to you both and Deaf Victoria for giving evidence today. My first question is: you mentioned in your conversations with the Secretariat back in May that OTA resources for the Deaf community are not easy to locate. What are some examples of where OTA resources cannot be located and what are some ways in which the location of such resources could be improved to assist the Deaf community?

Philip WATERS: Okay. I think it is really important to have, I guess maybe mentioning Auslan on the front page or the landing page, other languages just to show that it is accessible in other languages—for example, using Auslan, just clicking on that as a link; having videos there for Deaf and hard-of-hearing people to access themselves; and having people describing their lived experience as an organ donor. I think that is really important, because that will help convince people first. Usually for people who can hear, they already are convinced, I think. So if they go to the website, then they get more information because they already know what it means. But for Deaf and hard-of-hearing people, they will not go to that particular website because they do not have the information beforehand. So I think it is fitting in with the community, educating the Deaf and hard-of-hearing community members, having a video just explaining why it is important to be an organ donor, and in the video having deaf and hard-of-hearing people themselves explaining what it is like having that lived experience.

Chris CREWITHER: Are there ways that we can, I guess, more generally better communicate with the Deaf community around organ and tissue donations but also generally via the Victorian government?

Philip WATERS: There is. At Deaf Victoria we share a lot of information with our community members about things that are happening in the society, like empowering people, their rights et cetera. We do not usually share information if it is not accessible, but we do share and promote information that is accessible for all community members. Also when we meet with members of the community, if there are issues that they raise, then we try and find access for them. So usually that is where we share things. Sometimes it is because they might not understand, and we might not have access.

Chris CREWITHER: We have heard from other witnesses about the potential to reutilise our drivers licence system like they do in South Australia to improve the registration rates. For example, in South Australia they have a 72% registration rate, where they link the AODR, the Australian organ donation register, with the South Australian licence system. But compared with 72% in South Australia, we are at a 23% registration rate in Victoria, where we do not use that system. I do not know that there are statistics for the driving rates for people

who are deaf versus the general community, but I imagine perhaps the rates of driving and having licences may be a little bit lower—you can correct me if I am wrong. But given that may be the case, do you have any thoughts on that as a mechanism to increase donations in Victoria?

Philip WATERS: Yes. I think it would definitely increase the rate for organ donation, and deaf and hard-of-hearing people do have drivers licences. They have to do an assessment though, I believe, to support those people who need to—I guess, when they train to drive, sometimes there could be barriers for deaf and hard-of-hearing people learning to drive, but the drivers themselves, when they get their licence, they have high motivation to actually drive. So if they want to become an organ donor, they probably think that it is not important, it is not a priority for them at the time and they probably would not register because of a lack of motivation. So I agree with any organ donation that when there is an increase that is really, really good, but I do not want the situation to happen where a deaf person or a hard-of-hearing person does not know the reason why, or why their family members are organ donors or are taking their power away from them without their consent. So I think deaf and hard-of-hearing people actually need to know what organ donation is first before you try and increase the registration number, because they need to understand what it is for and what is involved.

Chris CREWETHER: I have got more questions, but I know there are time limits so I will pass to someone else.

The CHAIR: Thank you, Chris. Cindy, would you like to ask some questions?

Cindy McLEISH: Yes, thank you. Thank you for appearing before us, Philip. It may have been a little bit out of the blue for you. I am interested to know about your –

Philip WATERS: Yes, it was.

Cindy McLEISH: registration to be a donor. You said earlier that you were an organ donor. How did that come about for you?

Philip WATERS: Oh, that was way back when I was at university, back in the day; the late 90s, around about that time, that is when I signed up. I do not remember how that came about.

Cindy McLEISH: Do you know if you are still on the register? Because we have heard from the OTA today that –

Philip WATERS: Yes, I am still on the register.

Cindy McLEISH: Oh, you are.

Philip WATERS: Yes. I think it might have been an information session. It is in MyGov somewhere. I think I checked it a few years ago, and it is still there. I signed up when I was at the student union at that time at the university, and they said all students had to be a union member. So I think that was one of the key ways we can get people to sign up as a registered donor [Zoom dropout] as it seemed to work for me back then.

Cindy McLEISH: Can I ask what relationship you have with the Victorian deaf society?

Philip WATERS: Alright, we have a very close relationship with the Victorian deaf society. It has changed its name, it is now called Expression Australia. We have a memorandum of understanding with them. They are a service provider, they provide different services for deaf and hard-of-hearing people, for example interpreting services; video production, they can create videos to provide access for deaf people; they provide support workers; support coordination for NDIS participants who have funding; employment services, they also provide that for deaf and hard-of-hearing people looking for employment. We are on the same floor in the building, as a subtenant. We are an advocacy organisation,.

Cindy McLEISH: Do you share resources and information?

Philip WATERS: What do you mean by sharing?

Cindy McLEISH: Well, I am probably getting to the fact that they had a grant a couple of years ago, 2018, from the OTA and produced a video for YouTube on organ and tissue donation in Auslan, and whether or not—I believe you did not know much about that.

Philip WATERS: That is right. I started two years ago. I have not seen that video.

Cindy McLEISH: Right, okay. Maybe it is a good one to follow up.

Philip WATERS: Yes, absolutely. I will definitely follow that up with Expression and see what has happened with that video resource. There are some videos that maybe are still online, I think.

Cindy McLEISH: Yes, okay. That is all my questioning. Thank you very much.

The CHAIR: Thank you, Cindy. Annabelle, do you have any questions?

Annabelle CLEELAND: Thank you so much. This has been very informative. I wanted to take a shift from the focus on the potential organ donor who might have a hearing impairment to communicating to family members that are deaf or have a hearing impairment. Do you believe enough is being done to communicate with family members that might have a hearing difficulty in hospitals? What am I trying to say here—are our donor coordinators adequately trying to communicate with deaf and hearing-impaired family members when they are talking about potential organ donation of a family member when they are next of kin? Longwinded, sorry.

Philip WATERS: If you could just clarify your question somewhat—is the donor coordinator communicating to deaf and hard-of-hearing members, is that what you asked?

Annabelle CLEELAND: Yes, family members and next of kin to a potential donor.

Philip WATERS: Yes, okay. I think it is really important to make sure that we think about communication if it is with a deaf or hard-of-hearing person. You need to have an interpreter there or basically ask that person what their requirements are in regard to their communication needs, how they understand the information. Sometimes it will be written down with pen and paper, sometimes it could be gesturing, sometimes it could be a little bit of the Auslan alphabet. Showing them the video of what you mentioned before—hopefully that is on YouTube or on the Expression Australia website—just having an iPad there to show them the video clip and going through that information with them. Try to make everything visual when you are explaining things. And if you give them a form and that is it for them to fill out, the deaf and hard-of-hearing people probably would not fill it out because they do not know what it is for, so you need to explain what it is for, the reasons behind it and what the benefits are before you actually give them the form.

Annabelle CLEELAND: So have you heard of any situations where a conversation in a hospital may not have occurred because they were not able to communicate with deaf or hearing-impaired family members?

Philip WATERS: I have not. I am not aware of any, no.

Annabelle CLEELAND: Sure. Back to following from Chris as my last question—so I appreciate your time—about the former licence registration, which is no longer the case; it is a federal database, but previously when we had a licence registry there was a physical sticker that identified you as a donor. Would this help? Do you believe going back to a physical identification would help that conversation with families that may not have occurred because of fractured relationships or that communication between family members?

Philip WATERS: I do. I think that would definitely be of benefit. Anything that is visual would be absolutely beneficial, I think. Linking it back to a website or something like that, maybe even having that on the drivers licence.

Annabelle CLEELAND: I will pass it over to Gary, who would like a supplementary question to mine, if that is okay. If it is not good, I will correct you.

Gary MAAS: Sorry. I just was also interested with that licensing question, because there is a move to digital licences in Victoria, if what you just said would apply in the digital realm as well.

Philip WATERS: Yes. Absolutely. I think specifically the cards that we have at the moment are what I have. So when I became an organ donor—I believe there is a card that we get given, and I put that in my wallet. So if you think about a situation, for example, where you were taken to hospital because it is an emergency, and you need to make a decision, you probably need to find out how to communicate with the paramedics or even the nurse at the hospital, and I think it is really important to show them that you are an organ donor so that they would know that you have actually given consent. If you rely on verbal communication to let the paramedics or staff at the hospital who are taking care of you know—verbal communication will be probably very difficult for deaf and hard-of-hearing people.

Gary MAAS: Thank you.

The CHAIR: Thanks. All done?

Annabelle CLEELAND: Yes.

The CHAIR: Great. I have just got a couple of questions now.

Philip WATERS: All right.

The CHAIR: We have heard from other witnesses and we have spoken about different touchpoints where people can register to become an organ donor, such as drivers licences or enrolling to vote. Are there any kinds of touchpoints like that that you think would be particularly applicable to people from the Deaf and hard-of-hearing community?

Philip WATERS: I think it goes back to education and disseminating information, depending on whether deaf and hard-of-hearing students go to school—maybe not universities or TAFE, but probably a lot earlier than that, capturing them when they are in year 11 or year 12. I think that is where the teaching staff can explain to students and unpack the content of organ donation. It is interesting because organ donation—well, you need to be aware earlier I think in regard to ‘organ’ and what it actually means and unpacking that for people who are deaf and hard-of-hearing people. So get the word out through education, even community groups, every few years, maybe by having consultations with community groups. And marketing too—do some marketing promotional material for deaf and hard-of-hearing people in your campaigns.

The CHAIR: Yes. Great.

Philip WATERS: Oh, sorry; another one too—another strategy: you could probably ask the general practitioners, maybe encourage them to speak to their deaf and hard-of-hearing patients about being organ donors.

The CHAIR: It is like you read my mind, because my next question was whether you thought it would be beneficial if GPs and other health professionals were having those conversations.

Philip WATERS: Yes. Absolutely. It would definitely benefit them. And I think about communication as well. Communication can be difficult sometimes for deaf and hard-of-hearing people. From my experience, communicating with the GP is not always the best. The GP or nurse or all the medical staff are very short and succinct with their information due to communication barriers so they tend to bundle us out of appointments, so we do not get all the information in that regard. So compared to people who can hear, most deaf people probably do not fully understand their medication or the medical issues that they are having. So then again it goes back to having a discussion about organ donation—is that going to be the same? Are they only going to have limited information, or will they need to have more information? Will they need to contact somebody else to get that information?

The CHAIR: Great. Another question from Annabelle.

Annabelle CLEELAND: Thank you. It is actually following on from Ella’s. Are you aware of Lifeblood, the Australian blood donation service, communicating with the Deaf community in a successful campaign?

Philip WATERS: Not that I am aware of, no.

Annabelle CLEELAND: Okay.

The CHAIR: Anything else?

Annabelle CLEELAND: No, that is it.

Philip WATERS: Sorry about that. I am really sorry. I am not aware of that at all. Is that a federal program?

Annabelle CLEELAND: Sorry, it is not a program, but I was wondering if they have had a marketing or awareness campaign, because we have heard from them about potential collaboration opportunities, and I was just seeing if there was something resonating in a different field that might be relevant.

Philip WATERS: Right. I think the collaboration idea would be fantastic. It is the same issue that we have with blood donation organisations. There are not a lot of deaf and hard-of-hearing people that actually talk about that or go to provide blood. So even at community events or activities and things like that, I do not see anything like that being provided.

I think the last thing I want to raise too is the data. It will be interesting to find out how the data is monitored in regard to population and donation—organ donation, blood donation or whatever it is—and what percentage of those people are deaf and hard of hearing or have disabilities or are other language users. That will be really interesting for me to know—to know who is actually missing out—because they are part of the population. We do not know if it is a high population or if it is a low population, but it would be really nice to find out, and then we can target those groups and invest your efforts, I guess, for that percentage.

Annabelle CLEELAND: We usually give questions on notice, so we appreciate receiving questions on notice. We will definitely ask those questions. I really appreciate your contribution, Philip.

Philip WATERS: Okay. Thank you. I appreciate that.

The CHAIR: Thank you, Philip. I think having a greater understanding of who is and who is not registering to become an organ and tissue donor is something that is of great interest to the Committee, so hopefully we will get some more answers on that as our work progresses.

Philip WATERS: Great. I am looking forward to it. I am looking forward to the outcome whenever it is delivered.

The CHAIR: Are there any final questions from Committee Members? No. I think we are all done. Philip, thank you so much for appearing before the Committee today and for your contribution to the inquiry, and thank you, Marc, for also attending.

Philip WATERS: Thank you.

The CHAIR: The Committee really appreciates the time and effort you have taken, and we will provide you a transcript of the hearing today for your review. The Committee will now take a 45-minute break before the next witness. I declare this hearing adjourned. Thank you very much.

Witness withdrew.