



ABN: 71 822 552 336

Amputees out on limb everyday

27/2/2021

The Inquiring Secretary

Parliament House

Hobart Tas 7000

Re: Government Administration B

Special Report on Resolution to Commence Inquiry (28 October 2020)

Dear Honourable Members of the Committee,

We are pleased to present our submission to this inquiry. We welcome any feedback should it be considered as relevant to your inquiry and would be happy to discuss our concerns in person.

**The TAS Inc Submission inquiry in accordance with Sessional Order 4 (14)
Government Administration Committee B in relation to the Tasmanian Government's responsibilities under its co-arrangement with the National Disability Insurance Scheme (NDIS).**

Background

The Tasmanian Amputee Society Inc (TAS) is the peak body for amputees and people living with limb difference in Tasmania. TAS was founded as a non-profit charity in April 1994 by a group of amputees at the time when the responsibility of servicing amputees in Tasmania transitioned from being the responsibility of the Federal Government via The Commonwealth-operated Repatriation Artificial Limb and Appliance Centres (RALAC) to being managed by Tasmanian Government Department of Health via Tasmanian Artificial Limb Scheme (TALS). The service was and is currently delivered by Orthotics and Prosthetic Services Tasmania (OPST). At this time TAS were instrumental in getting the best deal per capita of the Federal Funding for our State. In February 1995 we organised a meeting in Sydney of many state organisations representing the then estimated 50,000 amputees within Australia to determine if a national peak body should be established. In 2004 Limbs4Life became the peak body for Amputees in Australia. TAS works closely with Limbs4Life on amputee matters and are represented on National Amputee Advisory Council (NAAC). The role of the Council is to provide feedback and recommendations relating to the

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wellbeing of the amputee community, children and youth living with limb differences their families and primary care-givers. TAS also has a representative on the Tasmanian Health Departments Tasmanian Amputee Model of Care Project.

TAS provides support to amputees their families and carers, living with limb differences; access to specific health-based resources to inform amputees, and advocates for fair and equitable outcomes to allow people to obtain the best outcome that allows them to live an ordinary life the same way as can all Tasmanians who do not have a disability.

Since the establishment of OPST who also manages (TALS), 98 percent of the services to Tasmanians living with limb difference or requiring orthotics is provided by OPST in three centres: Hobart, Launceston and Burnie. Amputees in all states and territories of Australia have access to choice over their prosthetic provider, with the exception of Tasmania. (source: Tasmanian Health Department). Even territories with smaller populations such as the Australian Capital Territory and the Northern Territory offer both private and public services and as such, individuals living with limb loss can choose their preferred provider. Participants who have NDIS funding have the option of accessing one other service based in Launceston. The underlying premise of the NDIS is to allow people living with a disability to live an ordinary life and have choice and control over where they can access a preferred provider. In Tasmania no progress has been made towards this, and Tasmanian amputees are still limited to one service in their own state.

By comparison, The Victorian Artificial Limb Funding Program (VALP) provides clear pathways to how productivity and service can be shared among providers. In Victoria, there are twelve separate facilities which oversee the VALP, although the number of people living limb difference in other states such as Victoria and NSW are significantly higher than amputee population in Tasmania.

Sometime in 2017, the Tasmanian Health Department undertook a review of TALS but is yet to finalise, make recommendations and provide a draft copy as promised by the Tasmanian Health Department back in 2019. NSW and Victoria with a higher population of amputees and more providers completed their reviews within 18 months. We understand that the Tasmanian Health Department are seeking a project manager to complete the TALS review. We do not know if funding is available to complete this review. We assume that the current

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Inquiry by the Tasmanian Legislative Council covers different aspects of services to people living with limb difference.

Responses to Tasmanian Government's responsibilities under its co-arrangement with the National Disability Insurance Scheme (NDIS) to provide support for people with disabilities with particular reference to:

1. Consideration and management of the State based costs of long-term care and support for people who are not eligible for the NDIS:

To meet the eligibility criteria of the NDIS, participants must have a significant permanent lifelong disability requiring ongoing support over their life time that affects a person's ability to participate in everyday activities; be an Australian citizen or hold a permanent visa or a Protected Special Category visa; have a permanent disability that significantly restricts daily living; and be aged less than 65 when first accessing the NDIS. People are required to provide evidence of their permanent lifelong disability. Evidence must be provided by an Allied Health professional such as doctor, prosthetist, psychologist or treating professional. Some people living with a limb difference disability may not be deemed eligible to access NDIS funded supports, along with people who are over 65. The National Access Team with the NDIS makes the decision if someone meets the criteria or whether supports are more appropriately funded via mainstream and community supports (the Health care System). This cohort are required to access mainstream or community based services such the Age Care system, public health care system or through their compensation payout in respect to damages related to personal injury. Veterans who either lost their limb as a result of injuries received while serving, or who have a Gold Card, will have their prostheses and related supports paid for by the Department of Veterans Affairs or the Defence Force. NDIS participants cannot access funding that is duplicated by other mainstream or community services. Sometimes the lines can be blurry resulting in confusion and both NDIS and health system reporting that one or the other has responsibility to fund the consumer of a particular service. Psychosocial, nursing, home care or Physiotherapy are examples.

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For people over 65, or those living with minor lower limb difference (for example, diabetes related disabilities do not meet the eligibility criteria listed on NDIS list A and B conditions which are likely to meet under the NDIS Operational Guidelines, NDIS Rules and NSIS Act) being able to access NDIS funding is discrimination as the majority of Tasmanians living with a limb difference who have a permanent and ongoing disability despite their activity level do not enjoy the same access to services or assistive technology that people with NDIS funding enjoy. People able to access NDIS funding have better opportunity in their ability to retain employment, gain employment and contribute to the overall economy. They are better equipped to return to a similar “quality of life” compared to people that rely on the Aged Care System or mainstream services. There is already a huge difference in funding between the NDIS and the Aged care system and the type of services that are funded. The funding system heavily favours NDIS participants both financially and with the amount of services provided. This gap will most likely get wider over time because of financial limitations with the Tasmanian Health budget. People that do not have access to NDIS supports are likely to be requested by the Tasmanian Health system to make a contribution for componentry in relation to their prosthesis if deemed by the Tasmanian Health Service that is above standard componentry.

Some people have commented on being rejected for a prosthesis under the Tasmanian Health System. Examples include an 87-year-old who said:

“We were very disappointed that I didn’t get the option to have a prosthesis. I am 87 and in reasonable health. I could have managed if I was given a go. We were never given the option to receive a leg. They said it was too hard to fit something due to stress on body. Please help us.”

Consumers have raised inadequacies within the public system. Some comments related to funding for prosthetics, for example, “government funding for prosthetics is totally inadequate.” “Only provides for basic limbs”. “People who ‘happen to get sick’ are significantly disadvantaged compared with those who are compensable”, and “Being a public patient I feel I am not able to access the best type of prosthetics available.” (source: Limbs4 Life survey 2017).

This difference in funding may also limit the knowledge and availability of appropriately qualified and experienced prosthetic professionals within the Tasmanian Health Service. As providers in other states have greater competition, diversity and resources Tasmanians

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living with limb difference are at disadvantage and have limited choice and control over where they can access services. In future this will affect the quality and relevance of the prosthetic equipment supplied to amputees within Aged care and those who rely fully on the Tasmanian Health System or other mainstream services. There is also a lack of knowledge about amputees within the Tasmanian Health System. In Tasmania, some people living with limb difference are not aware of the services available to them (some of these supports are free). This applies to both public and private sectors and is most likely due to the lower numbers of amputees and access to providers in Tasmania compared to Victoria where more competition and options are available to consumers of services. One person commented. *"In my experience I was not able to get a referral to more experienced interstate help when I needed it"*. Another commented: *"I accidentally became aware of the TAS voluntary Peer Support Program. I was not aware it existed until 10 years from date of my amputation, until I had a prosthesis that didn't limit my lifestyle; and when severe pain issues developed, it has taken another 12 years to resolve these. On contacting the TAS I was provided with options and referred to services that resolved my issue"*. With the flexibility of choice, control and access to information, this amputee would have been able to get on with living an ordinary life. It took this person a 22 year long journey to get a quality prosthetic leg that didn't cause severe pain or limit their lifestyle. His experience was extremely frustrating and at times very expensive. Many amputees over 65 are worried about future services, equipment and funding.

2. The range of support services available to Tasmanians who are not on, or eligible for, the NDIS:

The TAS provides a free service to people living with limb difference or people who maybe facing an amputation via the Peer Support Program. Only an amputee who has taken the journey and has lived experience understands the barriers that can be faced by other amputees. The TAS can match an experienced Peer Support Volunteer and provide practical support to people living with limb difference, including supporting families and carers. The TAS meets regularly to discuss issues that are related to amputees. The TAS operates a Volunteer Support Program that will match like for like to support amputees living with limb difference. Support can be provided face to face and allows the person to have contact with a Peer Support Volunteer prior to and following surgery, via phone or via virtual for those who would prefer to have contact on-line. Group support is another option amputees

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can access via regular meeting where a guest speaker presents topics of interest to amputees. Group activities provide an opportunity for amputees socially to discuss and resolve barriers that are related to real life situations. From Jennifer wife/partner of Glen 51 (amputee).

"Meeting other amputees really helped my husband both prior to and following surgery. It helped with decision making and better prepared Glen in his journey. It also made a big difference to me as a partner of an amputee. I was able to have a chat with another carer of an amputee. We had no idea what to expect and what our lives would be like after he lost his leg as we thought that he could not return to work or drive again. The support and information were of great value - practical and factual".

People facing amputation initially need to access the Tasmania Health System for their interim prosthesis (The interim prosthesis is stage one of prosthetic therapy --the provision of an interim prosthesis. This will usually happen during the first few weeks or months after amputation). Each case is different depending on the individual circumstances. Once they have moved onto their definitive prosthesis (the definitive prosthesis is the prosthesis fitted once the limb is ready to be fitted with a long term prosthetic limb), if eligible for NDIS, once the Prosthetic and Orthotic Script quote is approved by the NDIS they get on with their life. Generally people with funding in their plan can access the latest technology when a prescription is recommended. NDIS funding can be self managed, plan managed, or Agency managed. It is important that payment is processed within the current NDIS funding period. For example if internal Tas Health systems are not well structured reimbursement to Tasmanian Health system could be complicated as funding in a person's plan is determined by a start and end date. For non-eligible consumers the options to the latest technology are not normally funded by the Tasmanian Health system unless a contribution is made by the person requiring a particular prosthesis. An OPST manager once described the situation as follows for amputees wanting to access the latest technology: They compared a current Holden model to the model of 10 years ago. Amputees accessing OPST are most likely to receive the 10 year old model. One amputee commented about why he chose to pay for the cost of his prosthesis: *"the basic 'standard' prosthesis was pretty ordinary, so I had to pay lots to upgrade to allow me to do the things I needed to do everyday".*

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Non-eligible NDIS amputees can access services through the Tasmanian Health system located in Hobart, Launceston and Burnie. Typical services required by an amputee may include:

- The treating surgeon who will discuss options with the person facing amputation and Allied Team such as the Prosthetist and or Physiotherapist.
- The Occupational Therapist who will assist amputees with day-to-day activities, like personal care, domestic tasks such as meal preparation, accessing your place of residence, education or work readiness.
- A Physiotherapist who can assist with the exercise program and assist with walking (gait), building strength and balance, and learning how to use equipment such as walking frames and wheelchairs etc.
- Prosthetist and/or Orthotist will design, manufacture the device and make decisions around the best components to suit the needs, activity level and lifestyle of the amputee with input from the amputee. They will also help the person learn how to take off and put on their prosthesis, maintain it and look after the residual limb.
- Social Workers provide counselling assistance to the amputee and their family, provide emotional support and refer to other appropriate services such as Centrelink, transport, disabled parking, Companion Card taxi cards etc.
- The nursing team provides support around medications, personal hygiene, dressing and any wound care and diabetic management, possible manual handling training to support workers and family where required and health care plan etc.
- Patients also have the option of accessing services through the Medicare system for such things as counselling, physiotherapy, health care plan and other allied health services with a referral from their treating doctor. Community services providers can assist with transport getting to and from medical appointments such as Community Transport Tasmania. People wishing to have employment can seek support from Disability Employment Services or via mainstream employment services.

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- Patients can access the Health system via OPST, access through rehabilitation doctors in all regions. The OPST prosthetist will make a referral to only Rehabilitation Specialist Dr Lucy Madebwe who is based in Hobart and has a long waiting list. Dr Madebwe is the only Rehabilitation Specialist currently available to patients. Previously Launceston had Dr Suzie Inglis, Rehabilitation Specialist who was connected to OPST came from Melbourne, visiting Launceston regularly, about once a month. One user of this vital service commented:

"She was brilliant – a good overall knowledge of prosthetics, as well as the impact of amputation on the whole body. A pity she wasn't looked after, or valued by the hospital, so that she has moved on. There seems to be a lack of knowledge about the impact on health of long-term amputees – who overviews this – the care of the spine and the 'good' foot"? (name withheld due to privacy)

Many GP doctors are not knowledgeable about amputees' overall health implications or amputation sites. Most people living with limb difference will be referred to a doctor who specialises in sports injuries. Another issue is that amputees are often linked with Rehab Specialists who deal with geriatric patients –

"This happened to me when I was about 40 and was referred to Dr Andrew MacLaine-Cross; he was excellent, but this is unsatisfactory for younger amputees. And Dr MacLaine-Cross is now no longer seeing private patients – I believe that you can only see him through hospital clinics." (name withheld due to privacy)

Upper and lower limb amputees have a unique set of variables and potential inherent problems when it comes to residual limb (stump) care – a range of medical things such as pressure points, ulcers, neuromas, haematomas, bone spurs, circulation, skin break-down, and so on. We need to have regular access to a medical professional who specialises in these things so that we can be more proactive and avoid problems, rather than always treating the problems. Comment from consumer:

"I can go for many years without anyone else seeing the condition of my residual limb – who oversees this? Not the prosthetist – no one looks at it or feels the condition and identifies any potential problems. Who knows what is normal? It's only as we become experienced

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amputees that we begin to know and understand our own unique set of problems – and we often find that we are informing the doctor about aspects of our care".

We believe that there are clinics available through OPST in Hobart, but these are infrequent and there is a long waiting list, as well as the travel component. People coming from the north or northwest of the state may have to take the day off from their normal activities to attend these clinics and may require overnight accommodation to access the service. What we need is more immediate access to a health professional when there is a problem – it's no good waiting for months to see someone if you are having difficulties.

3. Funding for organisations that service those not eligible for the NDIS:

Most organisations have the capacity to apply to be provider of NDIS services as long as the meet the following criteria:

- Be endorsed NDIS Quality and Safeguards Commission who regulate NDIS providers, provide national consistency, promote safety and quality services, resolve problems and identify areas for improvement;
- Understand the goals of the NDIS and the role of registered providers;
- Provide services that are funded by NDIS (under NDIS Price Guide);
- Understand the benefits of being a NDIS provider;
- Understand what consumers want from the organisation;
- Meet the formal requirements of the NDIS Quality Framework Commission.

A large percentage of Allied Health professionals are deregistering as a NDIS provider due to the cost and burden of auditing, compliance processes placing the mainstream and community sectors under stress.

Organisations and other services who not NDIS registered organisations can apply for funding under the NDIS Information, Linkages and Capacity Building program with is managed by Federal Government Department of Social Services via the Community Grants Hub for projects intended to build independence of individuals with a disability. These are usually short-term options for 18 to 24 months.

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The Federal Government funds people who are living with limb loss, above the age of 65 requiring support, through the Aged Care System.

Organisations such as Diabetes Tasmania and the Cancer Council of Tasmania can provide information and prevention on how to manage and reduce the impact potential limb loss.

4. Workforce development and training opportunities for the disability support sector, including allied health:

TAS provides free accredited training and information sessions for people living with limb difference and can provide information to Allied health professionals on how to refer and assist people living with limb difference. Peer Support Volunteers are accredited to support people living with limb loss and their families. Peer support is not about counselling but helping people through issues that they are going through by a person that has taken the same journey and experienced barriers and overcome them.

Our program is accredited by AOPA and the Tasmanian Health Department.

Peer Support must meet the following criteria: It is required that volunteers are checked for suitability for the program and are at least 3 years post amputation surgery (i.e. they have had a chance to adapt to limb loss and have a lived experience and positive mind set). Peer support volunteers do not provide counselling.

The TAS volunteer training program

- outlines codes of conduct, personal boundaries and communication/listening skills/the do's and the don'ts;
- Requires completion of police and criminal conviction checks;
- Requires completion of privacy and confidentiality agreements;
- Working with Vulnerable people clearance.

There is a post-visitation review process to ensure consumer satisfaction. In addition, the consumer of the visitation is followed up on to determine if any concerns have come from the visitation. Further follow up sessions maybe offered if required or requested.

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Prosthetists and Orthotists can access workshops via AOPA or via the Health System. The Tasmanian Health Service provided internal personal development options for their employers.

Accredited Allied Health professionals can access personal training from their professional bodies such as Australian Physiotherapy Association or Occupational Therapy Australia who hold regular information and webinars.

5. Other Matters

In comparing people that have NDIS funding to those funded by the aged care or mainstream service there is inequality between people's circumstances, particularly the capacity to acquire a functional prosthesis and their ability to make independent decisions about what device best suits individual needs and choice of which provider to access. This needs to be reviewed to allow those Tasmanians who miss out to have the same access to services as their peers enjoy who have access to NDIS funding.

In Tasmania, diabetes is the leading cause of non-traumatic limb amputation. Information from the Tasmania Health Service who may require amputation are usually above 50 years of age and have other health issues that impact on their health and in particular diabetes which places them at risk of other health complications. The incidence of amputations in Tasmania is increasing due to the diabetes epidemic in Tasmania. There are more than 4,400 amputations every year in Australia as a result of diabetes. This is the second highest rate in the developed world. The number of amputations is placing stress on the Tasmanian Health System.

Below outlines the figures for Tasmania: PLOS One Study Geographic variance of lower limb amputation. (2007/8 – 2011/12)

Demographics Tasmania

Description	Data
All amputations	873
Above knee	71
Below knee	128
Partial foot	236

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Toes	420
Other	18
Over 60	528
35 – 60	274
<35	36
Male	560
Female	278
T2 Diabetes	365

Source: Geographic Variation of the Incidence Rate of Lower Limb Amputation in Australia from 2007-12: Michael P Dillion, Lauren V. Fortington, Muhammad Akram, Bircan Erbas, Friedbert Kohler

During the late 1990's to approximately 2007, The Tasmanian Health Department conducted the Statewide Planning and Implementation Committee which was chaired by a Director from Tasmanian Health Department. The Committee comprised a combination of Allied Health professionals, rehabilitation specialists, consumers and other stakeholders of the Tasmanian community. This was an invaluable resource for all stakeholders accessing Tasmanian Health Services as it provided a mechanism for interagency organisations to discuss pertinent issues and improve services to consumers and gave Allied Health professionals opportunities to liaise with other allied health professionals and consumer groups. Consideration should be given to establishing a similar Committee.

To support consumers of the Tasmanian Health Service to have better outcomes for amputees, the current system needs to be reviewed.

Recommendations

Prosthetists, orthotists and other related Allied Health Professionals be required to meet some minimum accreditation/registration and have access to appropriate personal development to enable them to be up-to-date with the latest changes to the sector.

Establishment of a Tasmanian Health services panel which includes stakeholders and consumers together with health care professionals and Tasmanian allied health personnel.

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Information relevant to the person living with a limb loss condition should be easily accessible, as well as relevant resources and information kits on where to get services and Peer Support. People would like to know more about advances in prosthetics and related products such as water/shower legs and new technology. However, many said that they were not aware of new prosthetic products and aids as they became available.

Improve access to services and reduce waiting times to obtain Allied Health services.

Non NDIS eligible consumers of the Tasmanian health system access to appropriate equipment to aid their rehabilitation and recovery in a timely manner without lengthy paper trails (internal bureaucracy and red tape) to enable them to live an ordinary life and build individual capacity.

Non NDIS, compensation payout consumers in respect to damages related to their personal injury. Veterans who either lost their limb as a result of injuries received while serving, or who have a Gold Card, will have their prostheses and related supports paid for by the Department of Veterans Affairs or the Defence Force have equitable funding above the current basic prosthetic components.

Allow private providers to access the market to allow for greater choice and control for consumers accessing OPST (TALS).

Be more willing to respond with transparency to enquires made to Tasmanian Health Department in a timely manner. This statement refers to the Tasmanian Health review into the TALS. The Tasmanian Health Department despite several requests by stakeholders have declined to provide any information. At the TAS face to face meeting in November 2018 in Campbell Town we were promised by The Tasmanian Health Department to have a draft copy of recommendation by December 2018.

Allow both NDIS and non NDIS participants to have access to health professionals who understand the day to day issues people living with limb difference experience- e.g. a specialist GP who is able to make assessments and recommend practical interventions that will improve the quality of life for amputees.

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That people living with limb difference have access to Rehabilitation Specialists in each region of Tasmania and to be available to see amputees at least once a year to review how they are going and refer on to other Allied Health specialists when required.

Set up, at least on a yearly basis, where people can attend capacity building therapy clinics that involve multiple Allied Health specialists and providers of componentry as happens in other states.

Please feel free to make contact via email to peter.hatters@bigpond.com or by mobile 0438523015.

Yours Faithfully

Peter Hatters

C.E.O Tasmanian Amputee Society Inc
on behalf of the Board of the Tasmanian Amputee Society Inc

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