

Submission to the Inquiry into Disability Support Services in Tasmania

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Glossary

Amputee	A person living with limb loss, due to the absence or surgical removal of a limb or limbs
Assistive technology	Adaptive, and rehabilitative devices for people with disabilities or older persons to assist them to lead independent lives
Central fabrication	An off-site location where the raw prosthetic cast is sent to the socket to be manufactured
CRPD	The Convention on the Rights of Persons with Disabilities
Fit for purpose	Prosthetic device manufactured for a particular use (e.g. for walking)
Limb loss	Acquired absence of a limb or limbs
NDIS	National Disability Insurance Scheme
OPST	Orthotic Prosthetic Services Tasmania
Prosthesis (artificial limb)	A device which helps to replace the mobility or functionality of a missing limb/s
Prosthetic provider	A trained clinical practitioner who manufactures prosthetic devices (artificial) limbs
Sleeve	A suspension sleeve is used to connect the prostheses to the user
Socket	The shell that encases a person's residual limb (stump)
Stump	Residual limb
TALS	Tasmanian Artificial Limb Scheme

1. Submission background

Limbs 4 Life is Australia's national peak body for people living with limb loss and welcomes the opportunity to provide a submission in response to the Inquiry into Disability Support Services in Tasmania.

The comments and recommendations presented in this submission are premised on almost two decades of supporting amputees and widespread local and international research in the field of amputee needs. It also draws upon a recent Limbs 4 Life survey, responded to by 53 individuals, which canvassed Tasmanian amputees' responses to this inquiry's questions and has facilitated de-identified comments throughout.

Limbs 4 Life has been providing support to the amputee community in Tasmania for thirteen years. Over this time we have been made aware of inequitable and untenable amputee related supports and services; matters which we raised in communications, a face-to-face meeting with a previous Tasmanian Government Minister for Health and during meetings with senior Department of Health representatives in 2018.

Furthermore, we also contributed to a Department of Health Inquiry which focused on the consumer and stakeholder experience of the Tasmanian Artificial Limb Service in 2018 which, to the best of our knowledge, has not been finalised nor resulted in positive and necessary changes for the provision of amputee-related care and support. We have also engaged in individual advocacy on behalf of several Tasmanian amputees in dire need of urgent support.

The scope of our submission provides responses to a number of matters which fall under the remit of the Inquiry's Terms of Reference. It is Limbs 4 Life's position that the most significant issue for Tasmanian amputees' is difficulties accessing assistive technology and prosthetic services in a timely and efficient manner. In response to the inquiry questions we provide significant commentary regarding this matter and offer recommendations for improving outcomes for Tasmanian amputees who require assistive technology to live a safe, independent and participatory life. We also include direct feedback and comments from amputees who wished to vocalise their thoughts to this inquiry.

Sadly, the lack of access for those ineligible for the NDIS support is creating a wider gap between the amputee 'haves' and the 'have-nots'. Not only is this intolerable, but it is discriminatory and in violation of human rights.

We trust that Limbs 4 Life's submission will assist the Committee to understand the issues faced by Tasmanian amputees ineligible for the NDIS, our past attempts to redress these and other amputee related matters with government representatives, and consider our proposed recommendations to improve support for this disability group in the future.

1.1 Summary of key issues

- Annually, lower limb amputations alone account for almost 9,000 amputations across Australia. Within a five-year period from 2008 – 2012, 873 lower limb amputation procedures were performed in Tasmania (an average of 175 per annum); 66 per cent of which were males and 33 per cent female, with a mean age of 63.1 years. Upper limb amputation over this period is not available.
- Amputees ineligible for the NDIS receive funding through the Tasmanian Artificial Limb Scheme (TALS) to access Orthotic Prosthetic Services Tasmania (OPST) clinics. OPST is a state-wide public service with clinics in Hobart (Royal Hobart Hospital), Launceston (Launceston General Hospital) and Burnie (North West Regional Hospital).
- There is only one private prosthetic provider in Tasmania, however TALS-funded clients are unable to access service from this provider unless they choose to self-fund.
- Limbs 4 Life has raised concerns about the provision of prosthetic servicing, wait times and lack of choice and control in terms of access to prosthetic assistive technology in correspondence and meetings with the Minister for Health and other Tasmanian Government representatives from as far back as 2017. Senior Department of Health representatives commenced an inquiry into these matters in 2018, which Limbs 4 Life participated in. However, despite repeated requests, we have never received a copy of the report and arising outcomes.
- Provision of timely and fit for purpose assistive technology, in particular prosthetics, is a fundamental disability and human right for amputees.
- Prosthetics are vital assistive technology enablers which support amputees to access and feel included in their place of residence, local communities, lifelong learning settings and workplaces. However, delayed access to prosthetic services and inequitable funding for those ineligible for the NDIS present as barriers to achieving these outcomes in Tasmania.
- The type of prosthetics provided through the Tasmanian Artificial Limb Service (TALS) are generally not as advanced as those available through the NDIS or require co-contribution if one of better functionality is required. Furthermore, amputees can often experience lengthy waiting times for vital appointments or have to travel considerable distances to attend an Orthotic Prosthetic Service Tasmania (OPST) clinic. Basic prosthetics and delays in accessing this service puts people at a greater risk of falls, back and hip problems, unnecessary stress on their sound limb, poor mental health, and inability to participate in work and contribute to the economy.
- There are only three OPST clinics in Tasmania – Hobart, Launceston and Burnie. And, unlike other states, there is no ‘travelling clinic’ to meet the needs of amputees in other locations, such as Northwest Tasmania. Consequently, some amputees must travel significant distance to see their prosthetist which in most cases require multiple visits for prosthetic fitting and subsequent gait training. In those cases, these amputees incur unfunded travel costs and spend considerable time driving or using public transport to attend appointments.
- Amputees in Tasmania have limited choice in relation to the prosthetic provider available to them. If they do not have a positive outcome with their OPST prosthetist the only other option is to attend an OPST clinic in another location or personally fund the cost of seeing the only private provider in the state. Indeed, some amputees reliant on OPST have even travelled to other states to see a prosthetist that could meet their needs.

- Some OPST clients are being told that the delays and wait times are up to six to eight weeks for the delivery of prosthetic componentry and products, despite the fact Australian suppliers hold vast amounts of stock that can be sent to Tasmania within 24 - 48 hours. And where stock needs to be sent from manufacturers overseas, these products generally reach Australian shores within 5 working days. The consequence of these delays can cause critical issues which result in skin breakdowns, ulcerations and, in worst case, hospitalisation.
- The prosthetic clinic in Burnie (North West General) does not manufacture prosthetic sockets. Instead clients' socket casts are sent to either Hobart or Launceston for central fabrication, extending the wait time of up to 3 weeks for a socket turnaround.
- Overall, the issues of fragmented and lengthy wait times to access to prosthetic provision and essential products is a human rights and systemic matter that the Tasmanian Government should be aware of and seek to resolve as an outcome measure in this Inquiry.
- Rehabilitation is vital for amputees to learn to adjust to the loss of a limb/s and involves a multidisciplinary healthcare team. Rehabilitation involves not only critical physical training, but also other supports to facilitate independence, accessibility and socio-economic participation planning and goal setting.
- The effective and appropriate provision of rehabilitation and in areas as close to a person's own community is a requirement of state parties that are signatories to The Convention on the Rights of Persons with Disabilities.
- It is unclear why the rehabilitation facility for amputees is based at Mersey Community Hospital in Latrobe but not connected to the Burnie prosthetic clinic at North West Regional Hospital, requiring amputees to be transferred from one to the other for prosthetic servicing.
- Presently there is only one Hobart-based Rehabilitation Consultant (doctor) to oversee an amputee's rehabilitation plan. This doctor plays a critical role in planning an amputee's post-surgery rehabilitation journey, making it critical that this skill shortage is addressed in other locales such as Launceston and Burnie, as well as Northwest Tasmania.
- The Tasmanian Government should, like many other states, implement A Minimum Standards of Care for Amputees which factors in the care needs for lower limb and upper limb amputees. In developing such Standards, amputee consumer bodies and stakeholders should play an active role in their development. Using a co-design approach ensures that the knowledge of those with lived experience or professional knowledge is captured and utilised. As such, representatives from Limbs 4 Life, LaTrobe University and the Australian Prosthetic and Orthotic Association (governing body for prosthetic providers) should be invited to the table.
- A formal and managed Peer Support Program, delivered by trained and experienced amputee peers, should be made available to all consenting Tasmanians who experience amputation. The option for the provision of peer support should be made standard practice as part of the Care Standards and offered to all people pre or post amputation, along with their family members.
- The Tasmanian Artificial Limb Scheme (TALS) needs increased funding in order to meet the demands of a growing population of older amputees. This would facilitate funding for prosthetics that are more advanced and meet the needs of each individual, allow for employment of additional prosthetists, servicing availability in all key regions, and ensure timely access to appointments (including emergency ones).

- Take an 'open market' approach, as used in other states, by approving all prosthetic providers to service TALS-funded amputees.
- Peer support is an efficient and effective way to support people with disabilities and/or chronic illness to adapt to their new condition. It is vital that the Tasmanian Government fund the provision of a formally managed peer support program for amputees in Tasmania, in recognition that it is an important addition to rehabilitation as noted by researchers, the World Health Organization, The Convention on the Rights of Persons with Disabilities and in existing Amputee Minimum Standards of Care used in other Australian states.

1.2 Summary of recommendations

Recommendation 1

That the Tasmanian Government recognise that the provision of appropriate assistive technology is a human right for all amputees, regardless of whether they are eligible or ineligible for the National Disability Insurance Scheme, and that should underpin all decisions made in regards to improving access to state-funded prosthetic services and advanced prosthetics.

Recommendation 2

Tasmanian Artificial Limb Scheme (TALS) funding should be increased to reflect that the current and prospective number of Tasmanian amputees ineligible for the NDIS and are in need of prosthetics suited to their activity level which in turn will enhance and promote positive psycho-socio-economic outcomes.

Recommendation 3

The Tasmanian Government invest in increasing the number of OPST clinics and/or open the market to include private providers to ensure that amputees have access to prosthetic servicing in all key state regions and at times outside of regular business hours. This would result in reduced wait times, minimise the need for some amputees to travel vast distances, or limit some from having to self-fund travel to the mainland to access timely prosthetic services.

Recommendation 4

Investigate why some amputees attending Tasmanian prosthetic clinics are experiencing excessive wait times for prosthetic componentry and consumables delivery.

Recommendation 5

Investigate why some amputees are experiencing such lengthy wait times for appointments. Determine how a client is lost in a system and revise approaches to ensure that this does not happen.

Recommendation 6

Make the Burnie prosthetic clinic a fully functional facility enabling staff to manufacture prosthetic sockets on-site, thus reducing wait times required for the purpose of central fabrication.

Recommendation 7

The Tasmanian Government should increase the number of Rehabilitation Consultants available to amputees across the state, and address the skill shortage issues that only having one Hobart-based doctor presents. Consideration should be paid to placing such doctors in hospitals with rehabilitation facilities in order to coordinate locally-based rehabilitation planning and care.

Recommendation 8

Amputee rehabilitation units need to be connected to prosthetic facilities to ensure that individuals can transition back in to independent living as soon as possible. It does not make sense that amputee rehabilitation is undertaken at Mersey Community Hospital with clients then moved to Burnie for prosthetic treatment and care. The two should be co-located to facilitate ease of access and seamless integration for amputees undergoing rehabilitation.

Recommendation 9

The Tasmanian Government should implement 'Minimum Standards of Care for Amputees', which explore the care needs of upper and lower limb amputees. Representatives from Limbs 4 Life, the Australian Orthotic Prosthetic Association (AOPA), LaTrobe University and treating healthcare staff should be involved to capture their knowledge and insights, thus evidencing a co-design and social model approach to the development of these standards.

Recommendation 10

Alleviate the burden on OPST and provide amputees over 65 years with choice by opening the market to private providers to service TALS-funded amputees.

Recommendation 11

Recognise that peer-to-peer support is an efficient and effective means of socially, emotionally and practically assisting any new amputee to adapt to their 'new normal' and ensure it is made available as a minimum standard of care.

Recommendation 12

Resource Limbs 4 Life, Australia's only peak national organisation for amputees and developer of the best practise Peer Support Program, with the funds to continue offering and expanding peer support to older (and all) Tasmanian amputees; an investment in not only individual lives but also health system cost reductions.

2. About Limbs 4 Life

Limbs 4 Life's mission is to provide information and support to amputees and their families while promoting an inclusive community.

Our philosophy is to *empower amputees with knowledge and support to make a real difference, because no one should go through limb loss alone.*

Limbs 4 Life is the peak body for amputees in Australia, founded as an incorporated charity in 2004. Limbs 4 Life provides services to thousands of amputees and their care givers, who rely on its programs and support for assistance prior to or after a limb amputation. Limbs 4 Life is supported by over 200 trained Peer Support Volunteers, located across Australia, who visit people pre or post an amputation.

Since its formation, Limbs 4 Life has greatly extended the supports available to amputees, their families, primary care givers and healthcare staff. Limbs 4 Life's services include provision of:

- Best practice Peer Support Programs
- Evidence-based health literacy resources and wellbeing information
- Independent support and advocacy to assist people to navigate healthcare and disability systems
- Access to social and economic inclusion activities.

Limbs 4 Life advocates for amputees by initiating or taking part in research, provides recommendations to government, responds to submissions, and educates the community about amputation. For more information visit www.limbs4life.org.au

3. Amputee population and limb loss causes

3.1 Tasmanian amputee population

Annually, lower limb amputations alone account for almost 9,000 amputations across Australia.¹ Within a five year period from 2008 – 2012, 873 lower limb amputation procedures were performed in Tasmania (an average of 175 per annum); 66 per cent of which were males and 33 per cent female and a mean age of 63.1 years.² Unfortunately, data pertaining to upper limb amputations in Tasmania are not currently available. This does not account for the additional number of amputation procedures which took place on the mainland due to surgical complexities.

3.2 Amputation and limb loss causes

The aetiology of surgical amputation of major limbs (upper and/or lower limbs) in Australia is varied and diverse, with the main causative factors including diabetic-related complications, vascular disease, trauma, cancer, and infections. Such limb loss can occur at any stage within an individual's lifetime. In addition, members of the amputee community comprise those born with congenital deficiencies of major limbs, which sees this cohort experience a lifetime of living with limb loss.

Notably, Australia has an appalling record when it comes to diabetic-related amputations with the rate of such limb loss increasing by 30 per cent in the past decade and resulting in our country having the second highest rate of such amputations in the developed world.³ Of grave concern is the fact that major limb amputations are 38 times more likely in Indigenous Australians aged 25-49 years than in the general population.⁴

Lower limb amputation has become an area of increasing concern for those working in modern healthcare in western countries due to its prevalence in amputations arising from the ageing population and increase in lifestyle related illnesses such as diabetes and peripheral vascular disease.⁵

4. Prosthetic services in Tasmania

Amputees needing prosthetic servicing are predominately serviced by the state government and to a lesser degree one private prosthetic provider. Amputees ineligible for the NDIS can only access prosthetic services through state-government Orthotic Prosthetic Services Tasmania (OPST) clinics, although a small number elect to self-fund visits to the only Tasmanian-based private provider or mainland-based prosthetic providers.

4.1 State-government prosthetic servicing

Orthotic Prosthetic Services Tasmania (OPST) is a state-wide public service with clinics in Hobart (Royal Hobart Hospital), Launceston (Launceston General Hospital) and Burnie (North West Regional Hospital). And unlike some other states, there are no public ‘travelling clinics’ whereby prosthetists visit regional or remote locations to service the needs of amputees who are significantly impacted by geography. Publicly referred prosthetic services are funded and governed under the Tasmanian Artificial Limb Scheme (TALS), which is administered by OPST. Clients funded through other bodies such as Department of Veterans’ Affairs, the NDIS, MAIB and Workers Compensation may also access prosthetics from this service.

Information on the OPST web page states that “OPST plays an important role in the treatment and rehabilitation of clients through the provision of orthotic, prosthetic and specialised seating services. Access to OPST is prioritised dependent on urgency and accordingly attended to within acceptable time-frames”.⁶

However, as noted throughout this submission older Tasmanian amputees are being let down by OPST clinics in terms of lack access to prosthetics in a timely and efficient manner, unacceptable appointment wait times, product delivery and fitting delays, and limited state-wide servicing. This, in turn, is impacting on amputees at psycho-socio-economic levels and placing them at greater physical and mental health risks.

4.2 Private prosthetic servicing

There is only one private prosthetic provider in Tasmania. This service is based in Launceston with a remote service offered in Hobart on a fortnightly basis. Unlike New South Wales, Western Australia,

Queensland, Victoria and South Australia, where even publicly funded clients can access some private providers, clients funded under the TALS program are unable to access services from this private provider. This limits amputees' funded under TALS with access to a choice of provider.

Limbs 4 Life has advocated in the past for all amputees in Tasmania (regardless of their funding stream) to access services from all providers which, in turn, would reduce lengthy wait times on the public service. This however was met with resistance and, as such, clients of prosthetic services continue to have no choice of provider and continued lengthy waiting times; something mitigated in the aforementioned states by taking an 'open market' approach in allowing public clients use private providers. To increase positive patient service outcomes there is no viable reason why treatment and clinical options for TALS-funded amputees not to be extended to include the private provider, rather than the restrictive practices currently in place in Tasmania.

5. Previous communications with the Tasmanian Government

Limbs 4 Life has raised concerns about the provision of prosthetic servicing, wait times and lack of choice and control in terms of access to prosthetic assistive technology with Tasmanian Government representatives from as far back as 2017. Limbs 4 Life also met with senior Department of Health representatives and took part in a resulting inquiry into these matters in 2018 but, despite multiple requests to receive a copy of this report and arising outcomes, this has not been made available. In addition, Limbs 4 Life has advocated on behalf of Tasmanian amputees to travel to Victoria for urgent services as they were unable to achieve a suitable prosthetic outcome in their home state.

Our concerns for Tasmanian amputees are significant, and we are gravely concerned that this disability cohort are being left behind their peers located in mainland jurisdictions. This is particularly the case for those amputees' ineligible for the NDIS and reliant on state-based funding and services to receive the assistive technology and prosthetic services they are reliant upon, and entitled to as per rights afforded in The Convention on the Rights of Persons with Disabilities (CRPD) and United Nations Universal Declaration of Human Rights (UDHR) to which Australia is a signatory.

Limbs 4 Life has, over many years been made aware of the need to improve prosthetic services in Tasmania, so that it is delivered in an efficient and effective manner and at a level provided to amputees in other parts of Australia. For that reason we have repeatedly raised this issue with Tasmanian Government Ministers, policy makers and managers of health services.

5.1 Communications and engagement with the Tasmanian Government

The following table outlines the CEO of Limbs 4 Life, Melissa Noonan, communications and meetings with Tasmanian Government representatives, and the outcomes of these.

Date	Method	Representative/s	Purpose and outcomes
May 2017	Meeting	The Hon. Michael Ferguson, Minister for Health	• Meeting held with the Minister for Health in Launceston to describe and outline concerns facing amputees in Tasmania.

			<ul style="list-style-type: none"> • Meeting also included the Policy Officer for the Australian Orthotic and Prosthetic Association (AOPA) and a public services consumer. • Request by Minister Ferguson to submit additional information via letter subsequent to the meeting.
May 2017	Letter (sent via email)	The Hon. Michael Ferguson, Minister for Health	<ul style="list-style-type: none"> • Summary of concerns raised during meeting with the Minister for Health. • Recommendations and considerations to assist in sourcing solutions.
June 2018	Meeting	<p>Paula Hyland, Chief Allied Health Officer, Department of Health</p> <p>Kendra Strong, Department of Health</p>	<ul style="list-style-type: none"> • Met with Ms Hyland and Ms Strong in Melbourne on 6 June 2018 • Department of Health conducted an inquiry into consumer and stakeholder experience of the Tasmanian Artificial Limb Service • We are aware that these representatives met with key stakeholders in Tasmania, such as healthcare providers and amputees, to learn about issues. • We are aware that these representatives met with public system prosthetic funding managers in other Australian jurisdictions to discuss operations and arrangements in those various locations. • Draft report completed in November 2018, but a final report not shared with Limbs 4 Life or any other stakeholders who contributed to this inquiry. • Our upstanding is that this report is still pending approval.
May 2019	Letter	The Hon. Leonie Hiscutt MLC to Minister Ferguson	<ul style="list-style-type: none"> • The Hon. Leonie Hiscutt corresponded with Minister Ferguson outlining issues relating to the provision of voluntary evidence-based peer support for people immediately pre and/or post amputation • Copy of correspondence received from Ms Hiscutt's office – but we received no further correspondence addressing this concern from Minister Ferguson

July 2019	Letter	The Hon. Michael Ferguson, Minister for Health	<ul style="list-style-type: none"> • Response received from Minister Ferguson's office indicating that a thorough review was taking place and draft recommendations would be provided to the Department of Health and Secretary for consideration. • Inquiry into matters raised initiated and led by the Chief Allied Health Officer, Paula Hyland. • We have not received any further correspondence in relation to this matter and associated correspondence, but understand that it has been in draft since 2019.
February 2020	Letter	Senator Jacqui Lambie	<ul style="list-style-type: none"> • Letter sent to Senator Lambie outlining concerns previously raised with Minister Ferguson (such as lack of service provision, significant waiting time delays for provision of prosthetics). • Telephone call response from Senator Lambie's advisor seeking additional information about impact of return servicemen/women and provision of prosthetics.

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

6.1 Summary of issues

- Provision of timely assistive technology, in particular prosthetics, is a fundamental disability and human right for amputees.
- Prosthetics are vital assistive technology enablers which support amputees to access and feel included in their place of residence, local communities, lifelong learning settings and workplaces. However, delayed access to prosthetic services and inequitable funding for amputees ineligible for the NDIS present as barriers to achieving these outcomes in Tasmania.
- Tasmanian amputees ineligible for the NDIS receive only basic prosthetics through the Orthotic Prosthetic Services Tasmania (OPST), via funding from the Tasmanian Artificial Limb Service (TALS).
- Basic prosthetics and delays in accessing this service puts people at a greater risk of falls, back and hip problems, unnecessary stress on their sound limb, poor mental health, and inability to participate in work and contribute to the economy.

6.2 Assistive technology is a disability and human right

Assistive technology is an umbrella term for a device or system that allows a person to perform tasks that they would otherwise be unable to do, or increases the ease and safety with which tasks can be performed.⁷ Assistive technology devices are critical enablers of mobility, communication, functionality, daily living, independence, community engagement and workforce participation.

The World Health Organization states that “Without assistive technology, people are often excluded, isolated, and locked into poverty, thereby increasing the impact of disease and disability on a person, their family, and society.”⁸ Thus, the timely provision of appropriate assistive technology ensures people with disability have the prerequisite tools necessary to uphold their rights, safeguard themselves against harm and act on any instances of abuse or neglect that occur in personal and/or workplace settings and gain positive quality of life outcomes.

A lack of timely access to functional assistive technology to facilitate participation and inclusion is not only a denial of human rights but also demonstrative of discrimination and neglect. It highlights environmental, attitudinal and systemic barriers to socio-economic participation.

The Convention on the Rights of Persons with Disabilities (CRPD) notes in its general obligations that State Parties must promote the availability and use of new technologies, including assistive technologies, give priority to provision of these at an affordable cost and offer accessible information about these to people with disabilities.⁹ Furthermore:

- Article 20 (b, c, d) requires State Parties to take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities by facilitating access to assistive technologies and associated mobility training, and encouraging entities that produce such technologies take into account all aspects of a person’s mobility.¹⁰
- Article 26 (3) indicates that State Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.¹¹

With respect to amputees, a key assistive technology device used by this cohort is prosthetic limbs. Assistive technology is very individualised, and required to enhance a person’s safety, independence, and socio-economic participation.

It is Limbs 4 Life’s position that access to assistive technology is a human right that enables participation in civil society across a person’s life course.¹² Equal access to affordable and appropriate assistive technology enables amputees to participate in our society and fulfil their potential. Prosthetics and alternative mobility devices are vital to support people with limb loss to access and feel included in their place of residence, local communities, lifelong learning settings and workplaces. However, delayed access to prosthetic services and inequitable funding for those ineligible for the NDIS present as barriers to achieving these outcomes in Tasmania.

6.3 Prosthetics

It is widely reported that the main goal for a person with limb loss is to access a prosthesis that aids in replacing what is missing in a functional manner.¹³ Indeed, the role of prosthetics and advances in this technology over recent decades provide amputees with a wide range of options that can improve function, assist in preventing further health complications and enable an optimal quality of life.¹⁴

The type of prosthesis that a person utilises is contingent on the individual; taking account of the cause of amputation, location of the missing limb/s, any other health considerations, and their desired goals.¹⁵ Consequently, prosthetic limbs are custom made by qualified prosthetists, who work to manufacture and fit a device that best meets the individualised mobility and functional needs of their client.

Amputees utilising prosthetics are users of some of the most complex and technical assistive technology available. Considerable engineering and biomechanical advancements in recent years have led to the manufacture of sophisticated feet, knee and arm units which utilise dynamic response, microprocessor, bioelectric or bionic technology. Such products include the dynamic responsive feet, computerised microprocessor-controlled knees and some myoelectric arms, to name a few. The benefits to users of advanced prosthetics are better controllability, improved balance, fall reduction, reduced osteoarthritis incidence, and decreased energy consumption.^{16 17} Furthermore, recent trends in such assistive technology point to a more seamless integration of the capabilities of the user and the assistive technology they use, and lead to transformative mobility and participation capacity benefits.¹⁸ As these products cost considerably more than the very basic technology developed in the 1950s and 1970s, the introduction of the NDIS has enabled amputee participants to request these products as reasonable, necessary and fit-for-purpose devices which deliver impactful psycho-social-economic outcomes.

Conversely, amputees receiving prosthetic funding through TALS, administered by the Department of Health, are only funded for the provision of basic prosthetics; some of which are driven by passive technology developed in the 1950s and 60's. Such products include the solid ankle cushion heel (SACH) foot, 'split-hook' hand and mechanical friction knee, which require an exhaustive amount of energy and mental concentration to use. For a lower-limb amputee who needs to be on their feet for lengthy periods, such as those in the workforce or engaging in regular community activities, wearing a standard prosthetic foot or knee, which provide minimal stability and support, can have long-term negative physical, body-biodynamical, mental, social and economic impacts.¹⁹ A person is at a greater risk of falls, back and hip problems, unnecessary stress on their sound limb, poor mental health, and reduced ability to engage in the community if wearing a standard prosthesis that does not meet their individualised needs and lifestyle. For example it is not uncommon for prosthetic feet – such as the SACH foot - to snap if too much force is put through the toe load, leaving the user at risk and unable to ambulate at all. It is basic prosthetics which are provided to amputees reliant on the TALS, unless a person is willing to co-contribute and purchase a more advanced device. But many amputees are not in the position to do this or, even if they can, it can place a significant financial burden on the person and their family. Some Tasmanian amputees are not even given the options to make a co-contribution to achieve a better outcome.

It is worth noting that funding under the TALS scheme has not been increased in years, and therefore is not reflective of the growing population of people over 65 years living in Tasmania and/or the advancements in prosthetic technology. It is also not reflective of the fact that a significant number of amputees receiving TALS funding are still members of the workforce, and provision of an advanced and fit for purpose prosthesis would assist them to remain employed.

Prosthetic quality and suitability issues noted by Limbs 4 Life survey respondents

"I think more up to date prosthetic hips and legs could be provided especially for people of my age 75+. If they are older people they will be forced into retirement home or will need extra Govt support."

"The staff need to pay more attention to the cosmetic appearance of the prosthetic. My recent leg could be reduced in size and weight to provide a more acceptable outcome."

"I believe that there are more up to date prosthetics - must be better than what I have now."

"I believe mainland parts and fittings are more acceptable and up to date than what I get given here!"

6.4 Recommendations

Recommendation 1

That the Tasmanian Government recognise that the provision of appropriate assistive technology is a human right for all amputees, regardless of whether they are eligible or ineligible for the National Disability Insurance Scheme, and that should underpin all decisions made in regards improving access to state-funded prosthetic services and advanced prosthetics.

Recommendation 2

Tasmanian Artificial Limb Scheme (TALS) funding should be increased to reflect that the current and prospective number of Tasmanian amputees ineligible for the NDIS and are in need of prosthetics suited to their activity level which in turn will enhance and promote positive psycho-socio-economic outcomes.

7. The range of support services available to Tasmanians who are not on, or eligible for, the NDIS – the provision of assistive technology

7.1 Summary of issues

- Amputees ineligible for the NDIS can access basic prosthetics through the Tasmanian Artificial Limb Service (TALS). However, the type of prosthetics are generally not as advanced as those available through the NDIS or require co-contribution if one of better functionality is required. Furthermore, amputees can often experience lengthy waiting times for vital appointments or have to travel considerable distances to attend an Orthotic Prosthetic Service Tasmania (OPST) clinic.
- There are only three clinics in Tasmania – Hobart, Launceston and Burnie. And unlike other states, there is no ‘travelling clinic’ to meet the needs of amputees in other locations, such as Northwest Tasmania. Consequently, amputees must travel significant distance to see their prosthetist which in most cases require multiple visits for prosthetic fitting and subsequent gait training. In those cases, these amputees incur unfunded travel costs and spend considerable time driving or using public transport to attend appointments.
- Amputees in Tasmania have limited choice in relation to the prosthetic provider available to them. If they do not have a positive outcome with their OPST prosthetist the only other option is to attend an OPST clinic in another location or personally fund the cost of seeing the only private provider in the state. Indeed, some amputees reliant on OPST have even travelled to other states to see a prosthetist that could meet their needs.
- Some OPST clients are being told that the delays and wait times are up to six to eight weeks for the delivery of prosthetic componentry and products, despite the fact Australian suppliers hold vast amounts of stock that can be sent to Tasmania within 24 - 48 hours. And where stock needs to be sent from manufacturers overseas, these products generally reach Australian shores within 5 working days. The consequence of these delays can cause critical issues which result in skin breakdowns, ulcerations and, in worst case, hospitalisation.
- The prosthetic clinic in Burnie (North West General) does not manufacture prosthetic sockets. Clients’ socket casts are sent to either Hobart or Launceston for central fabrication extending the wait time of up to 3 weeks for a socket turnaround.
- Overall, the issues of fragmented and lengthy wait times to access to prosthetic provision and essential products is a human rights and systemic matter that the Tasmanian Government should be aware of and seek to resolve as an outcome measure in this Inquiry.

7.2 Provision of assistive technology in Tasmania

While the landmark introduction of the NDIS has certainly improved access to assistive technology for some amputees, there are still a great many who are ineligible for this scheme (largely people over 65 years) and their inequitable and unfair situation remains the same.

7.2.1 Orthotic Prosthetic Services Tasmania (OPST)

Amputees ineligible for NDIS funding access prosthetic devices via funding from TALS. This means that recipients are not benefiting from the latest advances in prosthetic technology. While individuals can co-contribute in order to be fitted with a prosthesis of their choice, this can put the

person under significant financial hardship. In many cases, financial co-contribution for the types of prosthetics routinely provided via the NDIS is out of reach for amputees over 65 years.

For example:

- Out-of-pocket costs to access a lower-limb prosthesis equal to what is provided under the NDIS would require \$10,000 – \$15,000 self-contribution for a below knee prosthesis and \$40,000+ for an above knee amputee.
- Upper limb amputees receiving state-based funding will be provided with an antiquated body-powered device (and hook) or heavy myoelectric basic device with limited funding set at approximately \$7,500. But should the person want more advanced upper limb technology they would need to co-contribute, up to \$45,000 or more, to make up the difference.

It is the recipients of prosthetics through TALS that are being left behind and at a greater risk of losing opportunities to safely and independently participate in the community, live independently and remain in the labour force. As noted earlier, there are many prosthetic devices which can serve to reduce falls in people of any age. It therefore makes sense to ensure that older people are funded for these supports, given they are more susceptible to risks of falls and injury which sees the healthcare system incur significant and unnecessary admissions and costs. Front end loading funding supports for this cohort would further serve to reduce the overall costs on government, society and the quality of life outcomes for older Tasmanian amputees.

7.2.2 Difficulties in accessing prosthetic providers, wait times and product delivery delays

The fitting and ongoing maintenance and repairs of prosthetics are vital for amputees to remain safe, healthy and able to contribute socially and economically.

As noted in the World Health Organization's 'Standards for Prosthetics and Orthotics', the provision of person-centred readily accessible maintenance and repair services ensures optimal functioning and comfort of products, maximises product lifespans, reduces the need for frequent renewals, is important for restoring functioning and preventing secondary deformities and avoidable impairments, improves user satisfaction, increases the cost-effectiveness of services, and ensures that more people are assisted.²⁰

Limited, or delayed, access to timely assistive technology provision, maintenance and products counters objectives and principles within Articles 5, 9, 20 and 25 of the Convention on the Rights of Persons with Disabilities; highlighting potential systemic flaws which can lead to socio-economic barriers.

Access, travel and wait times

OPST prosthetic providers are only available to see clients during business hours, and consequently some amputees, particularly those in employment and/or who rely on carers who work full-time, can find it difficult to attend these critical appointments.

Furthermore, amputees reliant on OPST providers can often experience lengthy waiting times to see a provider for the manufacture, supply, fit and/or maintenance of their prosthesis. Such delays can cause preventable complications that affect long-term limb fit, such as a loose fitting device, muscle atrophy, loss of flexibility, flexion contractures from sitting too long in a wheelchair, and mental

health issues. It can also have safety impacts and lead to greater risks of falls and related hospital admissions which, in addition to affecting the individual and their support network, also has a downstream economic effect on state government health budgets.

The provision of prosthetic services is complex and fragmented for people over 65 years. As noted earlier, there are only three public prosthetic providers to service amputees ineligible for NDIS support. These OPST providers are also NDIS- registered, and therefore service a mix of public and private clients.

Access and wait time issues were noted by Limbs 4 Life survey respondents

"I always experience delays with OPST."

"I have been waiting for many months, Causing skin breakdowns and no ability to work."

"I had my socket mould taken on the 03/02/2021 and was only just contacted on 13/03/2021 by the prosthetic department to say they had forgotten about me."

"It can take weeks to get an appointment. I used to live in Melbourne and used the state system. They always said come in same day."

"Yes I have had to wait, but I'm not alone. I simply endured and adapted."

"Yes 3 months wait, failure, start again, took another 3 months, still not satisfactory repairs and alterations over about 5 weeks. My stump became ulcerated, had to use wheelchair for 4 weeks. Still not good walking and not for a very long time or distance."

"12 months delay in scheduling for a new prosthetic."

"It took a few months to get my new prosthesis from OPST."

"I think the Tasmanian Government, DHHS could be more attentive and objective. Currently they can be aloof and evasive."

"I'm so disappointed with my lack of treatment."

"I have been waiting to see someone about getting a new prosthetic since September 2020. This has greatly affected my family and me personally and has slowed me down a lot through all facets of daily life."

"I'm still waiting for my prosthesis. Still stuck in a wheelchair. I can't leave the house and dependent on my wife for everything."

Travel and clinic opening time issues were noted by Limbs 4 Life respondents

"45 kms one way. But hard to get there before 4pm as I need to travel from work, and the clinic closes then."

"It would be good if OPST had a visiting service come to Mersey General Hospital. I have to use public transport to go to the Launceston clinic - it takes 1.5 hours each way by bus (I can't drive) and costs \$100, which is too expensive. There is no funding for travel."

"Well in an ideal world it would be lovely to have an Amputee/Prosthetic Clinic visiting our little town of Triabunna."

"I have 200kms return journey to go to the clinic."

"I live in Hobart but go to the private Launceston Prosthetics. I do not drive, but my wife takes time off work to drive us there."

"It can take me up to 3.5hrs to go to see my prosthetist."

"130kms each way to go to my appointments."

"It only takes 30 minutes. But that's not the point. It's the unnecessary trips back and forth regularly because my socket and sleeve only lasts a short time. They should last longer if made right."

"I go from Devonport to Melbourne. 18 hour round day trip. It's exhausting."

Product delays

As noted earlier, amputees require prosthetic componentry and consumable products (e.g. liners, sleeves, stump socks, lotions) to safely and comfortably ambulate.

Given the number of amputees in Australia, the major suppliers hold considerable stocks of componentry and consumables in Melbourne and Sydney. Where a product is not already easily available in Australia, these generally come from Germany, Iceland and the USA. And, in discussion with the major suppliers, such product usually reaches our shores within five working days.

Limbs 4 Life is greatly concerned that OPST has regularly advised clients that there will be a wait of up to six weeks to receive a product already in stock ex-Melbourne or Sydney; products that will generally only take 24 – 48 hours to reach Tasmania. Or in other instances amputees are told that products are not available in Australia; something that is rarely the case because of the vast range of stock already in the country. This is completely unacceptable, and one could question whether clients are being told the truth about product access, availability and delivery times.

Delays can mean that amputees have their mobility, independence and health compromised. They may be unable to use their prosthesis and must revert to using other mobility devices (e.g. wheelchair, crutches etc) and experience social and economic impacts.

Product delay issues were noted by Limbs 4 Life respondents

"I had to wait 8 weeks for just a sleeve!!!"

"I'm still waiting for my prosthetic leg as they forgot to order the parts! ... So I am still using a hospital supplied wheelchair which is broken and unsafe."

"Since September 2020 I am still waiting to see someone to help me get a new prosthetic because at the moment I am walking on a prosthetic foot which is one full size bigger than my natural foot, which is getting very frustrating for me and my family."

7.3 Recommendations

Recommendation 3

The Tasmanian Government should invest in increasing the number of OPST clinics and/or open the market to include private providers to ensure that amputees have access to prosthetic servicing in all key state regions and at times outside of regular business hours. This would result in reduced wait times, minimise the need for some amputees to travel vast distances, or limit some from having to self-fund travel to the mainland to access timely prosthetic services.

Recommendation 4

Investigate why some amputees attending Tasmanian prosthetic clinics are experiencing excessive wait times for prosthetic componentry and consumables delivery.

Recommendation 5

Investigate why some amputees are experiencing such lengthy wait times for appointments. Determine how a client is lost in a system and revise approaches to ensure that this does not happen.

Recommendation 6

Make the Burnie prosthetic clinic a fully functional one enabling staff to manufacture prosthetic sockets on-site, thus reducing wait times required for the purpose of central fabrication.

8. The range of support services available to Tasmanians who are not on, or eligible for, the NDIS – access to amputee rehabilitation

8.1 Summary of issues

- Rehabilitation is vital for amputees to learn to adjust to the loss of a limb/s and involves a multidisciplinary healthcare team. Rehabilitation involves not only critical physical training, but also other supports to facilitate independence, accessibility and socio-economic participation planning and goal setting.
- The effective and appropriate provision of rehabilitation and in areas as close to a person's own community is a requirement of state parties that are signatories to The Convention on the Rights of Persons with Disabilities.
- It is unclear why the rehabilitation facility for amputees is based at Mersey Community Hospital in Latrobe but not connected to the Burnie prosthetic clinic at North West Regional Hospital, requiring amputees to be transferred from one to the other for prosthetic servicing.
- Presently there is only one Hobart-based Rehabilitation Consultant (doctor) to oversee an amputee's rehabilitation plan. This doctor plays a critical role in planning an amputee's post-surgery rehabilitation journey, making it critical that this skill shortage is addressed in other locales such as Launceston and Burnie, as well as Northwest Tasmania.
- The Tasmanian Government should, like many other states, implement A Minimum Standards of Care for Amputees which factors in the care needs for lower limb and upper limb amputees. In developing such Standards, amputee consumer bodies and stakeholders should play an active role in their development. Using a co-design approach ensures that the knowledge of those with lived experience or professional knowledge is captured and utilised. As such, representatives from Limbs 4 Life, LaTrobe University and the Australian Prosthetic and Orthotic Association (governing body for prosthetic providers) should be invited to the table.
- A formal and managed Peer Support Program, delivered by trained and experienced amputee peers, should be made available to all consenting Tasmanians who experience amputation. The option for the provision of peer support should be made standard practice as part of the Care Standards and offered to all people pre or post amputation, along with their family members.

8.2 The role of rehabilitation

The loss of a limb is considered a major health and disability event which can impact on a person's functionality, mobility and independence. Following an amputation and acquiring this physical disability, restoring functionality and daily living abilities, reducing dependency on others, increasing mobility and optimising a person's quality of life and satisfaction are key rehabilitation and disability adjustment goals.²¹

People who experience an amputation spend a period of time in acute hospital settings recovering from the surgery, after which, in most cases, they are transferred to rehabilitation facilities to learn to adjust to the loss of a limb/s. Rehabilitation involves a multidisciplinary healthcare team to support new amputees to learn how to: ambulate safely; regain lower limb functionally, mobility and balance; use a wheelchair and/or other mobility aids (assistive technology); overcome fears; prepare for the fitting of a prosthesis (assistive technology); and, plan for socio-economic re-entrance into

the community and learn daily living tasks such as showering and toileting in a safe environment. The team is usually comprised of a rehabilitation consultant, physiotherapist, occupational therapist, prosthetist, social worker, and nursing team. Depending on the cause of amputation and any other issues affecting the person other allied healthcare workers may also be involved in their care (e.g. diabetic educator, dietician, exercise physiologist, podiatrist, psychologist),

With respect to lower limb amputations, it is estimated that recovery post-amputation occurs over a 12 to 18 month period and is inclusive of activity recovery, reintegration into society, and prosthetic management and training.²² It is also during this period that amputees seek funding supports to facilitate independence, accessibility and socio-economic participation which, depending on the cause and level of amputation and age of the individual, may be provided by a range of funding sources.

With specific respect to Article 26 'Habilitation and rehabilitation', The Convention on the Rights of Persons with Disabilities (CRPD) notes that:

- Article 26 (1) indicates that state parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
 - a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
 - b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
- Article 26 (3) indicates that State Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.²³

8.3 Rehabilitation facilities in Tasmania

Presently there are three amputee rehabilitation units in Tasmania – Hobart, Launceston and Latrobe.

Ideally, rehabilitation facilities should be made available in all key Tasmanian regions. This enables new amputees to participate in rehabilitation as close as possible to their community and valued others in their lives. With facilities closer to people's homes, there is then more scope for amputees to attend as an in-patient or day patient (depending on their individual situation and capacity).

It is unclear why the rehabilitation facility for amputees is based at Mersey Community Hospital in Latrobe but not connected to the Burnie prosthetic clinic at North West Regional Hospital, requiring amputees to be transferred from one to the other for prosthetic servicing.

It is critical that the Tasmanian Government explore issues impacting on rehabilitation facility setting locations to ensure broader reach and access. This aligns with requirements under Article 26 (1) of The Convention on the Rights of Persons with Disabilities.

8.4 Rehabilitation consultant role and access

A medical rehabilitation consultant is the doctor who oversees and coordinates an amputee's medical care. Their role is to ensure that the person's health and medical needs are being met. And, along with other members of the team, will make decisions related to prosthetic suitability, discharge planning and post discharge supports. A rehabilitation consultant is a busy role which requires a person-centred approach for the amputee, while also managing a diverse team of critically important healthcare providers attending to various aspects of the person's rehabilitation journey.

There is only one Hobart-based rehabilitation consultant in Tasmania. Given the complexity and immense workload related to amputation and recovery, it is unclear if this specialist has the capacity to meet the needs of all amputees state-wide. Limbs 4 Life has heard that the wait list to meet with this consultant post-amputation can be between three – four months. Limbs 4 Life has also been made aware that a previous rehabilitation consultant based at Launceston left there due to a lack of resources and private consulting room, with this position still vacant.

It is critical that the Tasmanian Government explore issues impacting on the ability to employ sufficient rehabilitation consultants and ensure they are accessible to the rehabilitation facilities across the state. This aligns with requirements under Article 26 (1) of The Convention on the Rights of Persons with Disabilities.

8.5 Model of care for Tasmanian amputees

Many Australian state health departments have implemented Minimum Standards of Care for Amputees. Such standards have been written specifically for healthcare professionals and health services to outline the minimum standards of care that people facing amputation, or already living with it, should expect in their jurisdiction. Often Limbs 4 Life, consumers and other key stakeholders are invited to assist in the development and co-design of such guiding documents, thus helping to ensure insights from those with the lived experience of amputation and professional expertise is a critical consideration.

The NSW 'Care of the Person following Amputation: Minimum Standards of Care'²⁴ document has established eight standards with accompanying practice application, evidence base, quality measures and associated resources per each. Put simply, their comprehensive eight standards, which take account of all types and levels of amputation, are:

- Standard 1. Care Coordination: care is coordinated, multispecialty, and interdisciplinary across all phases.
- Standard 2. Comprehensive care: a comprehensive care plan is developed and updated throughout the care journey.
- Standard 3. Counselling and psychological support: counselling and psychological support is available across all stages of care.
- Standard 4. Peer support: referral is offered to a peer support program.

- Standard 5. Falls prevention: education and training on falls prevention and safety, including how to get up from the floor in the event of a fall is provided to persons and their valued others.
- Standard 6. Discharge planning: discharge planning and transfer of care arrangements commence as early as possible with communication between all key stakeholders.
- Standard 7. Specialist paediatric care: a child with congenital limb loss or limb difference requires specialist care including access to a specialist Paediatric Limb Loss Service.
- Standard 8. Upper limb amputation: the person who has experienced an upper limb amputation requires access to a specialist upper limb amputee rehabilitation service.

Limbs 4 Life has been made aware of, but not invited to contribute to, the development of Standards of Care for Lower Limb Amputees in Tasmania. It is critical that a co-design approach involving all key amputee stakeholders, such as representatives from Limbs 4 Life, the Australian Orthotic Prosthetic Association (governing body for prosthetists), LaTrobe University (the tertiary institution which trains and educates prosthetists) and members of the acute and sub-acute rehabilitation team be invited to the table.

And as a national provider of Peer Support, delivered by trained and experienced amputee peers, Limbs 4 Life advocates for inclusion of peer support as a vital aspect of rehabilitation and care, and illustrates compliance with Article 26 (1) of The Convention on the Rights of Persons with Disabilities.

Amputee rehabilitation issues were noted by Limbs 4 Life survey respondents

"I would have really appreciated a referral to an amputee specialist pain professional from a larger state, that had vast practical experience gained from working with many more amputees ... I think that when the medical profession as a group in a small state, cannot find the answer to a problem faced by an amputee who wishes to remain active then it is time to refer that problem to more experienced professionals from a larger state."

"Ensure there are enough Occupational Therapists and Prosthetists within the State. Currently there is a waiting list to see an Occ Therapist. Prosthetists are also in short supply."

"An amputee clinic for training and prosthetics at the hospital in Latrobe would be great."

8.6 Recommendations

Recommendation 7

The Tasmanian Government should increase the number of Rehabilitation Consultants available to amputees across the state, and address the skill shortage issues that only having one Hobart-based doctor presents. Consideration should be paid to placing such doctors in hospitals with rehabilitation facilities in order to coordinate locally-based rehabilitation planning and care.

Recommendation 8

Amputee rehabilitation units need to be connected to prosthetic facilities to ensure that individuals can transition back in to independent living as soon as possible. It does not make sense that amputee rehabilitation is undertaken at Mersey Community Hospital with clients then moved to Burnie for prosthetic treatment and care. The two should be co-located to facilitate ease of access and seamless integration for amputees undergoing rehabilitation.

Recommendation 9

The Tasmanian Government should implement 'Minimum Standards of Care for Amputees', which explore the care needs of upper and lower limb amputees. Limbs 4 Life, the Australian Orthotic Prosthetic Association (AOPA) and LaTrobe University should be involved to capture their knowledge and insights, thus evidencing a co-design and social model approach to the development of these standards.

9. Funding for organisations that service those not eligible for the NDIS

9.1 Summary of issues

- The Tasmanian Artificial Limb Scheme (TALS) needs increased funding in order to meet the demands of a growing population of older amputees. This would facilitate funding for prosthetics that are more advanced and meet the needs of each individual, allow for employment of additional prosthetists, servicing availability in all key regions, and ensure timely access to appointments (including emergency ones).
- Take an 'open market' approach, as used in other states, by approving all prosthetic providers to service TALS-funded amputees.
- Peer support is an efficient and effective way to support people with disabilities and/or chronic illness to adapt to their new condition. It is vital that the Tasmanian Government fund the provision of a formally managed peer support program for amputees in Tasmania, in recognition that it is an important addition to rehabilitation as noted by researchers, the World Health Organization, The Convention on the Rights of Persons with Disabilities and in existing Amputee Minimum Standards of Care used in other Australian states.

9.2 Increase funding and improve the practice of the Orthotic Prosthetic Services Tasmania (OPST)

As noted earlier, OPST would appear to be under funded and possibly a key reason why it is not meeting the prosthetic needs of a growing population of older amputees in a timely and efficient manner.

It is estimated that only six prosthetists are employed by OPST across the state (according to the Australian Orthotic and Prosthetic Association professional member list). And prosthetic servicing is not offered in all key regions across the state, requiring older amputees to travel vast distances to attend their vital appointments.

As a consequence:

- Amputees cannot gain access to services outside of regular business hours, leaving them unable to receive urgent attention and repairs when the clinics are closed
- Amputees face lengthy and unnecessary wait times to receive appointments and in urgent situations are having to attend the mainland to receive essential prosthetic servicing.

Prosthetic servicing and funding issues were noted by Limbs 4 Life survey respondents

"They need to be more flexible with amputee clinic times."

"It took 10 years from amputation to achieve a prosthesis that did not cause pain or complications, and was comfortable to wear. This had a huge effect on my lifestyle and family and we all had to adapt because I could no longer be as active as I had been when I didn't have the pain. I have often enjoyed a lifestyle living and travelling in remote places and have learnt to repair and make minor modifications until I can make an appointment with a prosthetist. I think that the specialist medical advice that is being provided for amputees in a small state is limited due to the lower number of amputees and a lack of experience by the medical practitioners."

"The state service has been of no use because of excessive wait lists. I've had to go to Melbourne instead."

"I know they have many other clients to care for. But I am a very patient person."

"Have more providers or give us access to interstate services which are better than here."

"Needs more staff so you can get an appointment straight away."

"More communication from the departments as they never answer phone calls. Have more services available on the north west of Tasmania. The extremely long wait times for components is a disgrace. I am only 6 months into my amputation and am frustrated to say the least about the lack of service provided here in Tasmania."

"Better communication from prosthetics would be a good start. Tasmania feels like it is so far behind other States."

"Fast-track and increase providers in northwest Tasmania."

9.3 Fund peer support provision in Tasmania

As noted earlier peer support should form part of any minimum standards of care for people pre or post amputation. Peer support complements rehabilitation efforts and goals and provides

individuals with hope for the future. Limbs 4 Life currently offers and coordinates peer support visits across Tasmania, although we receive no funding at a state or Commonwealth level to do so.

9.3.1 Peer support benefits

Peer support is an efficient and effective way to support people with disabilities and/or chronic illness adapt to their new situation.

Peer support can be delivered via a range of methods targeted to support individual outcomes. Provided at one-on-one levels or in group-based settings, it is a strong enabler for recovery and adjustment to significant life changes and challenges. Peer support, for people living with disabilities and health conditions, has gained widespread attention across the world, including Australia, over the last decade. Indeed, peer support “has emerged as an innovative service delivery mechanism, particularly for those ill-served by traditional systems of care.”²⁵

Peer supporters, who are experts as a result of their own lived experience, are able to relate to, connect with and support individuals who are going through challenges in a unique way because of their experience. “Peer support may be social, emotional or practical support (or all of these) but importantly this support is mutually offered and reciprocated, allowing peers to benefit from the support whether they are giving or receiving it.”²⁶ Furthermore, a number of studies point to an intrinsic set of values and role-setting which must underpin any systemised peer support program, including: shared lived experience; reciprocity and mutuality; validating experiential knowledge; self-determination and empowerment; choice and control; empathy; discovering strengths and making connections; and, recovery.^{27 28 29}

The benefits of peer support have been widely researched and reported on. As part of the World Health Organization’s ‘QualityRights’ initiative, a strong evidence-base is provided to demonstrate peer support as being a vital and transformative component in implementing human rights and recovery approaches that are in line with the CRPD and other international human rights standards.³⁰

The World Health Organization identified the benefits of individualised peer support as being:

- Recipients of peer support: improved engagement with services and therapeutic relationships with providers, increased empowerment, personal growth, hope for recovery, and a reduction in in-patient admissions outside of their health plans
- Peer support providers: transforming their own challenging experiences into a source of knowledge, improved self-esteem and purpose, increased psychological and emotional well-being, enhanced social inclusion, and increased interpersonal skills and work capacity
- Government health systems and services: improved patient outcomes through strengthened therapeutic relationships, a decreased number of hospitalizations and a reduced length of stay leading to decreasing health-care costs.³¹

The World Health Organization identified the benefits of safe group-based peer support as being:

- the provision of a safe environment to freely express and share emotions and thoughts about one’s current situation and challenges

- sharing of information and experiences and learning from others in similar situations that can help provide ideas and solutions to overcome challenges and promote hope and recovery
- the opportunity to build new relationships and to strengthen social support networks, helping to reduce isolation and feelings of loneliness
- sharing of knowledge about available community resources and practical support to help group members access resources and support
- contributing to overall health and well-being.³²

Peer support is articulated as a right for persons with disability. Article 26 (1) of the CRPD, requires that States Parties take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.³³

It is Limbs 4 Life's position that access to a formally managed and risk mitigated peer support programs is a means through which people with disability can exercise their "potential for mutual growth and healing"³⁴. The literature strongly suggests that early intervention peer support is extremely beneficial for the individual, can deliver long-term health-based outcomes, can prevent long-term mental health concerns and is very cost effective. Early intervention engagement assists people with disabilities to understand the recovery pathway, provide valuable 'lived experience' from a person who has adapted to challenges and regained their independence, while also highlighting 'what is actually possible' for the person new to the challenges of limb loss and who may not be able to envision their 'future pathway'. While many healthcare providers are supportive of an amputee peer being part of the multi-disciplinary team model, sustainable funding for amputee peer support is lacking in Tasmania.

9.3.2 Fund peer support provision for older Tasmanian amputees

Limbs 4 Life is the only peak body for people with limb loss in Australia, providing national access to peer support for this cohort. This flagship service commenced in 2005, launched by Dr Brendan Murphy (now Secretary of the Department of Health), and was established to fill a gap in the provision of early intervention supports for new amputees. The Peer Support Program provides a vital link for individuals' pre or post amputation (and their families).

The Limbs 4 Life Program is a multi-modal one, delivered via one-on-one personal visits in acute and sub-acute settings and peer support group meetings. It is grounded by significant program logic, theory of change, research, policies, supervision, management, risk mitigation, and the comprehensive training and continuous upskilling of all peer support volunteers. So well regarded is our program, that the vast majority of requests for peer support are made by healthcare professionals with the consent of the person seeking a peer-to-peer connection. It is equally regarded by amputees wishing to be trained as a peer support volunteer, with our current volunteer workforce sitting at 187 members and 84 more waiting to be trained and formally accepted into the program. On average less than 10 per cent of new amputees in Tasmania are provided with access to peer support.

With growing rates of amputation, barriers to peer support access should be dismantled. Peer support should be deemed as an investment in not only improving the lives of people with limb loss, carers and rehabilitation teams, but also a measure which can realise tangible reductions in health system costs.

9.4 Recommendations

Recommendation 10

Alleviate the burden on OPST and provide amputees over 65 years with choice by opening the market to private providers to service TALS-funded amputees.

Recommendation 11

Recognise that peer-to-peer support is an efficient and effective means of socially, emotionally and practically assisting any new amputee to adapt to their 'new normal' and ensure it is made available as a minimum standard of care.

Recommendation 12

Resource Limbs 4 Life, Australia's only peak national organisation for amputees and developer of the well-regarded Peer Support Program, with the funds to continue offering and expanding peer support to older (and all) Tasmanian amputees; an investment in not only individual lives but also health system cost reductions.

10. Any other matters incidental thereto

Amputees who responded to the Limbs 4 Life survey also commented on desired improvements within the Department of Health and the need to establish an independent disability commissioner.

"There needs to be an independent disability commissioner who advocates/handles complaints against service providers/insurers regardless of funding source. I have made complaints about service providers which were ignored or laughed at. But there was no other independent agency to turn to."

"The Department of Health, as a whole, keep themselves at a distance. They should treat amputees just as importantly as all other medical eventualities."

"DHHS could be more attentive and objective. Currently they can be aloof and evasive."

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