Limbs 4 Life™
Empowering Amputees
Making a real difference together

A new National Disability Strategy

Submission: Stage 2 consultations

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Definitions

ALS	Artificial Limb Scheme
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
ATFA	Assistive Technology for All Alliance
CHSP	Commonwealth Home Support Programme
CRPD	The Convention on the Rights of Persons with Disabilities
EAF	Employment Assistance Fund
Limb loss	Acquired absence of a limb or limbs
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
OT	Occupational Therapist
Prosthesis (artificial limb)	A device which helps to replace the mobility or functionally of a missing limb/s
Prosthetic provider	A trained clinical practitioner who manufactures prosthetic devices (artificial) limbs
Stump	Residual limb

Please note: for the purpose of this submission all people living with limb loss, including young people with limb deficiency or limb difference, are referred to as amputees.

1. Submission background and recommendations

Limbs 4 Life welcomes the opportunity to provide a submission regarding the new National Disability Strategy. It is essential that the new National Disability Strategy adheres to The Convention on the Rights of Persons with Disabilities, not solely because Australia is a signatory to this, but also because this Convention recognises persons with disabilities as being active members of society with rights and an entitlement to make self-determined decisions in relation to their lives.

Limbs 4 Life agrees that a new National Disability Strategy must not be the sole responsibility of the Australian Government but pursued and delivered in partnership with all state and territory governments, thus helping to ensure that consistent and harmonised approaches inform activity for all levels of government. Furthermore, the new Strategy should take account of the important role that non-government sectors must play in improving outcomes, offering opportunities and effecting positive change in the lives of people with disability.

The scope of our submission focuses on the key enablers of and barriers to full, fair and equitable socio-economic participation of amputees – assistive technology, workforce participation, accessible built environments and peer support – and which National Disability Strategy 'Outcome Area' they relate to. Please note, as all amputees are reliant on fit-for-purpose assistive technology to fulfil their potential as equal members of our society this particular enabler intersects with all sections of this submission.

It is also notable that our submission, while reflective of the needs of all amputees, shines a particular spotlight on the fact that many older amputees are ineligible for the NDIS and thus being increasingly left behind their younger peers. Indeed, this issue is creating additional burdens on older amputees and creating a widening gap between the amputee 'haves' and the 'have-nots'. Not only is this intolerable, but it is discriminatory and in violation of human rights.

In order to respond to this submission Limbs 4 Life has drawn upon relevant literature, policies, legislation and international covenants governing disabled persons' rights and needs. Our response has also been informed by qualitative feedback from amputees regarding their lived experiences and de-identified case studies have been included.

We commend the Government for its development of a new National Disability Strategy, intended to influence implementation of systematic policies and plans that will underpin improvements and reforms across all levels of government in the coming decade. We appreciate that the Government is drawing upon expert reviews, reflecting on recommendations raised in various government inquiries and Royal Commissions, and importantly seeking insight from people with disabilities and the non-government organisations that support and advocate for them.

We trust that Limbs 4 Life's submission will assist in understanding the disability issues faced by amputees, and that the provision of contextual background knowledge and recommendations will ensure our community is included in further development and implementation of the new National Disability Strategy.

Recommendation 1:
An overarching recommendation is that a national and independent National Disability Strategy body be established. Ideally, this body should have:

- strategic responsibility for implementation of the National Disability Strategy, including development and oversight of Targeted Action Plans, the proposed Strategy Engagement Plan, performance indicators and annual public reporting of progress and outcomes
- clear terms of reference so that all stakeholders understand what falls within the brief of this strategic management and oversight body
- best-practice mechanisms put in place which enable people with disabilities, carers, disability organisations and disability advocacy organisations to engage in consultations, co-design of strategies and raise issues related to the National Disability Strategy
- capacity to recommend policy changes which reflect ones that would address National Disability Strategy outcome area needs and issues
- powers to conduct enquires into National Disability Strategy issues raised by stakeholders
- the ability to make recommendations to the Australian Human Rights Commission, or other relevant external agencies, to conduct formal enquiries where incidents of systemic human rights or disability discrimination is found to be occurring.

Establishment of such a body could then be used to enquire into, investigate and respond to many of the recommendations in this submission.

Recommendation 2:
Because the provision of assistive technology is so widely spread across various federal and state government departments and agencies, there is currently a limited ability to measure comparable data about the services and funding provided. And in some cases there is no requirement to publish any data whatsoever, such as those state-based departments responsible for management of artificial limb schemes. This impedes the public's ability to assess performance, measure outcomes and enable comparable linkage across the varying datasets. This also mitigates the ability of sector organisations, researchers, policy makers and providers to more easily identify gaps, failures, improvement opportunities and successes to inform change and better understand how people are faring.

It is recommended that the new National Disability Strategy require that:

- NDIS and My Aged Care outcomes and performance data be more widely shared. Furthermore, the ability to capture comparative assistive technology related details should be made easier with the recent transfer of the NDIS to the Department for Social Service, which also holds portfolio responsibility for My Aged Care.
- Commonwealth-funded state-based schemes and programs providing assistive technology publicly share outcomes and performance data, ideally using a common data collection and reporting instrument.

Recommendation 3:
In light of the United Kingdom (UK) and New Zealand (NZ) providing microprocessor knee prosthetics on their respective public funding system, in order to improve user outcomes and reduce downstream health and disability costs, the Australian Government should consider adoption of a similar policy transfer here. While many above knee amputees are being fitted with these devices if an NDIS participant, this is not the case for those acquiring their prosthetics via state-based artificial limb schemes. Much evidence and literature provided a rational case for implementation in those countries and, coupled with subsequent outcome and performance-based results since, offer much data to enable a sound justification for why such an approach should also be introduced in Australia.

The new National Disability Strategy has the capacity to prioritise this suggested equity-oriented policy transfer opportunity in recognition of its strong relationship to the 'health and wellbeing' outcome area.

Recommendation 4:
Timely access to prosthetic provision is currently marred by fragmented funding arrangements, prosthetic industry skills shortages, and disincentives which see NDIS participants prioritised over the less commercially viable artificial limb scheme funded amputees. This presents a clear risk to amputees' human rights, is discriminatory and demonstrates Australia's failure to meet its responsibilities on an array of Articles within the CRPD.

The new National Disability Strategy has the capacity to prioritise this suggested equity-oriented issue in recognition of its strong relationship to the 'health and wellbeing', 'personal and community support' and 'rights protection, justice and legislation' outcome areas.

Recommendation 5:
The new National Disability Strategy must prioritise the establishment of a funded National Assistive Technology Program, as advocated for by the Assistive Technology for All Alliance (of which Limbs 4 Life is a member), to streamline access and provide equitable support to people with disability who are excluded from the NDIS. This program should:

- Harmonise existing state-based assistive technology programs, in particular the state-based 'artificial limbs scheme' and 'aids and equipment program'. This would streamline access and drive nationally consistent outcomes for consumers while reducing administrative burden on governments, entice people to continue to reside at home and promote the same choice and control that NDIS participants are currently afforded.
- Be aligned with the NDIS Assistive Technology Strategy to address the inequity between the support that is provided under the NDIS and other service systems
- Be driven by key performance indicators relating to the timely provision of equipment, in line with the aspirations of the NDIS Participant Service Guarantee.

Recommendation 6:
That the Government invest in a nation-wide disability employment awareness and education campaign, in an effort to influence mainstream employment methods, dispel stigma and eliminate discrimination. The campaign should include use of multi-modal channels and platforms to increase

reach and scale. The campaign should be co-designed to incorporate input from people with various disabilities, industry bodies, disability employment sector organisations, peak disability bodies, disability specific organisations and subject-matter experts.

The new National Disability Strategy has the capacity to prioritise a national disability employment campaign in recognition of its strong relationship to the 'economic security', 'learning and skills', and 'inclusive and accessible communities' outcome areas.

Recommendation 7:
It is recommended that the Australian Government engage in a national strategy to engender greater employer awareness of, and employees' entitlements under, the Employment Assistance Fund (EAF). This would reduce limited knowledge of this program and ensure that people with disability gain access to timely assessment of workplace-specific assistive technology needs and the provision of reasonable and necessary devices and workplace modifications.

The new National Disability Strategy has the capacity to prioritise a national EAF awareness-raising campaign in recognition of its strong relationship to the 'economic security' outcome area.

Recommendation 8:
The new National Disability Strategy develop a targeted plan for greater inclusion of people with physical disabilities in the workplace. This plan could be initiated by an independent executive body responsible for oversight of the National Disability Strategy or become the responsibility of the Department of Social Services. The body with responsibility should engage with state and territory governments, disability employment providers, industry peak bodies, disability peak bodies and consumers, to develop a co-designed plan to better support, engage and retain people with physical disability in the workforce. The publicly accessible plan should clarify:

- Policies, practices and strategies for improving the workforce participation of people with physical disability, particularly in the areas of assistive technology and workplace modification provision
- How annual performance and outcome targets will be tracked and measured
- Levels of resources committed to achieving strategic goals.

Recommendation 9:
The Australian Government continue to fund the National Disability Advocacy Program. Currently an array of organisations have been funded via this grant to provide independent advocacy for all people with disability in designated regions. Ongoing provision of funding in current and/or new organisations will play a role in ensuring that people with disability have access to effective disability advocacy that promotes, protects and ensures their fair and equal enjoyment of human and employment rights.

The new National Disability Strategy has the capacity to prioritise the retention of advocacy service funding in recognition of its strong relationship to the 'economic security' and 'rights protection, justice and legislation' outcome areas.

Recommendation 10:
It is critical that the introduction of new, or reforms to existing, accessible environments and public transportation legislation, policies, projects or services scope the views of those most affected by any changes – people with disability themselves. It is therefore vital that all three tiers of government and businesses make significant efforts to capture the insights of people with disability, as well as those of carers, disability organisations and advocacy bodies. The new Disability Strategy can assist in achieving this by creating consultation guidelines which outline that all consultations are: announced in a timely manner; ensure that the accessibility needs of all participants are catered for; and, opportunities for meaningful involvement in design, development and evaluation is offered whenever possible.

The new National Disability Strategy has the capacity to prioritise this in recognition of its strong relationship to all six of the Strategy's outcome areas.

Recommendation 11:
The new National Disability Strategy should support the implementation of universal design principles as part of current and future changes to the National Construction Codes and Premises Standards. In particular, the National Disability Strategy should support and endorse the Australian Network for Universal Housing Design's stated position that 'Gold Level' of Livable Housing Design Guidelines be the minimum level of access.

The new National Disability Strategy has the capacity to advocate for adoption of the 'Gold Level' Livable Housing Design Guidelines in recognition of its strong relationship to the 'inclusive and accessible communities' and 'rights protection, justice and legislation' outcome areas.

Recommendation 12:
Amputees must be assessed as 'fit to drive' for the safety of not only themselves but the wider driving public. Accompanying this is the potential need for occupational therapy assessments, vehicle modifications (assistive technology) and expert driving lessons. These requirements can result in access inequality, particularly amongst those older amputees who are ineligible for the NDIS and find that vehicle modifications and assessments cannot be fully funded in their small state-based aids and equipment package.

To address this, the new National Disability Strategy must prioritise the establishment of a funded National Assistive Technology Program, as advocated for by the Assistive Technology for All Alliance, to streamline access and provide equitable support to people with disability who are excluded from the NDIS (as outlined in Recommendation 5).

Recommendation 13:
The taxi and ride sharing service industries are presenting ever changing, new and innovative landscapes for alternative transportation options for people with disability. In light of this evolution, it is important that provisions must be secured through government regulation and ongoing management of all existing taxi services and emerging ride sharing services to protect the human rights and safety of all users.

The new National Disability Strategy has the capacity to prioritise taxi and ride service regulation measures in recognition of its strong relationship to the 'inclusive and accessible communities' and 'rights protection, justice and legislation' outcome areas.

Recommendation 14:
As amputation results in a permanent and lifelong disability it is an imperative that all, not just some, states and territories introduce Minimum Standards of Care for Amputees. This will not only ensure that consistent care is implemented by the cross-disciplinary healthcare teams, but also inform amputees as to what they can expect as part of their medical, allied health, and community re-integration care and recovery plans. It is recommended that all Minimum Standards of Care include that:

- all amputees are provided with the option to be referral to a formally managed peer support program as part of their rehabilitation plan
- all amputees be provided with vocational and/or return-to-work plans, should that be part of a person's future goals.

The new National Disability Strategy has the capacity to prioritise the introduction of Minimum Standards of Care for Amputees in all states and territories in recognition of its strong relationship to the 'personal and community support' and 'health and wellbeing' outcome areas.

Recommendation 15:
The appropriate federal and state governments should audit the provision of peer support in Australia, and identify areas of under or over supply of this to specific disability cohorts. This instrument would assist in:

- identifying gaps in provision
- highlighting areas of over-supply, potentially supporting organisations to partner for consolidated peer support delivery
- providing governments with an evidence-base to ascertain where peer support funding should be directed, in particular those organisations that can demonstrate an explicit program logic and management approach but who lack in national or state government funding for sustainable delivery
- identify funding streams that enable funding of peer support provision to people with disabilities by people with disabilities.

The new National Disability Strategy has the capacity to prioritise an investigation into peer support provision and funding in recognition of its strong relationship to the 'personal and community support' and 'health and wellbeing' outcome areas.

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 impacts

3.1 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 diabetes-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.

Annually, lower limb amputations alone account for almost 9,000 amputations across Australia, largely due to diabetic-related complications, vascular disease and infection.[1] 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.[2] 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. [3]

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.[4]

3.2 Amputation recovery and 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, 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 goals.[5]

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.

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. [6] 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.

4. Assistive technology – enablers and barriers

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, 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.

In a World Health Organization brief, aimed at international policy makers involved in designing assistive technology policies and programs which address human and employment rights, noted that:

- Access to assistive technology is a fundamental human right, a legal obligation for all countries within the Convention on the Rights of Persons with Disabilities and a prerequisite for the full and equitable achievement of the Sustainable Development Goals.
- Access to assistive technology is an investment in a more participatory society; it gives people the means to be more independent enabling both users and their caregivers to have better access to education, society and employment opportunities.
- Improving awareness at all levels, empowering workforces that are fit-for-purpose, ensuring appropriate production and service provision, and safeguarding affordability through universal health coverage, are all key to ensuring equitable access to assistive technology. [9]

A lack of access to functional assistive technology to facilitate access, 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.[10] 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.[11]
- 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. [12]

With respect to amputees, key assistive technology devices used by this cohort include: prostheses; wheelchairs; mobility aids (e.g. walking sticks); adaptive computerised technology and communication programs; modified vehicles (e.g. modified pedals, hand controls); adjustable tables and chairs; and, modified homes or workplaces to enable accessibility (e.g. ramps, hand rails, flooring, seating). Assistive technology is very individualised, but all are 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.[13] Equal access to affordable assistive technology enables amputees to participate in our society and fulfil their potential. Prosthetics, alternative mobility devices and environmental modifications 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 systems present as barriers to achieving these outcomes.

Please note, the issue of unequal access to assistive technology and funding barriers has led to the creation of the Assistive Technology for All Alliance (ATFA), of which Limbs 4 Life is a key member,

and represents a growing concern that the lack of equity in the current arrangements is unjust and intolerable. For more information visit https://assistivetechforall.org.au/

The equitable provision of assistive technology is integral in the meeting following 'Outcome Areas' proposed in the new National Disability Strategy:

- Economic Security
- Inclusive and accessible communities
- Personal and community support
- Learning and skills
- Health and wellbeing.

4.1 Funding of assistive technology

Depending on a person's age, cause of amputation and/or location the provision of 'everyday' assistive technology and amputee-related supports are primarily funded through the NDIS, state-based artificial limb schemes, Department of Veterans Affairs (DVA), state-based aids and equipment programs, or the aged care system.

The fact that there are a number of funding programs which are not equitable or nationally consistent makes access complex and confusing for consumers to navigate.

As noted in the 'Shut Out' report "There are currently multiple aids and equipment schemes operating across the country. Many submissions argued that a nationally coordinated and funded equipment scheme would eliminate existing inequities and ensure portability across jurisdictions." [14] So, whilst these issues were raised then, and the 2010 – 2020 National Disability Strategy had promised to address these, that we are now a decade down the track and nothing has changed is of great concern. It is hoped that the new National Disability Strategy will finally correct these unharmonised arrangements.

While the landmark introduction of the NDIS during the period of the 2010 – 2020 National Disability Strategy has certainly improved access to assistive technology for some amputees, there are still a great many who are ineligible for this scheme (largely older Australians) and their inequitable and unfair situation remains the same.

4.1.1 National Disability Insurance Scheme (NDIS)

While the NDIS is enabling amputee participants to request goal-oriented reasonable and necessary assistive technology, home modifications and other supports, there is often no uniformity in the decision-making processes.

It is pleasing that the Australian Government has begun implementing an NDIS Participant Service Guarantee, in an effort to cut waiting times and improve access to services for NDIS participants.[15] It is also pleasing that from 2021 the NDIS will introduce Independent Assessments allowing for qualified healthcare providers, using internationally recognised and standardised tools, to inform fair and transparent determinations as to a person's functional capacity needs.[16] Limbs 4 Life hopes these measures have the desired outcomes, and result in more consistent decision making when assessing an individual's needs.

But the NDIS is not the panacea for supporting all people living with disability. It is critically important to remember that only those aged under 65 are eligible for NDIS coverage. Just as it is equally important to note that the NDIS is only projected to provide support to around 10% of Australians with disability. [17]

Furthermore, more older Australians are exercising their right to work beyond the age of 65, as evidenced by the fact that people in and above this age bracket currently account for 13% of the workforce population.[18] Yet, amputees who are still members of the workforce and were over 64 and lived outside of the trial and/or launch sites when they acquired an amputation, are ineligible for NDIS supports; supports that would greatly enhance their capacity to remain active members of the labour force.

The arbitrary decision to cap NDIS access at 64 years means that anyone who acquires an amputation past that age, must then rely on one of the various other funding programs to receive the assistive technology and support they need. And, unfortunately assistive technology provision made possible via those programs have time delays, lesser funding levels which have not increased for decades, offer limited technology, and often require financial co-contributions in order to reach parity with NDIS-funded peers.

4.1.2 State-based artificial limb schemes

Amputees excluded from the NDIS, due to age-related factors, are generally reliant on state-based artificial limb schemes to access prosthetics.

Across Australia there is disparity in the artificial limb scheme funding arrangements. While funding for each state and territory's scheme is provided by the federal government, the funding allocation per person, treatment approaches and supply of prosthetic componentry and associated consumables differs between jurisdictions. There is no national consistency or parity in supply, and amputees can often face long waiting times to be fitted with their first interim or definitive prosthesis. Unfortunately, there is no requirements for these schemes to publish annual aggregated and per-capita funding data which would transparently reveal allocation expenditure and allow for cost comparison against other funding schemes.

Unlike the NDIS, state-based artificial limb schemes deny amputees of 'choice and control' and are based on dated funding models. Consequently, amputees receiving assistive technology via an artificial limb scheme are primarily provided with standard prosthetic devices. This means that recipients are not benefiting from the advances in assistive technology which have occurred in recent decades and known to improve independence, balance, safety, functionality and socio-economic participation. [19] While individuals can co-contribute in order to be fitted with a prosthesis that provides greater physical and functional outcomes, 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 many older amputees.

For example:

- Out-of-pocket costs to access a prosthesis equal to what is provided under the NDIS would require $10,000 – $15,000 self-contribution for a below knee amputee and $40,000+ for an above knee amputee.
- Upper limb amputees funded through state-based artificial limb schemes will receive 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, as is often made available to peers funded by the NDIS, costs of this can begin at or be in excess of $35,000, and would require a co-contribution to make up the difference.

It is the recipients of prosthetics through artificial limb schemes, particularly, that are being left behind and at a greater risk of losing opportunities to safely and independently participate in the community and labour force. In fact, there are assistive technology prosthetic devices which can serve to reduce falls in people of any age (as will be outlined in section 5.2 'Provision of functional prosthetics and mobility devices'). It therefore makes sense to ensure that older people are funded for these supports, given they are more susceptive to risks of falls and injury which sees the healthcare system incur significant and unnecessary costs. Front end loading of funding supports for this cohort would further serve to reduce the overall costs on government, society and the quality of life outcomes for older Australian amputees.

Case Study: Robert and Steve

Robert is 67 years and lost his leg above the knee due to cancer. He does not meet the age-based eligibility requirements for the NDIS, resulting in the provision of prosthetic services from his state-based Artificial Limb Scheme. Prior to his amputation Robert was very active and wants to get back to the things he used to enjoy such as: bush walking, sailing and work.

Due to the restrictive funding of the Artificial Limb Scheme he has limited choice over the type of prosthesis he receives and currently uses a mechanical knee unit which does not suit his individual needs or enable him to achieve his personal goals. The knee unit compromises his safety resulting in regular falls. His endurance levels are poor due to the physical effort required to drive the prosthesis and he is mentally fatigued as he needs to concentrate with every step he takes to prevent his foot from rolling on a stone or crack in the pavement – also potentially leading to falls.

Robert has made minimal modifications to his home because he would need to self-fund the modifications as the waiting time is lengthy and he is not in a financial position to do so. Consequently, he only uses a shower-board across his bath for personal washing further increasing the falls risk.

Up until his amputation, Robert worked full-time. Unfortunately, the physical and mental fatigue experienced from using a mechanical knee have had a significant impact on his body and he has had to reduce his work hours to part-time as a result.

By contrast, Steve 61 years has access to an array of fully funded reasonable and necessary supports under his NDIS Plan. This is because he is several years younger than Robert and meets the age

eligibility requirements for the scheme. The NDIS has enabled him to trial a variety of prosthetic devices to determine which one best meets his needs. He was subsequently funded for a Microprocessor Knee Unit (MPK) and energy storing prosthetic foot in his NDIS Plan two years ago. All of the home modifications Steve has needed have also been funded through his NDIS Plan, including a ramp at the rear of his home, and a fixed seat in his now accessible shower.

Steve is able to lead an active lifestyle with his wife and two children because he has had access to the appropriate assistive technology to facilitate this. And unlike Robert, he has rarely experienced a fall because the knee unit prevents his from falling. Steve continues to work full-time.

4.1.3 State-based aids and equipment programs

Amputees in need of non-prosthetic assistive technology but ineligible for the NDIS or not receiving funding support via the aged care system and are reliant on state-based aids and equipment programs for provision of these. Such assistive technology may include wheelchairs, vehicle modifications, home modifications and solution-based devices.

Most state-based programs remain grossly underfunded, and there has been no commitment to keep up with the increasing costs of assistive technology; something that will only widen due to a growing population of older Australians now also living with disability, along with the increasing level of diabetic-related amputations.

The capped annual per-capita funding for the types of aids and equipment needed by amputees is often so low that they are expected to make a significant and, often prohibitive, financial contribution towards the cost of their vital device or modification. Furthermore, amputees accessing state-based aids and equipment programs often face long waiting times. And in some cases there is no provision of support at all. For example, the Medical Aids Subsidy Scheme (MASS) in Queensland provides no financial assistance for walking sticks, crutches, wheelchairs and other assistive devices.

Concerningly, it is not unheard of for amputees to wait more than a year to receive the wheelchair that they need to remain safe, independent and socially included. And Limbs 4 Life has made multiple requests to philanthropic bodies to grant funding for wheelchairs (and associated items such as seating and transfer boards) for amputees in aged care facilities; without which these individuals would have remained bed bound and at serious risk of significant physical risks (e.g. infection from bed sores and open wounds) and mental health deterioration.

Alarmingly, amputees living in residential aged care are either unable to or experience long delays waiting to access assistive technology provided through state-based aids and equipment programs. This is resulting in older amputees either going without, having to share ill-fitting or out-dated equipment with other residents, or drawing upon limited individual or family finances to purchase a much-needed product.

4.1.4 The aged care system

There are two main programs that exist under the aged care system to provide support to people in their own homes. These are the Commonwealth Home Support Programme and the Home Care

Packages Program. Neither of these programs provide funding for prosthetics, but do enable access to other assistive technology.

The Commonwealth Home Support Programme (CHSP)

The Commonwealth Home Support Programme (CHSP) provides a range of entry-level services to support older people who require assistance to maintain their independence at home.[20]

The CHSP can provide up to $500 of funding per person per calendar year for aids and equipment and home modifications (amongst other supports and services) although this cap can be increased to $1,000 with appropriate supporting evidence from an occupational therapist. As many older amputees are in need of assistive technology or changes to their home, such as a wheelchair or the installation of ramps to ensure safety, the maximum CHSP funding falls well short of providing these.

Where the funding is less than required to support a person's assistive technology needs they are then forced to financially co-contribute to purchasing the product/s or access assistance via a Home Care Package.

Home Care Packages Programme

The Commonwealth Home Care Packages Programme provides support to older people with complex needs to help them stay at home and approved aged care service providers work with care recipients to plan, organise and deliver Home Care Packages. [21]

Four levels of pre-determined annual funding are available under the Home Care Packages Programme which, unlike the NDIS, is not determined by a person's individualised need:

- Level 1: $8,927.90
- Level 2: $15,705.95
- Level 3: $34,174.95
- Level 4: $51,808.10 [22]

Many older people with disability with high complex needs for support, into which many older amputees fall, will be assessed as eligible for either a level 3 or 4 package. Unfortunately, Limbs 4 Life has been made aware that some amputees assessed as eligible for a level 3 or 4 package have been advised that the waiting list to receive one of these packages currently sits at around 12-18 months.

Older amputees can experience significant difficulty funding the assistive technology, aids, equipment and home modifications they need out of a home care package. The limited funds available mean that they are often forced to trade off one vital service to be able to afford another. For example, if an older amputee required a wheelchair and significant home modifications to be funded in a calendar year, this could leave them with little to no remaining funding to cover the costs of attendant care support, home maintenance or any of the other support services they may require. And if they are unable to access the appropriate support to remain at home safely and independently, then they may become one of the 19,000 older Australians forced into residential care because they can't access the appropriate support to stay at home each year.[23]

4.2 Provision of functional prosthetics and mobility devices

The capacity to independently mobilize is regarded by health-related measures as a key indicator for quality of life measures[24]; underscoring the need to provide assistive technology mobility enablers for amputees.

Many amputees are suitable candidates for a prosthesis, an assistive technology device, which aims to restore function, improve mobility, increase quality of life and associated with a greater likelihood of entering into or sustaining employment.[25]

However, due to health concerns some people may not be suitable candidates for a prosthesis or unable to because their level of amputation prevents a secure fit, in which case other types of assistive technology will be offered. In the case of lower limb amputees this is usually a wheelchair or crutches, and in upper limb amputees it may be nothing at all. Any prosthetic product or alternative solution, coupled with adequate training and tailored customisation, does not just target increased personal mobility or functionality but also provides access to human rights, societal participation, places of learning, workplaces and services.

4.2.1 Prosthetics

It is widely reported that the paramount goal for a person with limb loss, in particular lower limb amputees, is to secure a prosthesis that aids in returning what is missing in a functional manner.[26] Indeed, the role of prosthetics and advances in these 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. [27]

The type of prosthesis that a person utilises is contingent on the individual; taking account of the cause of amputation or limb loss, location of the missing limb, any other health considerations and their desired goals.[28] Consequently, prosthetic limbs must be 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.[29] [30] 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. [31] As these products cost considerably more than standard technology developed in the sixties and seventies, the introduction of the NDIS has enabled amputee participants to request these as reasonable, necessary and fit-for-purpose devices which deliver impactful psycho-social-economic outcomes.

Conversely, amputees ineligible for the NDIS and receiving prosthetic funding through state-based artificial limb schemes are only funded for the provision of standard prosthetics; some of which are

driven by passive technology developed in the 1950s. Such products include the solid ankle cushion heel (SACH) foot, 'split-hook' hand and mechanical friction knee. 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, mental, social and economic impacts. [32] A person may be at a greater risk of falls, back 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.

It is notable that in recent years microprocessor knees have been added to the prosthetic component list (under the publicly funded systems) for above-knee amputees in the United Kingdom and New Zealand government health-care systems. The primary reasons for this policy shift and associated expenditure is because these prostheses are shown to reduce safety risks, minimise fall risk, reduce hospital admission and rehabilitation costs, and increase users' socio-economic outcomes; representing a sound investment designed to reduce downstream amputee health-related government costs in those countries.[33] [34] Yet, an approach such as this has not been recognised in Australia, meaning that there is no entitlement to such devices whatsoever if a person's only funding source is a state-based artificial limb scheme.

While some amputees may never be a suitable candidate for a prosthesis many will be, and this should be encouraged and prosthetic options should be made easily available, soon after an amputation and when safe to do so. A 2020 'IMPACT Study' in the US demonstrated that delaying or not providing a prosthesis within 0-3 months increases direct healthcare costs by approx. 25% over the initial 12 months post amputation; further evidencing that early provision increases acceptance, mobility, return to work, quality of life and a reduction in short to longer-term associated government healthcare spending.[35]

Amputees don't want to be left behind or denied of the benefits that advanced prosthetics can provide. And the government should seek to engage in front-end investment in early-stage provision of advanced prosthetics in order to realise lifelong downstream health, disability and welfare cost savings.

4.2.2 Mobility devices

For those amputees who are unsuitable or unwilling candidates for prosthetics, primary mobility and locomotion is enabled through other assistive technology. Predominate alternative mobility devices include wheelchairs, unipedal walking frames and crutches. Various studies have identified that the determinant of prosthetic non-use and utilisation of alternative mobility devices includes factors such as: physical health (amputation level, comorbidities, degenerative changes to the intact limb); demographic characteristics (age, residential aged care); length of time between amputation and prosthesis fitting; bilateral amputations; and/or, prosthesis abandonment due to low satisfaction.[36]

Whilst some amputees will only ever ambulate using an alternative mobility device it is important to note that many prosthetic users are concurrent or supplemental users of such devices also. The main

reasons being practical ones, such as: toileting during the night whereby it is safer using a wheelchair than donning a prosthesis if sleepy; as a back-up if temporary prosthetic failure occurs; during periods of stump infection due to skin breakdowns; fatigue reduction; and/or transfer within the home after daily removal of their prosthesis. The need for access to alternative mobility devices to enable primary or temporary movement in the home, community or workplace is therefore critical for virtually all amputees.

The degree to which the person will use the device, how and where it will be used, health considerations, personal preference and recommendation from healthcare providers will influence the choice of device. For example, an older amputee reliant on a wheelchair may find that a manual chair is too difficult to use in terms of unsustainable energy expenditure, falls risk and manoeuvrability, and thus more suited to a power-assisted one. Whereas another amputee who primarily uses their prosthesis throughout the day may be better suited to a manual wheelchair when temporarily not wearing their prosthesis, and/or the need to ambulate during the night when they are sleepy and feeling unstable on their prosthesis. The variation in cost between a powered wheelchair and manual one is significant, with the former potentially costing $2,500 and the latter $20,000 or more.

Yet again, the issue of fragmented and inequitable funding arrangements is notable when exploring access to mobility devices. Again, some amputees who are NDIS participants have greater opportunity to request access higher-end mobility devices. Whereas their older peers reliant on state-based aids and equipment programs or living at home and in receipt of an aged care package receive such limited funding these products are often out of reach, require significant co-contribution and generally experience time delays in order to receive their much-needed product.

4.3 Access to prosthetic providers

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. [37]

However, as most Australian public and private prosthetic providers are only available to see clients during business hours, 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 public prosthetic providers (state dependent) can often experience lengthy waiting times to see a provider for the supply, fit and/or maintenance of their prosthesis. Such delays can cause preventable complications that affect long-term limb fit, such as swelling, 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 re-admissions which, in

addition to affecting the individual and their support network, also has a downstream economic effect on government health budgets.

Limited, or delayed, access to timely assistive technology provision and maintenance 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:

- Article 5 (3) requires that reasonable accommodation be provided to promote equality and eliminate discrimination; making limited access to prosthetic servicing at accessible times a denial of reasonable accommodation.
- Article 9 requires that access to facilities and services be provided on an equal basis with others; suggesting that the profession should pursue a goal of eliminating time-bound barriers and obstacles that impede amputees from accessing prosthetic servicing outside of normal business hours and within reasonable waiting periods.
- Article 20 (d) requires that entities manufacturing assistive technologies support the mobility goals of persons with disabilities; with accessible prosthetic service appointment limitations potentially discriminatory constraint to amputees' independence.
- Article 25 requires that health services and early intervention be provided to minimise and prevent further disabilities; making barriers to accessible prosthetic servicing a potential example of benign neglect.
- Article 26 (3) advocates for the provision of effective and appropriate measures to enable persons with disabilities to attain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life; making limited access to prosthetic servicing or repairs outside of working hours a potentially discriminatory practice.

The provision of prosthetic services is complex and fragmented in Australia for people over 65 and/or those who did not have amputations in time to be eligible for NDIS supports. In relation to artificial limb scheme provision, some states have long standing agreements with public funded services (ACT, Tasmania,) while other states are open to both public and private providers and regularly allocate funding to new clinics (NSW, Qld and WA). Both Victoria and South Australia have a mix of mainly publicly funded services and minimal private providers. In the Northern Territory the only option is public facilities. NDIS provision, on the other hand, is a competitive marketplace with a mix of private providers and public facilities servicing NDIS participants. It is also worth acknowledging that an NDIS participant will have their travel costs covered if there are limitations in the choice and control of provider, largely meaning that those in rural and remote areas can attend a provider of their choice if only one choice is located nearby. Whereas a person reliant on artificial limb scheme funding will not have travel costs funded, and therefore must either wait from a traveling clinic to attend their home town (or one nearby) or be out-of-pocket and cover transport and related costs to attend a central service as required. This is creating an enormous inequitable gap between the amputee 'haves' and the 'have-nots' and placing an additional burden on older Australians who may not have the physical or financial capability to travel.

Limbs 4 Life acknowledges the current challenges of skill shortages in the prosthetic provider workforce and the difficulty in delivering easily accessible services in rural and remote locations.[38]

Limbs 4 Life is also aware that not all public and private prosthetic providers will be in the position to offer servicing outside of normal business hours.

Another underlying factor that needs to be considered in regards to the prosthetic workforce industry is the hourly labour rates issue. While the NDIS pay prosthetic providers approximately $192 per hour, the hourly rate to manufacture a prosthesis under state-based artificial limb scheme funding is less. This then begs the question about priorities. What is the incentive for a private prosthetic provider with a vast array of overheads to manufacture, supply and fit a prosthesis and provide service under the various artificial limb schemes for a lesser hourly rate? There needs to be an incentive for providers to continue to treat amputee's ineligible for NDIS supports, who are largely over 65 years, rather than prioritising those who are NDIS participants and delivering a greater hourly rate to the provider. Addressing this would overcome the issue of those who are not NDIS eligible being placed on ever lengthening waiting lists.

Overall, the issue of fragmented access to prosthetic provision is a human rights and systemic matter that the government should be aware of and seek to resolve as an outcome measure in the new National Disability Strategy.

Case studies: limited access to prosthetic appointments

"My employer was often unreasonable about my prosthetic appointments during the day and I was not allowed to take time off. Prosthetic providers rarely operate outside of regular business hours" (Female, above-knee amputee, Queensland, 59 years)

"I am self-employed and drive trucks for a living. Any time off the road is money for me. Since becoming an amputee I've been unable to access prosthetic appointments at a time to suit me. My 'leg guy' is a single operator and if he is unwell or goes on leave and I need an urgent repair done, I'm in trouble." (Male, below-knee amputee, regional New South Wales, 53 years)

4.4 Home environment modifications

Modifications to home environments is a critical enabler for amputees to live a safe, independent and good quality of life. Furthermore, minimising difficulties in activities of daily living not only benefits the person but also alleviates burdens placed on carers, reduces the need for additional support services and can delay entry to an aged care facility. [39]

A person's home is where they engage in the majority of their daily living activities such as bathing, preparing food, eating, sleeping, relaxing and socialising. And the relationship between a person and their dwelling is critical to their sense of safety, efficacy and wellbeing.[40]

Home modification describes "structural changes made to the homes of older people and people living with a disability" and typically prescribed by an occupational therapist in order to support a person's ability to live independently at home.[41] [42] It is critically important that any significant home modifications are not only prescribed by an occupational therapist, but designed and built in accordance with universal design principles which increases usability, safety, health and social

participation.[43] Without taking this approach, amputees are at risk of substandard modifications which may not take account of their specific needs and compromise the structural reliability of their dwelling.

Because the impact of limb loss is individualised the types of home modifications required can vary greatly. In particular the home modification requirements of a lower limb amputee, with mobility limitations, as compared to an upper limb amputee, with functional restrictions, can significantly differ. But common modifications required by amputees may include installation of ramps, grip bars, widening of hallways and doorways for wheelchair users, and changes to bathroom and wet areas to promote safe ambulation.

Amputees' access to home modification funding is contingent on which funding support scheme they are attached to. In the case of older amputees accessing funding for home modifications through the aged care system, there may be considerable delays in approvals, inadequate provision or denial of funding altogether. Amputees who are reliant on state-based aids and equipment funding are unlikely receive any support for home modifications, but if granted it will be minimal, such as a ramp, hand or grab rail.

Many older Australians want to live at home for longer.[44] And the Australian Government also wants more older Australians to 'age in place' and remain living in their home rather than entering residential aged care, even when the impacts of old age affect their mobility and mental ability (e.g. the increasing risk of illness or disability).[45]

Since 1 July 2019, all older people with disability who do not meet the age eligibility requirements for the NDIS have been required to access services from the aged care system.[46] As noted earlier, there are two main programs that exist under the aged care system to provide support for home modifications to assist people in their own homes - the Commonwealth Home Support Program and the Home Care Packages Program. However, due to pre-determined funding levels amputees over the age of 65 and ineligible for the NDIS often experience limited funding, significant time delays in accessing home modifications under these funding programs or the need to trade off one vital product or service in order to afford reasonable modifications to their dwelling.

Independent, accessible, accommodated and self-determined living feature within the CRPD:

- Article 4 imposes a general obligation on State Parties to undertake, or promote research and development of universally designed goods, services, equipment and facilities.
- Article 19 (a) requires State Parties to ensure that persons with disabilities have the opportunity to choose their place of residence. Article 9 obliges State Parties to ensure that persons with disability are able to access all aspects of their physical and social environment.
- Article 28 (1) requires State Parties to provide an adequate standard of living for persons with disabilities and their families.

The Australian Network for Universal Housing Design (ANUHD) is presently advocating that the Australian Government regulate "minimum access in the National Construction Code for all new and extensively modified housing".[47] Part of the rationale for this is that current housing designs do not meet the needs of people with mobility difficulties, that an increased supply is critical to the success

of the NDIS and Aged Care Reforms, and that regulation in the National Construction Code will provide cost and production efficiencies. Indeed, the ANUHD considers the minimum standard for new builds and modified homes to be the 'Minimum Housing Design Gold Level' as outlined in the 'Livable Housing Design Guidelines', and Limbs 4 Life supports efforts for this regulatory change to form part of the new National Disability Strategy endeavours and commitments.

None or inadequate home modification funding puts amputees, and those who live with them, at risk of living in compromised dwellings. This suggests that Australia is not meeting its requirements under the CRPD while also negating the Australian Government's commitment to enabling more older Australians to safely age in their own homes for longer.

Case study: Roger

Roger, who is 66 and lives in South Australia, returned home following a below knee amputation. Due to health complications Roger is unable to use a prosthesis and replies on a wheelchair to ambulate around his home. Roger's wheelchair does not fit through his bathroom door.

As a result, Roger has been showering using a garden hose in his backyard. On some occasions Roger's wife Jenny will take Roger to the local caravan park so that Roger can have a warm shower.

Roger cannot afford the cost of home modifications to widen his bathroom doorway and is waiting on approval for a home care package in hope that the costs for this work will be covered.

4.5 Recommendations

Recommendation 1:

An overarching recommendation is that a national and independent National Disability Strategy body be established. Ideally, this body should have:

- strategic responsibility for implementation of the National Disability Strategy, including development and oversight of Targeted Action Plans, the proposed Strategy Engagement Plan, performance indicators and annual public reporting of progress and outcomes
- clear terms of reference so that all stakeholders understand what falls within the brief of this strategic management and oversight body
- best-practice mechanisms put in place which enable people with disabilities, carers, disability organisations and disability advocacy organisations to engage in consultations, co-design of strategies and raise issues related to the National Disability Strategy
- capacity to recommend policy changes which reflect ones that would address National Disability Strategy outcome area needs and issues
- powers to conduct enquires into National Disability Strategy issues raised by stakeholders
- the ability to make recommendations to the Australian Human Rights Commission, or other relevant external agencies, to conduct formal enquiries where incidents of systemic human rights or disability discrimination is found to be occurring.

Establishment of such a body could then be used to enquire into, investigate and respond to many of the recommendations in this submission.

Recommendation 2:
Because the provision of assistive technology is so widely spread across various federal and state government departments and agencies, there is currently a limited ability to measure comparable data about the services and funding provided. And in some cases there is no requirement to publish any data whatsoever, such as those state-based departments responsible for management of artificial limb schemes. This impedes the public's ability to assess performance, measure outcomes and enable comparable linkage across the varying datasets. This also mitigates the ability of sector organisations, researchers, policy makers and providers to more easily identify gaps, failures, improvement opportunities and successes to inform change and better understand how people are faring.

It is recommended that the new National Disability Strategy require that:

- NDIS and My Aged Care outcomes and performance data be more widely shared. Furthermore, the ability to capture comparative assistive technology related details should be made easier with the recent transfer of the NDIS to the Department for Social Service, which also holds portfolio responsibility for My Aged Care.
- Commonwealth-funded state-based schemes and programs providing assistive technology publicly share outcomes and performance data, ideally using a common data collection and reporting instrument.

Recommendation 3:
In light of the United Kingdom (UK) and New Zealand (NZ) providing microprocessor knee prosthetics on their respective public funding system, in order to improve user outcomes and reduce downstream health and disability costs, the Australian Government should consider adoption of a similar policy transfer here. While many above knee amputees are being fitted with these devices if an NDIS participant, this is not the case for those acquiring their prosthetics via state-based artificial limb schemes. Much evidence and literature provided a rational case for implementation in those countries and, coupled with subsequent outcome and performance-based results since, offer much data to enable a sound justification for why such an approach should also be introduced in Australia.

The new National Disability Strategy has the capacity to prioritise this suggested equity-oriented policy transfer opportunity in recognition of its strong relationship to the 'health and wellbeing' outcome area.

Recommendation 4:
Timely access to prosthetic provision is currently marred by fragmented funding arrangements, prosthetic industry skills shortages, and disincentives which see NDIS participants prioritised over the less commercially viable artificial limb scheme funded amputees. This presents a clear risk to amputees' human rights, is discriminatory and demonstrates Australia's failure to meet its responsibilities on an array of Articles within the CRPD.

The new National Disability Strategy has the capacity to prioritise this suggested equity-oriented issue in recognition of its strong relationship to the 'health and wellbeing', 'personal and community support' and 'rights protection, justice and legislation' outcome areas.

Recommendation 5:
The new National Disability Strategy must prioritise the establishment of a funded National Assistive Technology Program, as advocated for by the Assistive Technology for All Alliance (of which Limbs 4 Life is a member), to streamline access and provide equitable support to people with disability who are excluded from the NDIS. This program should:

- Harmonise existing state-based assistive technology programs, in particular the state-based 'artificial limbs scheme' and 'aids and equipment program'. This would streamline access and drive nationally consistent outcomes for consumers while reducing administrative burden on governments, entice people to continue to reside at home and promote the same choice and control that NDIS participants are currently afforded.
- Be aligned with the NDIS Assistive Technology Strategy to address the inequity between the support that is provided under the NDIS and other service systems
- Be driven by key performance indicators relating to the timely provision of equipment, in line with the aspirations of the NDIS Participant Service Guarantee.

5. Workforce participation – enablers and barriers

Australians who experience amputation often acquire and are impacted by this disability during their working years. While some amputees may never be able to re-enter the workforce post-amputation, largely due to the type and reason for amputation, many are able to and seek just such participatory opportunities.

International meta studies conducted within developed nations have found the return-to-work rate of amputees range from 43% to 70%, with between 22% to 67% of those retaining the same occupation and the remainder having to change vocation or leave employment altogether. [48] [49]

Various studies also found that return-to-work with the previous or a new employer is often contingent on: age; gender; education level; cause of amputation; time since amputation; vocational rehabilitation; amputation impairment factors (e.g. amputation level, comorbidity, persistent stump problems, mobility); access to prosthetic fitting and maintenance; pain; and, factors related to employment (e.g. salary, employer support, government supports and social support network). [50] [51] [52] [53] [54]

Research has also shown that barriers to amputees' gaining and maintaining employment can be ameliorated via implementation of a variety of measures in workplace settings. These include employers and colleagues having greater general disability awareness, recognition that stump and phantom pain can affect functionality, understanding the need for prosthetic appointments, provision of job and task adjustments, making reasonable and necessary workplace modifications,

and provision of workplace-specific practical aids and assistive technology. [55] [56] [57] As does creating a workplace culture whereby disability, and the unique impacts of amputation, is appreciated and respected organisation-wide.

As is well understood, employment for people with disability plays an important role in enhancing physical and mental health wellbeing, self-esteem, social network expansion, personal agency, and financial independence. Thus, the socio-economic value of workforce participation should not be underestimated and supported at policy, individual workplace and equity principle levels.

However, given that the current unemployment rate for Australians with a disability is nearly double that of those without one and that we rank poorly on OECD rates for disability employment much still needs to be done in Australia to mitigate workplace barriers and increase labour force participation. [58] [59] [60] At an amputee-specific level, it is critical that employers and government-funded disability employment support services better understand the needs of this unique physical disability cohort and put into place measures that will assist amputees to experience integrated, inclusive, meaningful, and sustainable employment outcomes.

The equitable provision of assistive technology is integral in the meeting following 'Outcome Areas' proposed in the new National Disability Strategy:

- Economic Security
- Inclusive and accessible communities
- Rights protections, justice and legislation
- Personal and community support
- Learning and skills
- Health and wellbeing.

5.1 Instruments guiding lawful disability employment and support arrangements

A number of covenants, standards and legislation guide the provision of employment services and support for people with disability in Australia. The key ones being: The Convention on the Rights of Persons with Disability; the Disability Discrimination Act; The Fair Work Act 2009; and, National Standards for Disability Services. It is notable that these are not only concerned with increasing employment opportunities through the reduction of barriers, but also address the critical role that assistive technology and accessibility plays in accommodating and enabling people with disability to enter into and participate in the workforce.

The Convention on the Rights of Persons with Disabilities

Specific Articles within The Convention on the Rights of Persons with Disabilities commit Australia to increasing employment opportunities, mitigating discriminatory practices which impede it, and reaffirms that provision of assistive technology and access to healthcare are vial human rights which reduce barriers to socio-economic participation. With specific regard to employment and labour market participation:

- Article 5(2) requires that, in order to meet equality and non-discrimination obligations, all appropriate steps are to be taken to ensure that reasonable accommodation is provided. [61]

- Article 8(2a) requires that, in order to meet awareness-raising obligations, recognition of the skills, merits and abilities of persons with disabilities, and their contributions to the workplace and labour market must be promoted. [62]
- Article 9(1a) requires that access to facilities and services be provided on an equal basis with others, including workplaces. [63]
- Article 26(1) requires that effective and appropriate habilitation and rehabilitation measures are taken 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. *[64]*
- Article 27(1) requires a recognition that persons with disabilities have a right to work, on equal basis with others, and safeguard and promote the realisation of the right to work. It also notes that the right to work, including those who acquire a disability during the course of their employment, includes the opportunity to gain a living through freely chosen work that is open, inclusive, accessible and facilitated through reasonable accommodation. [65]

Disability Discrimination Act 1992

The Disability Discrimination Act 1992 makes it unlawful to discriminate against a person with disability, in many areas of public life, including: employment; education; accessing and using services; housing; and, accessing public places.

Under the Act, people with disability are protected against direct and indirect disability discrimination. With respect to employment, the Act makes it unlawful to discriminate in relation to:

- the recruitment process, such as advertising, interviewing, and other selection processes
- decisions on who will get the job
- terms and conditions of employment, such as pay rates, work hours and leave
- promotion, transfer, training or other benefits associated with employment
- dismissal or any other detriment, such as demotion or retrenchment. [66]

While the Act outlines that there are lawful exceptions available to employers, such as when someone with a disability cannot perform the inherent requirements of a job, it articulates that employers must consider how a person with disability could be provided with reasonable adjustments to assist them to perform a role. An adjustment is reasonable on the proviso that it does not impose 'unjustifiable hardship' on the employer. Unjustifiable hardships can be proven if an adjustment to the workplace would be too expensive, difficult, time consuming or cause some other hardship. [67]

As an employer may not know what reasonable workplace changes are required by a person, they can be advised by the individual and/or government agencies or organisations which represent people with disabilities. Examples of reasonable adjustments include:

- changing recruitment and selection procedures
- modifying work premises
- changes to work design, work schedules or other work practices
- modifying equipment
- providing training or other assistance. [68]

The Fair Work Act 2009

The Fair Work Act 2009 [69] notes that there are two formal ways that employers and employees can make workplaces more flexible for people with disabilities. Firstly, certain employees (including people with disabilities) have the right to request flexible working arrangements. Secondly, both parties can negotiate to change certain terms in an award, enterprise agreement or other registered agreement. Certain arrangements may include (but are not limited to): hours of work; patterns of work; and, locations of work.

National Standards for Disability Services

The National Standards for Disability Services was endorsed and adopted by the Standing Council on Disability Reform Ministers from all jurisdictions in 2014. The six standards underpin the practices of Australian Government funded employment service providers and advocacy agencies funded under the National Disability Advocacy Program. The standards have a focus on person centred approaches and promote choice and control, and significantly informed by The Convention on the Rights of Persons with Disability and the 2010 – 2020 National Disability Strategy. [70]

The six standards are:

- **Rights.** The service promotes individual rights to freedom of expression, self-determination and decision-making, and actively prevents abuse, harm, neglect and violence.
- **Participation and Inclusion.** The service works with individuals and their families, friends and carers to promote opportunities for meaningful participation and active inclusion in society.
- **Individual Outcomes.** Services and supports are assessed, planned, delivered and reviewed to build on individual strengths and enable individuals to reach their goals.
- **Feedback and Complaints.** Regular feedback is sought and used to inform individual and organisation-wide service reviews and improvement.
- **Service Access.** The service manages access, commencement and leaving a service in a transparent, fair, equal and responsive way.
- **Service Management.** The service has effective and accountable service management and leadership to maximise outcomes for individuals.

5.2 Assistive technology, workplace modifications, accessibility and funding constraints

Workplace-related assistive technology, modifications, accessible premises and work spaces, and flexible practices are critical for some people with disability, and in particular amputees, to enter into and sustain labour force participation and perform specific employment roles. Furthermore, provision of these play critical roles in ensuring that amputees' human and employment rights are ascribed.

A discriminatory and neglectful lack of access to these accommodations has the opposite effect, resulting in amputees being unable to perform their role, experience personal difficulties, the need to personally fund vital resources and/or an inability to maintain/regain employment. Whereas, conversely, adequate provision of appropriate and fit-for-purpose assistive technology enables

amputees to fulfil their workplace responsibilities, ensures safety and comfort, demonstrates company support and/or supports return to work post-amputation.

A number of studies note that amputees can be accommodated in the workplace on the proviso that the person will be able to safely perform the required tasks without risk to themselves or others and that it doesn't place the employer under undue hardship. Such reasonable accommodations may include:

- making the physical workplace environment accessible
- providing assistive equipment
- transferring an employee to a different job or location
- providing flexible scheduling
- tools to accomplish jobs
- suitable desks, chairs and computers
- accessible buildings and facilities (such as ground floor access to work stations and parking)
- transport. [71] [72]

In order to gain workplace support amputees and their employers rely on the Australian Government's Employment Assistance Funding (EAF) to apply for reasonable, necessary and fit-for-purpose workplace modifications and accessibility funding. [73] Provided via Job Access, this scheme is designed to support employers' capacity to engage people with varying disabilities in workplaces. As a physical disability cohort, amputees often need workplace modifications to facilitate task-specific activity, access to premises, use internal workplace facilities, ensure safety, and minimise discomfort or pain. Furthermore, these modifications and adjustments enable amputees to engage with colleagues and customers, as well as participate in team-wide activities. The EAF is also able to fund prosthetic devices if the specific purpose of that device is work related.

A Limbs 4 Life employment survey, used to inform our submission to the Disability Royal Commission's 'Issues and Attitudes Paper', canvassed amputees' workplace experiences and transformative ideas for making employment more accessible, inclusive and enjoyable. [74] Concerningly, a number of respondents noted that they and their previous or current employer were unaware that the EAF program even existed. Subsequently, this suggests that employers are missing out on funding aimed at supporting amputees in their workplaces; the consequences being individuals going without task-specific devices, employers self-funding these or, more concerningly, the loss of employment altogether.

Case studies: accessibility and Employment Assistance Fund issues

Inaccessible workplace

"Basic lack of consideration: for example, wheelchair ramp from car park to entrance ends in a 160mm steep, effectively preventing entry without assistance." (Male, below-knee amputee, Victoria, 70 years)

"The workplace failed me by not installing an accessible toilet for me for 7 years. They were afraid if they asked the owners of the building to put in the toilets suitable to me, they might start charging more rent." (Female, below-knee amputee, South Australia, 59 years)

Employment Assistance Fund

"I initiated application to Job Access as my company had no idea that there was any such thing." (Male, below-knee amputee, Victoria, 51 years)

"*Funding from Job Access that was provided for workplace modifications were spent updating the coordinator's office area."* (Male, above-knee amputee, New South Wales, 34 years)

5.3 Inclusive workplace culture and leadership

Studies highlight that strong leadership and positive disability friendly workplace cultures foster social inclusion, rehabilitation goals, improved quality of life and income, increased job satisfaction and retention, social network expansion and career progression amongst people with disabilities. [75] [76] Furthermore, the Australian Network on Disability highlights that businesses which employ people with disability can attract and retain talent, build reputation and brand, improve marketing and customer retention, mitigate risk, and uphold rights. [77]

Conversely, workplaces that do not commit to diversity and inclusion can lead to impacts and barriers within a person's self-confidence, anxiety/amotivation, health and wellbeing, and inter-personal domains. [78] [79] In addition, such workplaces have greater propensity for bullying and harassment occurrences, with the by-product being anxiety and depression amongst victims. [80] [81] Indeed, workplaces that fail to provide people with a working environment or workplace culture free from harassment and bullying may be in breach of the Disability Discrimination Act 1992, and face sanctions associated with such contraventions.[82]

Amputees provided significant commentary about exclusive workplace cultures in their responses to the aforementioned Limbs 4 Life employment survey. Those who experienced discriminatory and neglectful experiences pointed to poor disability awareness, bullying, workplace exclusion, and reprisal upon making complaints as key concerns.

Case studies: poor disability leadership and practices

"I worked for a government department within the Premier's office and was called stumpy behind my back and told by another employee because he "knew I could take the joke"." (Female, below-knee amputee, 44 years)

"My employer has set up a Disability Awareness Committee, but guess what I have not been invited to be on this committee even though I am the only disabled person employed by my organisation! Employers need to listen to the needs of disabled employers and gain understanding. They should not assume that as long as they 'comply' to certain standards that they are improving their practices. They seem to think it's too personal to ask people about what they need. But it is all about communication and not about assumption." (Male, below-knee amputee, Western Australia, 50 years)

5.4 Recommendations

Recommendation 6:
That the Government invest in a nation-wide disability employment awareness and education campaign, in an effort to influence mainstream employment methods, dispel stigma and eliminate discrimination. The campaign should include use of multi-modal channels and platforms to increase reach and scale. The campaign should be co-designed to incorporate input from people with various disabilities, industry bodies, disability employment sector organisations, peak disability bodies, disability specific organisations and subject-matter experts.

The new National Disability Strategy has the capacity to prioritise a national disability employment campaign in recognition of its strong relationship to the 'economic security', 'learning and skills', and 'inclusive and accessible communities' outcome areas.

Recommendation 7:
It is recommended that the Australian Government engage in a national strategy to engender greater employer awareness of, and employees' entitlements under, the Employment Assistance Fund (EAF). This would reduce limited knowledge of this program and ensure that people with disability gain access to timely assessment of workplace-specific assistive technology needs and the provision of reasonable and necessary devices and workplace modifications.

The new National Disability Strategy has the capacity to prioritise a national EAF awareness-raising campaign in recognition of its strong relationship to the 'economic security' outcome area.

Recommendation 8:
The new National Disability Strategy develop a targeted plan for greater inclusion of people with physical disabilities in the workplace. This plan could be initiated by an independent executive body responsible for oversight of the National Disability Strategy or become the responsibility of the Department of Social Services. The body with responsibility should engage with state and territory governments, disability employment providers, industry peak bodies, disability peak bodies and consumers, to develop a co-designed plan to better support, engage and retain people with physical disability in the workforce. The publicly accessible plan should clarify:

- Policies, practices and strategies for improving the workforce participation of people with physical disability, particularly in the areas of assistive technology and workplace modification provision
- How annual performance and outcome targets will be tracked and measured
- Levels of resources committed to achieving strategic goals.

Recommendation 9:
The Australian Government continue to fund the National Disability Advocacy Program. Currently an array of organisations have been funded via this grant to provide independent advocacy for all people with disability in designated regions. Ongoing provision of funding in current and/or new

organisations will play a role in ensuring that people with disability have access to effective disability advocacy that promotes, protects and ensures their fair and equal enjoyment of human and employment rights.

The new National Disability Strategy has the capacity to prioritise the retention of advocacy service funding in recognition of its strong relationship to the 'economic security' and 'rights protection, justice and legislation' outcome areas.

6. Accessible physical environments – enablers and barriers

Accessible physical environments are critical enablers for people with disabilities to access the interconnected domains of social community, sporting and leisure activities, health services, transportation, civic and political processes, and any other services and programs offered in public and private facilities. In doing so a person's independence, safety, security, inclusivity and choice is maximised.

Access to the physical environment is often best achieved when it is mainstreamed, is designed for all, and involves input and consultation from those with disability and other members of the community. In recent decades we have seen much incremental progress in improving accessibility and the removal of obstacles within the physical environment domain. However, in some respects we are yet to make such accommodations instinctive and ingrained, rather than only by those with the capacity, inclination or legal requirement to do so. It must be remembered that people with disability are not the only beneficiaries of accessible environments, but so too are those with limitations due to the effects of ageing, people who experience temporary injuries or parents negotiating access with prams or very young children.

Article 9 of the CRPD requires that State Parties provide people with disability a general right to access:

- Article 9 (1) outlines that to enable persons with disabilities to live independently and participate fully in all aspects of life, State Parties shall take appropriate measures to ensure to persons with disabilities access, on equal basis with others, access to the physical environment, to transportation, to information and communications and to other facilities and services open or provided to the public. Furthermore, these measures shall include identification and elimination of obstacles and barriers to accessibility including in relation to buildings, roads, transportation and other indoor and outdoor facilities including schools, housing, medical facilities and workplaces.
- Article 9 (2, a, b) requires that State Parties shall also take appropriate measures to implement minimum standards and guidelines for the accessibility of facilities and services open to the public; and ensure that private entities that offer facilities and services which are open to or provided to the public take into account all aspects of accessibility for persons with disabilities.

Physical environment barriers have been reported by amputees as obstacles to full and inclusive community participation. Such barriers include difficulties negotiating steep or uneven terrain, public building access, public transport access and parking, and when encountered can negatively influence the ability of an amputee to participate in community activities and physical activity. [83]

Physical environments often fall within the responsibility of government and non-government bodies, highlighting an ongoing need for such agencies and businesses to mitigate the access barriers experienced by amputees' and others living with disability, and in doing so make access for all, and not just those with disability, the norm.

Gaining access to physical environments, and the services and technology required to do so is integral in the meeting following 'Outcome Areas' proposed in the new National Disability Strategy:

- Economic Security
- Inclusive and accessible communities
- Personal and community support
- Learning and skills
- Health and wellbeing.

6.1 Built and physical environment access

The built and physical environment, as it pertains to people with disability, includes outdoor environments, streets, parking, public buildings, sporting and leisure facilities, medical and allied health facilities, and other public service buildings.[84] A lack of access to the built and physical environment can limit a person's ability to participate in everyday life, lifelong learning and the labour force, makes them more dependent on others, and potentially jeopardises their safety.

As noted in the 2009 'Shut Out' report "… the impact of the built environment on people is something many rarely considered. For many people with disabilities the built environment acts as a powerful barrier to their full inclusion in the community." [85]

Under the Disability Discrimination Act it is against the law for public places to be inaccessible to people with disabilities and requires that organisations make adjustments to their premises so that they are accessible. However, in some circumstances a person or organisation can seek an exemption if the cost or difficulties to provide complete accessibility can be proven to be an "unjustifiable hardship".

A wide range of national Standards and Codes, set out how to provide safe, equitable and designed access to buildings, facilities and services within buildings, and other parts of the built environment (e.g. parks, parking, street furniture, pathways, playgrounds).[86] These include the Building Code of Australia and Premises Standards, which outline the standards for public access to buildings for people with a disability as they apply to new or upgrades to existing ones. However, these do present with some limitations, such as failing to take account of wheelchair dimensions and motorised scooters in Standards which alone would fail to meet universal design principles.[87]

Whilst the issue of complexity in laws, legislations and policies across all three levels of government was also raised as a barrier to accessibility in the 'Shut Out' report, the above noted issues highlight

that Australia is still experiencing challenges in relation to accessibility compliance, enforcement and design responses which extend beyond the standard Disability Discrimination Act requirements.

Furthermore, it is critical that the provision of assistive technology and access to the built environment are seen as interdependent needs. These necessarily go hand in hand for amputees. As discussed in section 5 'Assistive technology – enablers and barriers', inequitable and disparate assistive technology arrangements has a direct and negative impact on amputees' ability to participate in their community.

Case study: John

John is a 47 year old above knee amputee who lives in Victoria. Every three years John needs to physically attend his local Council office to update his accessible parking permit. While updates have been made to the Council offices, the disability parking and gradients updates seemingly don't meet the needs of people with mobility issues. As a consequence, John is always fearful upon leaving the building and walking down the very steep hill to get back to his car. As John says, "It's ridiculous!".

John joined the council's Access and Equity Committee to ensure he could be a voice advocating for change for the rest of his community. On the days of the meetings, and at a personal expense, he leaves work early so he can represent vulnerable members of his community. Sadly, prior to joining the committee plans to amend the carpark were already in place and aside from widening the parking bays no other changes were made.

"This is such a disgrace – it affects not only people like me but also elderly people too. We pay rates to these Councils – why set up a committee when we, as residents are not listen to? To this day, I struggle to access that building and despite voicing my concerns there are no plans in place to change this".

6.2 Transportation

Accessible transportation enables people with disability to gain access to their local community, employment, healthcare facilities, places of learning, and recreational and cultural activities. This includes not only public transportation, but also accessible taxis and modifications to a person's private vehicle. Barriers and obstacles to accessible transportation can lead to exclusion; which in turn can affect a person's autonomy and independence and lead to impacts on a person's physical and mental health.

With respect to accessible public transport the compliance-oriented Commonwealth Disability Standards for Accessible Public Transport 2002 defines this service as "an enterprise that conveys members of the public by land, water and air, and includes both publicly and privately owned services." Critically, this document informs standards, targets and compliance to remove discrimination from services. It is approaching its fourth review period by the Transport and Infrastructure Council, and informed by the Accessible Transport Taskforce and National Accessible Transport Steering Committee (comprised of technical experts from government, industry and the disability community), with Ministers endorsing a forward work program for reforms to these Standards in August 2019. The access provisions due to receive legislative amendments in late 2021

and reforms to be finalised in 2023 embrace four guiding principles: people with disability have a right to access public transport, accessibility is a service, not an exercise in compliance; solutions should meet the service needs of all stakeholders and be developed through co-design; and, reforms should strive for certainty. [88] As the Taskforce has representation from only two disability organisations, it is critical that its promise to engage in stakeholder and public consultation in early 2021 takes place in a timely manner in an effort to capture the voice of all people with disability across Australia, taking account of the ever changing needs of this diverse cohort who are reliant on various forms of transportation for access and mobility.

However, it is concerning that, as identified during a 2019 Human Rights Commission Consultation, operators and providers indicated uncertainty about how equivalent access provisions in the Standards are interpreted as a disincentive to their use, and the need for more general guidance to assist in increased use.[89] It is hoped the impeding reforms will clarify these matters for those operating in the broad public transportation sector.

It is pleasing that state and local governments have drawn upon this overarching document to inform their own more recent jurisdictional accessible action plans to effect changes in their locales. One such example being the Victorian Government 'Accessible Public Transport in Victoria Action Plan 2020 – 2024' which will over five years implement infrastructure, updated tools, better information as means of reducing and eliminating barriers across all modes of transport in collaboration with all transport agencies.[90]

6.2.1 Public transport

Some amputees are casual users of public transport, while others rely on this as their only mode of transportation because they are no longer able, fit or willing to drive a motor vehicle. Indeed, amputees' access to public transport doesn't only facilitate mobility and community participation, but under the CRPD it is recognised as a human right.

In a 2018 Disability Resource Centre consultation with an array of people with varying disabilities, it was revealed that barriers affecting all modes of transport related to the provision of transport information, priority seating and parking, public attitudes and personal safety, transport staff conduct and community consultation.[91]

As amputees are users of public transportation it is important that they are included in ongoing and future development of public transport action plans which reflect their unique needs; and at all three levels of government.

6.2.2 Driving and vehicle modifications

Driving is an important means by which amputees can obtain or regain their independence, and for lower limb amputees, their mobility. One of the integral roles in the rehabilitation of amputees is functional independence, with returning to driving a motor vehicle an important step toward because it allows the pursuit of social and vocational, helps to preserves self-esteem and often represents the ultimate freedom.[92]

The determination as to whether an amputee, or person with congenital limb loss, is permitted to drive a car, motorcycle or truck is based on their capacity, fitness-to-drive assessments, and

sometimes evaluation and testing by a qualified occupational therapist. And if approved, restrictions may be placed on licences such as 'automatic only' or the requirement to have vehicle modifications (assistive technology) installed in the driver's car. In relation to vehicle modifications, lower limb amputees may require the fitting of left-foot accelerator pedal, the installation of spinner knobs or hand controls in the case of upper-limb amputees, or for more complex cases the use of a wheelchair hoist to lift the chair onto the roof of the vehicle.

But complexity, confusion and inconsistent national arrangements are associated with both licence approvals and vehicle modifications. Despite the nationally consistent 'fitness to drive' regulations, the approval and conditions associated with driving differs between jurisdictions. Limbs 4 Life is only too aware of this lack of consistency, a matter which greatly troubles amputees in our community who become cognisant that their outcome differs from a peer merely because they live in a different state or territory.

Furthermore, inconsistent funding arrangements impact on a person's ability to receive funding for both their driving assessments and/or installation of driving-related assistive technology. For example:

- An amputee eligible for NDIS funding can receive support for occupational therapy training and assessments and, if required, provision of modifications to their vehicle.
- A person ineligible for the NDIS must fund any occupational therapy assessment costs out of their own pocket, and is only able to apply for funding towards necessary vehicle modifications through their state-based aids and equipment program which may be insufficient to cover the full cost. In this case the person may not be in the financial position to co-contribute to the costs, which may delay their return to driving or prevent them from ever driving again.

The lack of national harmonisation in driving and vehicle modification requirements, coupled with the inequitable funding arrangements, leads to considerable frustration amongst people with limb loss who are keen to commence driving for the first time or return to doing so after a recent amputation.

Case study: Mario

Mario lives in country Victoria. He recently underwent a below knee amputation of his right leg. Mario is 79 years of age and needs his vehicle to access his doctor, for shopping and keeping in touch with his community.

Mario lives 40 minutes outside of a major regional town and was required to undergo driver re-testing to obtain his licence. Sadly for Mario the occupational therapist (OT) instructor had to travel 1.15 hours to meet Mario. Mario had 2 x driving lessons and an assessment.

The total out of pocket cost that Mario incurred was $3,425.00. In comparison, an NDIS participant would pay nothing!

6.2.3 Parking

Amputees with limited mobility, whether a driver or passenger, may find that parking closer to their destination facilitates greater independence, socio-economic participation, safety and physical health considerations.

The Australian Disability Parking Scheme includes a nationally recognised Australian Disability Parking Permit, which allows permit holders parking concessions that facilitate parking in spaces showing the international symbol of access and time specific concessions.[93] Whilst this is a national program, it is managed by state and territory governments in manners which are not nationally consistent. For example, applications are made directly to state government bodies in the Australian Capital Territory, New South Wales, South Australia, Queensland, Tasmania, Western Australia and the Northern Territory. However, in Victoria applications must be made via an application in a person's local council area, due to the fact that if VicRoads were to administer the program they would enforce an annual fee on permit holders to the tune of $55.00. Whereas in other jurisdictions, although it is administered by a government department or agency, the fee is either waived on the basis of disability, or a small one-off initial payment is required.

While all permit holders can use these when travelling interstate, the rules and concessions differ between each jurisdiction putting the onus on the driver with disability to check the parking rules and conditions in the state they are travelling to.

While the introduction of a national scheme, albeit state-managed, is enabling; that the application process, permit costs, and rules differ between each jurisdiction demonstrates a non-harmonised barrier for people with disability who want to independently travel either locally or interstate.

6.2.4 Taxis and ride share services

For amputees unable to easily access public transport or drive independently, an alternative option may be the use of taxis or ride sharing services. This may be particularly the case where there is limited access to public transport, such as in rural and remote locations or where public transport stops are beyond a person's walking or wheelchair capabilities.

While NDIS packages may include transport funding options, between $1,606 - $3,456 depending on circumstances[94], they are often insufficient to cover a person's need to pay for alternative transport costs over the course of a year. As non-public transport costs can be prohibitive, it can act as a significant barrier and disincentive to participating in the wider community, accessing vital health services and taking part in the workforce. And while the Australian Government 'mobility allowance' is funded for those with a disability and engaged in paid work, volunteering, self-employment, vocational training or life skills training for at least 32 weeks every four weeks on a continuing basis, the mere $99.50 payment[95] per fortnight is grossly insufficient to cover the cost of alternative transport options.

Across Australia, state governments subsidise taxi travel by half, usually up to a total trip fare of between $50 - $60 plus lifting fees for wheelchair users. With the growth in ride sharing services, such as Uber, there has been some concern that it may threaten the ongoing viability of wheelchair-accessible taxis, and further restrict alternative transport options for those who use this government subsidised service. At present there is no data evidencing this. However, with UberWAV currently piloting its wheelchair customised vans it is hoped this service will be scaled out more broadly and

give passengers greater options. Although Uber users cannot claim a disability subsidised fare, it is something the company has been lobbying for with state governments in recent years. However, a 2020 trial enabling up to 100 Geelong-based Multi Purpose Taxi Program members take subsidised Uber fares may see the trial expanded across Victoria or other states, and potentially become a permanent arrangement in all or parts of Australia.

6.3 Recommendations

Recommendation 10:
It is critical that the introduction of new, or reforms to existing, accessible environments and public transportation legislation, policies, projects or services scope the views of those most affected by any changes – people with disability themselves. It is therefore vital that all three tiers of government and businesses make significant efforts to capture the insights of people with disability, as well as those of carers, disability organisations and advocacy bodies. The new Disability Strategy can assist in achieving this by creating consultation guidelines which outline that all consultations are: announced in a timely manner; ensure that the accessibility needs of all participants are catered for; and, opportunities for meaningful involvement in design, development and evaluation is offered whenever possible.

The new National Disability Strategy has the capacity to prioritise this in recognition of its strong relationship to all six of the strategy's outcome areas.

Recommendation 11:
The new National Disability Strategy should support the implementation of universal design principles as part of current and future changes to the National Construction Codes and Premises Standards. In particular, the National Disability Strategy should support and endorse the Australian Network for Universal Housing Design's stated position that 'Gold Level' of Livable Housing Design Guidelines be the minimum level of access.

The new National Disability Strategy has the capacity to advocate for adoption of the 'Gold Level' Livable Housing Design Guidelines in recognition of its strong relationship to the 'inclusive and accessible communities' and 'rights protection, justice and legislation' outcome areas.

Recommendation 12:
Amputees must be assessed as 'fit to drive' for the safety of not only themselves but the wider driving public. Accompanying this is the potential need for occupational therapy assessments, vehicle modifications (assistive technology) and expert driving lessons. These requirements can result in access inequality, particularly amongst those older amputees who are ineligible for the NDIS and find that vehicle modifications and assessments cannot be fully funded in their small state-based aids and equipment package.

To address this, the new National Disability Strategy must prioritise the establishment of a funded National Assistive Technology Program, as advocated for by the Assistive Technology for All Alliance,

to streamline access and provide equitable support to people with disability who are excluded from the NDIS (as outlined in Recommendation 5).

Recommendation 13:
The taxi and ride sharing service industries are presenting ever changing, new and innovative landscapes for alternative transportation options for people with disability. In light of this evolution, it is important that provisions must be secured through government regulation and ongoing management of all existing taxi services and emerging ride sharing services to protect the human rights and safety of all users.

The new National Disability Strategy has the capacity to prioritise taxi and ride service regulation measures in recognition of its strong relationship to the 'inclusive and accessible communities' and 'rights protection, justice and legislation' outcome areas.

7. Peer support – enablers and barriers

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

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."[96]

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."[97] 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.[98] [99] [100]

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.[101]

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.[102]

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.[103]

Peer support is articulated as a right for persons with disability in Article 26 (1) of the CRPD, requiring 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.[104]

It is Limbs 4 Life's position that access to carefully managed and risk mitigated peer support programs is a means through which people with disability can exercise their "potential for mutual growth and healing"[105]. The literature strongly suggests that early invention peer support is extremely beneficial for the individual and can deliver long-term health-based outcomes. Early intervention engagement assists people with disabilities to understand the recovery pathway moving forward, 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 disability 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 peer support that responds to the needs of people with specific disabilities and carefully delivered by organisations with subject matter expertise is limited or lacking in Australia.

The equitable and accessible provision of peer support is integral in the meeting following 'Outcome Areas' proposed in the new National Disability Strategy:

- Inclusive and accessible communities
- Personal and community support

- Learning and skills
- Health and wellbeing.

7.1 Need and benefit of amputee peer support

While physical rehabilitation is provided post amputation, gaps exist with the provision of psycho-social rehabilitation, such as peer support.[106] The provision of peer support from those who have already made positive adjustments to amputation is recommended for all people incurring a major limb amputation. [107]

Much literature attests to amputees experiencing difficulty performing skills and daily tasks, loss of independence, feelings of inferiority, reduced wellbeing, change to or loss of employment, identity changes, feelings of sadness and shock, and impact on sexual life. [108] [109] Such effects may reduce over time, reappear during life transitions, or continue over a lifetime. To address this, it is highly recommended that peer support be routinely provided to amputees.

Findings from Monash University's study into the health and wellbeing of amputees highlight the critical role that volunteer-based peer support plays.

"Peer support volunteers helped recent amputees feel better about their situation, alleviated fears that accompanied the amputation, and responded to worries and concerns. A number of our participants had visits from peer support people around their amputation, which they found beneficial, not only helping them to become aware of what they could do physically after their amputation, but also to help them to come to terms with their loss. Receiving a peer support visit had significant mental health benefits for recent amputees, as these visits allowed them to see that a 'normal' life was possible. For them, this often meant a life not dramatically different from before. This understanding of returning to their normal lives was particularly important for those who were depressed after their amputation and felt that the amputation was the end of their lives. Where they had no opportunity to chat with a long(er) term amputee, participants often expressed their desire to do so, and when they did, found that the opportunity to discuss their experiences with another amputee was a defining moment in their rehabilitation process. While formal aspects of rehabilitation largely stop upon discharge from the rehabilitation hospital, many very important parts of the adaptation process occurred outside of the hospital, when individuals need to re-learn many aspects of daily life and the basic skills associated with managing their amputation in their home environment. Peer support was important in this respect."[110]

7.2 Minimum standards of amputee care

At present not all jurisdictions have enacted Minimum Standards of Care for Amputees. While state-based Minimum Standards of Care exist in New South Wales, South Australia and Queensland, other jurisdictions are yet to introduce this as a practice of care.

Care Standards play a crucial role assisting healthcare providers in the management of people who have undergone amputation and all indicate that peer support should form an integral part of an amputee's recovery and rehabilitation.

7.3 Amputee peer support provision and barriers

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 peer-to-peer support. 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; 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 providers 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 167 members and 105 more waiting to be trained and formally accepted into the program. On average 1,500 people are the recipients of Limbs 4 Life managed peer support annually.

Limbs 4 Life has never received sustainable government funding to support this vital service, and instead relies on meagre public donations or short-term philanthropic grants to deliver it. Although, it must be acknowledged that in recent years, Limbs 4 Life has been the recipient of short-term NDIS ILC grants to provide place-based peer support in two states (South Australia and Victoria). While welcomed, this does not address the continuing need for sustainable funding to ensure ongoing delivery of our Peer Support Program on a national scale, which is rising due to mounting annual rates of amputations.

Already the Australian Government has demonstrated a belief in peer support as one means of improving mental health and suicide prevention, and shown an appetite for funding peer workforces through intermediary Primary Health Networks or directly to larger organisations.[111] [112] Similarly, the Australian Government has recognised the important role that peer support plays in supporting parents of young children with a disability through the Department of Social Services funding of MyTime.[113] It is therefore questioned why this has not been extended to amputees, given that this is the largest physical disability cohort in Australia and one which experiences unique physical and mental health challenges, also.

With growing rates of disability, barriers to peer support access should be dismantled over the coming period of the new National Disability Strategy. Peer support should be deemed as an investment in not only improving the lives of people with disability and carers, but also a measure which can realise tangible reductions in health and welfare system costs.

7.4 Recommendations

Recommendation 14:

As amputation results in a permanent and lifelong disability it is an imperative that all, not just some, states and territories introduce Minimum Standards of Care for Amputees. This will not only ensure

that consistent care is implemented by the cross-disciplinary healthcare teams, but also inform amputees as to what they can expect as part of their medical, allied health, and community re-integration care and recovery plans. It is recommended that all Minimum Standards of Care include that:

- all amputees are provided with the option to be referral to a formally managed peer support program as part of their rehabilitation plan
- all amputees be provided with vocational and/or return-to-work plans, should that be part of a person's future goals.

The new National Disability Strategy has the capacity to prioritise the introduction of Minimum Standards of Care for Amputees in all states and territories in recognition of its strong relationship to the 'personal and community support' and 'health and wellbeing' outcome areas.

Recommendation 15:
The appropriate federal and state governments should audit the provision of peer support in Australia, and identify areas of under or over supply of this to specific disability cohorts. This instrument would assist in:

- identifying gaps in provision
- highlighting areas of over-supply, potentially supporting organisations to partner for consolidated peer support delivery
- providing governments with an evidence-base to ascertain where peer support funding should be directed, in particular those organisations that can demonstrate an explicit program logic and management approach but who lack in national or state government funding for sustainable delivery
- identify funding streams that enable funding of peer support provision to people with disabilities by people with disabilities.

The new National Disability Strategy has the capacity to prioritise an investigation into peer support provision and funding in recognition of its strong relationship to the 'personal and community support' and 'health and wellbeing' outcome areas.

8. Concluding comments

To create an inclusive society which enables all people living with disability to reach their full and effective participation on an equal basis with others we must ensure their access to fair, meaningful and sustainable opportunities to partake in all aspects of life. In turn, this will enable people with disabilities to prosper physically, mentally, socially and economically. We must continue to ensure that all members of our Australian society work collectively to ensure that attitudinal, environmental and structural barriers to people with disability fulfilling their potential are reduced and eliminated. Simultaneously we must also ensure that people's human rights are safeguarded, and at all times.

As noted within this submission, amputees are failing to be treated equally within the areas of assistive technology provision and access to the built environment, and many also face barriers to labour force participation. Nor are amputees being offered access to peer support as a mandatory minimum standard of care prior to or post an amputation.

It is our hope that the new National Disability Strategy will embrace lessons learned over the period of the previous one, thoughtfully consider Limbs 4 Life's recommendations and ensure that the contextual limb loss information presented herein enables planning and implementation which takes account of the unique needs and aspirations of the amputee community.

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