Limbs 4 Life
Empowering Amputees

Submission to the Victorian State Disability Plan 2021-2024 Consultation

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Definitions

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
CRPD	The Convention on the Rights of Persons with Disabilities
Limb loss	Acquired absence of a limb or limbs
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
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
SWEP	State-wide Equipment Program
VALP	Victorian Artifical Limb Program

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.

Submission background and recommendations

Limbs 4 Life welcomes the opportunity to provide a submission in response to the Victorian State Disability Plan 2021 – 2024 (the Plan) consultation paper. It is essential that the new Plan embraces a human rights-based approach, underpinned by a social model of disability, drawing upon related treaties, laws and recommendations made by state and federal government inquiries and Royal Commissions. The new Plan must recognise people with disability as active members of our society with rights and an entitlement to make self-determined decisions in relation to their lives.

Limbs 4 Life believes that the new Plan must take account of its connection to other Australian Government strategies, the NDIS, and new National Disability Strategy and recommendations made as part of inquires. Furthermore, the new Plan should highlight the important role that non-government sectors and actors can play in improving outcomes, offering opportunities and effecting positive change in the lives of people with disability and their support networks.

Our submission provides feedback and recommendations in relation to all six topics. However, we have placed a particular focus on the unequal provision of assistive technology and other supports; something which is contingent on whether an amputee is a NDIS participant or not. Indeed, this issue is creating additional burdens on older amputees (and carers) and creating a

widening gap between the amputee ‘haves’ and the ‘have-nots’. It is also why Limbs 4 Life fully endorses the Assistive Technology for All Alliance’s submission and recommendations.

In our response, we also highlight the compromising health and disability impacts that a lack of access to hospital-based prosthetic servicing during the COVID-19 lock-down measures has had on many Victorian amputees, and advocate for policy, practice and program changes in the event of a future pandemic surge.

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 Plan development, actions and implementation.

Recommendations

Recommendation 1
The next State Disability Plan should be informed by a human rights approach which recognises that many sectors of society have a role to play in assisting people with disability to lead a meaningful and inclusive life.

Recommendation 2
To engage hard to reach communities draw upon the expertise and connections of disability organisations, carers and/or peer support workers to assist in and/or promote, co-design and deliver consultations.

Recommendation 3
Publish submissions and summaries of consultations that have assisted in contributing to and informing the new Plan, where consent to do so has been provided.

Recommendation 4
Engage people with disability, carers, peer support workers and disability organisations to assist in meaningfully co-designing aspects of the next Plan and associated actions, using multi-modal methods and remunerate accordingly to reflect that contributors are sharing their expertise, time and knowledge.

Recommendation 5
Include an outcome about people’s intimate lives in the new Plan, and draw upon recommendations made by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability to ensure that reducing assault and abuse is a key action and outcome.

Recommendation 6
Introduce a new awards platform to acknowledge, celebrate and champion people with disabilities in the Victorian community, and include people with disability on the awards committee and associated planning and deliberation activities.

Recommendation 7
The new Plan should include actions which raise awareness of disability within the wider community, to mitigate some of the entrenched stigma and discrimination still held by members of the public. A focus should also be placed on improving employer and workplace disability awareness and their sanctionable responsibilities under disability and anti-discrimination legislation.

Recommendation 8
The new Plan should include a timetabled requirement that all Victorian Government buildings meet universal design compliance, and that all government policies, programs and services be developed and monitored through a universal design lens.

Recommendation 9
Transfer responsibility for oversight of the new Plan to the Department of Premier and Cabinet, to reflect that the new Plan will involve whole-of-government and cross-ministerial portfolio responsibility for associated initiatives, policies, priorities and performance.

Recommendation 10
Consider situating the Office for Disability in the Department of Premier and Cabinet to reflect that disability issues and matters require efficient and whole-of-government coordination, actions and accountability.

Recommendation 11
That the Victorian Government support the Assistive Technology for All Alliance's call for an intergovernmental agreement to be established to develop a funded national aids, equipment and assistive technology program, including agreement on the process and timeframes for implementing a national program.

Recommendation 12
Strengthen the new Plan by including a separate section devoted to assistive technology, with particular emphasis on meeting the assistive technology needs of people with disability in Victoria who are ineligible for the NDIS.

Recommendation 13
Take immediate action to increase access to prosthetic assistive technology by increasing funding for the Victorian Artificial Limb Program (VALP) to provide a higher subsidy for consumers and to reduce wait times.

Recommendation 14
Take immediate action to establish a centralised body to administer the Victorian Artificial Limb Program (VALP), rather than spreading costs and administrative burden across 13 hospitals.

Recommendation 15
Take immediate action to increase access to assistive technology by increasing funding for the Victorian State-wide Equipment Program (SWEP) to provide a higher subsidy for consumers and reduce lengthy wait times.

Recommendation 16
The new Plan should include a commitment to consider and implement recommendations made as part of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability to improve the lives of people with disability and ensure greater inclusivity across public and provide mainstream services.

Recommendation 17
Amend Victoria's Disability Act 2006 to resolve and clarify Victoria's responsibilities to provide and fund disability services, especially the provision of assistive technology to people with disability in Victoria who are ineligible for the NDIS.

Recommendation 18
Ensure that Victorian prosthetic provider clinics based in hospital settings are made available to amputees, provided all hygiene and safety practices are observed, during any potential future pandemic-related restrictions or lock-downs.

Recommendation 19
Prosthetic providers are one of the very few allied health providers that do not offer services outside of normal business hours. The Victorian Government must work with this industry, in particular public hospital based providers, to ensure that services are made available at times that meet the needs of working (employed) amputees.

Recommendation 20
Invest in disability organisations who hold a trusted position with unique disability cohorts so that alternative community engagement and resilience building activities can be rolled out to their communities in the event of a future COVID-19 lockdown measure.

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 and pathways
- 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

Amputee population and limb loss impacts

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, with 1,700 of these taking place in Victoria; 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]

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 and acquiring this physical disability, restoring functionality and daily living abilities, reducing dependency on others, increasing mobility and optimising a person's quality of life and satisfaction are key rehabilitation and disability adjustment goals.[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.

Topic 1: Improving how we describe disability and disability inclusion in the next plan

The new State Disability Plan should embrace a human rights-based approach, described as ones which "are about turning human rights from purely legal instruments into effective policies, practices, and practical realities. Human rights principles and standards provide guidance about *what* should be done to achieve freedom and dignity for all. A human rights-based approach emphasises *how* human rights are achieved." [7]

Furthermore, the PANEL Principles[8] to human rights-based approaches, developed by the Scottish Human Rights Commission, and recognised by the Australian Human Rights Commission, should help to inform the new State Disability Plan. By embracing the five underpinning principles, people

with disability will be at the core of all policies and practices, people will be empowered to know and exercise those rights, and mechanisms in place to seek remedies when rights are violated. The five PANEL Principles are:

- **Participation:** people should be involved in decisions that affect their rights.
- **Accountability:** there should be monitoring of how people's rights are being affected, as well as remedies when things go wrong.
- **Non-Discrimination and Equality:** all forms of discrimination must be prohibited, prevented and eliminated. People who face the biggest barriers to realising their rights should be prioritised.
- **Empowerment:** everyone should understand their rights and be fully supported to take part in developing policy and practices which affect their lives.
- **Legality:** approaches should be grounded in the legal rights that are set out in domestic and international laws.

Question: How should we set out a description of disability and a human rights approach in the next state disability plan?

Limbs 4 Life supports the Victorian Government's assertion that the social model of disability will underpin the next State Disability Plan. Affirming the social model will help to ensure that the Plan's foundation takes account of the structural, attitudinal and environmental barriers to inclusion that can be experienced by Victorians living with disability.

Drawing upon the United Nation's Convention on the Rights of Persons with Disabilities, which is based on a human rights approach, as part of the definition, will also facilitate empowerment, participation, equity in identified actions and help to ensure that there is an understanding of the intersectionality of discrimination, stigma and disadvantage faced by particular social groups.

Question: Are there other statements you'd like the next plan to say about what disability is, what it means to you, and how Victoria needs to do its work to be more inclusive?

Further considerations include an understanding that:

- people with disability are heterogenous, just as the wider society is
- people with the disability should be considered as their own best experts, given their lived experience
- people experience the impacts of their disability in ways that may differ from peers living with the same condition
- a person's disability identity is self-determined and can be a complex and evolving one
- a person with disability should be supported to exercise their rights, and have adequate support to do so
- a person's network of support, in particular informal carers, should be acknowledged as playing an important role in their lives and carer's insights and needs must be considered

- the strengths and capabilities of people with disability should be brought to the attention of the wider society, as a means of increasing awareness, and minimising the still pervasive stigma and discrimination experienced
- governments, businesses, organisations, individuals and communities all have a role to play in breaking down barriers and exclusionary practices that do not enable people with disabilities to be active members of society.

Amputees are one such disability group that are diverse and heterogenous and can therefore experience a wide range of systemic socio-economic barriers that are impactful on their physical and mental health wellbeing and inclusion.

Recommendation 1
The next State Disability Plan should be informed by a human rights approach which recognises that many sectors of society have a role to play in assisting people with disability to lead a meaningful and inclusive life.

Topic 2: Finding better ways to include people with disability in making the next plan

Question: What groups do we need to reach out to and how should we engage with them?

Limbs 4 Life is appreciative that the Victorian Government is committed to reaching and engaging with a diverse range of people with disabilities. To ensure reach and accessibility it is important to consider the needs of different demographics, such as disability type/s, age, gender, health conditions, socio-economic status, cultural background and gender identity.

While an extensive list of hard-to-reach groups has been provided in the Consultation Paper, Limbs 4 Life is of the view that carers and family members who support people with disability, and often form a person's network of support, should also be included as critical contributors to consultations. The knowledge, experience and skills of carers and family members can offer insights as well as being partners when the Victorian Government wishes the engagement of people with disability in consultations. In addition, people who have recently acquired a disability and currently still in acute or rehabilitation settings, as well as their network of support, should be offered the opportunity to take part. Amputees are one such group who, due to the loss of a limb/s, have suddenly acquired a disability and spend a considerable amount of time in health settings post amputation. This community, as well as other individuals who have recently acquired a disability, should be invited to take part, but with respect given to the fact they may not yet understand the complexities of their disability or are yet to adjust to living with a disability and the impacts it may have on their lives and those around them.

It is important that any engagement should be meaningful, accessible and participatory and avoid actual or perceived tokenism. Multiple engagement and participation strategies, which reflect varying needs and capabilities, should be utilised to maximise engagement with all participants. These include methods such as:

- specific to one type of disability or multiple disabilities
- individual or group-based
- face-to-face, virtually, by phone or other virtual methods
- accommodating those in metropolitan, regional and rural areas equally
- ensuring high levels of access, including transportation and respite support.

The Victorian Government should consider engaging specific consumer diagnostic-based organisations and/or peer support workers to promote, co-design and/or assist in the delivery of consultations. Often disability organisations have established relationships and built levels of trust with their disability community and can work in collaboration with the Victorian Government when planning and delivering consultations and engagement activities. This is particularly important when engaging with communities who may be fearful of, or have limited trust in, bodies of authority, such as the government.

Question: What are some of the things we can do to let people know that we have taken their advice seriously and have brought it into the development process?

Where possible, all those individuals and organisations that have participated in consultations should be provided with a copy of the final Plan and acknowledged in an appendix, along with a description of how public consultations contributed to its development and the resulting recommendations, outcomes and actions. Furthermore, all submissions and summaries of consultations should be published, provided consent to do so has been given by contributors.

There is also an opportunity to broadly share the new State Disability Plan with the wider public, as a means of increasing awareness, raising knowledge about disability and reinforcing that all members of society have a part to play in realising aspects of the Plan's new vision. This includes but is not limited to: general members of the public; employers; schools; tertiary education providers; corporate businesses; peak industry bodies; and, all government departments.

Question: What codesign approaches do you think would be good for the next state plan and have you come across any that worked well?

Genuine and meaningful co-design (co-production) involves participation from people with the lived experience of disability itself, as well as impacted carers and family members. It is a model that has, over decades, enabled people living with disability or health conditions to share their insights for development of new or evaluation of existing activities, programs or policies. Broad and balanced representation from an array of stakeholders, taking account of their differences and varied lived experience, is vital for participation to be genuine and equitable. What is critical to realise is that consultation alone is not co-design, but only part of a broader approach.

Researchers indicate that the principles of co-design democratise the design and delivery of services, and harness the expertise of the lived experience of end users. "Co-design is understood to be inclusive of all stakeholders and recognising a range of expertise. The processes are inherently respectful and involve negotiation. They seek to maximise participation through conversations that are open, empathetic and responsive to all stakeholders. Ideas are constantly evaluated and refined through the interaction of all participants. Similarly, co-production involves the engagement of people with the lived experience in the design and delivery of policy and services."[9]

People with Disability WA (PWDWA) describe co-design "as a process that involves key stakeholders in defining, developing, implementing and reviewing a necessary change (to improve access, inclusion and participation)" and have created a rigorous and robust toolkit for use by organisations, governments and researchers wishing to meaningfully implement this method.[10] This model could be considered whilst planning, building, developing and evaluating activities and programs which fall under the scope of the new Plan.

Additional co-design participation considerations include:

- making activities ones that facilitate individual empowerment and upskilling
- fairly remunerating people for their time, knowledge and lived experience
- ensuring that participation is accessible and accommodating, including the provision of technology and transportation as required
- use multi-modal approaches and appropriate accommodations to engage and support people's participation, in recognition that demography, co-morbidities, different literacies, mental health, housing, age, culture, gender and access to technology may act as barriers to contribution
- engage peak disability organisations, disability advocacy bodies and peer support workers, who play a trusted role in the lives of people with disabilities, to support participation for diverse disability communities
- ensure that other stakeholders who will play a role in actioning aspects of the Plan are involved in consultations (e.g. government department staff, employers, health providers, educators).

Recommendation 2
To engage hard to reach communities draw upon the expertise and connections of disability organisations, carers and/or peer support workers to assist in and/or promote, co-design and deliver consultations.

Recommendation 3
Publish submissions and summaries of consultations that have assisted in contributing to and informing the new Plan, where consent to do so has been provided.

Recommendation 4
Engage people with disability, carers, peer support workers and disability organisations to assist in meaningfully co-designing aspects of the next Plan and associated actions, using multi-modal methods and remunerate accordingly to reflect that contributors are sharing their expertise, time and knowledge.

Topic 3: Strengthening the state disability plan outcomes framework

Question: What do you think about a new outcome around people's intimate lives?

It is recognised that intimate lives, from intimate friendships to intimate relationships, are beneficial for people with disabilities as they result in greater self-acceptance, less internalised stigma, the breaking down of stereotypes, bodily autonomy, and more camaraderie.[11]. Furthermore, an acknowledgement of intimate lives offers scope for recognising that people with disability can be more vulnerable to assault and abuse; highlighted in research[12] [13] and described by victims and carers during Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability hearings[14].

Furthermore, several Articles in United Nations Universal Declaration of Human Rights and the Convention on the Rights of Persons with Disabilities treaties place obligations on State parties to respect aspects of the intimate lives of people in general and persons with disability specifically. As acknowledged in the consultation paper, the new Plan is being informed by these instruments and will be consistent with a human rights outcome framework that should support people with disability to live self-determined, positive and safe lives.

Question: What do you think about a new outcome around recognition and pride?

Limbs 4 Life supports the introduction of a new outcome around recognition and pride for people with disability.

Research indicates that self-identity and pride can assist in reducing the stigma surrounding the label 'disability'. And those who self-identify are more likely to develop pride in their disability which in turn can help build individual resilience and change public attitudes about the 'disabled' label.[15] However, it is well understood that because disability is itself mired in stigma that people don't want or are reticent to associate with that label. This is where policy makers and the community more broadly can use its capacities to increase opportunities for people with disabilities to feel a sense of pride through formal recognition.

The Victorian Disability Awards presently recognise the contributions that service providers, individuals and volunteers make in supporting people with disability. However, the Awards fail to recognise the achievements and contributions that people with disability make in the community. In its current form, these Awards suggest that people with disability are 'users' of disability

services but not contributors to our broader society. Whilst it is important to recognise the achievements of service providers, the lack of provision of an Awards platform that does not recognise individuals living with disability suggests a lack of inclusivity.

The Victorian Disability Awards should be re-developed to include ones which celebrate and champion the achievement of people with disabilities. Further considerations in achieving this include:

- avoid tokenism by building a competitive process for applications
- offer awards across a wide range of categories (e.g. systemic change agents, advocacy, volunteering, the arts, science, sport, employment, education, research etc)
- invite people with disability to form part of the awards committee, deliberating in awards selection/ provision and event planning.

Recommendation 5
Include an outcome about people's intimate lives in the new Plan, and draw upon recommendations made by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability to ensure that reducing assault and abuse is a key action and outcome.

Recommendation 6
Introduce a new awards platform to acknowledge, celebrate and champion people with disabilities in the Victorian community, and include people with disability on the awards committee and associated planning and deliberation activities.

Topic 4: Introducing overarching approaches to strengthen government commitments under the new plan

Question: What do you think about including community attitudes and Universal Design as guiding approaches in the new plan?

Limbs 4 Life views inclusion of community attitudes and universal design as a guiding approach in the new Plan.

Article 4 of the Convention on the Rights of Persons with Disabilities require State parties to "ensure and promote the full realization of all human rights and fundamental freedoms of all persons with disabilities without discrimination on any kind on the basis of disability". These require State parties:
b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities.
c) To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes.

e) To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise.
f) To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines.

Community attitudes

Poor disability awareness, stigma and discrimination still features in our community. And it is well understood that these factors can affect all aspects of person's life, as well as that of their support network of family and friends. Stigma and discrimination can impact on a person socially and economically; it can lead to social exclusion, limit access to services and affect ability to gain and sustain employment. It can also result in people with an existing disability suddenly acquiring new health challenges or disabilities, such as ones related to mental health.

Poor disability awareness and stigma within workplaces still pervade, and much can be done to ameliorate and mitigate this practice. 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.[16] 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.[17] [18] In addition, such workplaces have greater propensity for bullying and harassment occurrences, with the by-product being anxiety and depression amongst victims.[19] [20]

A Limbs 4 Life employment survey, used to inform our submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability's 'Issues and Attitudes Paper', canvassed amputees' workplace experiences and pointed to poor disability awareness, bullying, workplace exclusion, and reprisal upon making complaints as key employment discrimination and stigma concerns.[21]

Universal design

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, transport, and other public service buildings.[22] 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. Amputees are one such disability group vulnerable to socio-economic exclusion when physical environments are not universally designed and accessible.

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. It should also be informed by universal design principles which increases usability, safety, health and social participation.[23] 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 organisations, businesses and governments 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.

Of course, universal design isn't just restricted to the built and physical environment but also is increasingly informing the development and deployment of programs and service provision.

Question: What are other ways we can strengthen the design and accountability of commitments under the next state plan?

Whole-of-government approach

As the new Plan will involve whole-of-government responses and actions to achieve outcomes, it must also be coordinated and monitored in that fashion. Transferring responsibility for Plan oversight and monitoring is therefore best located within the Department of Premier and Cabinet, given its cross-ministerial portfolio responsibility for coordinating state-wide initiatives, policies, priorities and performance.

Furthermore, as people with disability often have needs and aspirations which cut across multiple portfolios, the Office for Disability would be better centrally situated within the Department of Premier and Cabinet to ensure efficient and whole-of-government coordination of disability-related actions and initiatives.

Alignment with government strategies and inquiries

The new Plan can be further strengthened by aligning it with other state and federal government strategies and inquiry recommendations. These include, but are not limited to:

- 'Every opportunity' strategy, with a target of six per cent employment of people with disability across all Victorian Government departments by 2020, increasing to 12 per cent by 2025.
- Victorian Carer Strategy 2018 – 2022
- National Disability Strategy
- Royal Commission into Victoria's Mental Health System
- Royal Commission into Aged Care Quality and Safety
- Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Recommendation 7

The new Plan should include actions which raise awareness of disability within the wider community, to mitigate some of the entrenched stigma and discrimination still held by members of the public. A focus should also be placed on improving employer and workplace disability awareness and their sanctionable responsibilities under disability and anti-discrimination legislation.

Recommendation 8
The new Plan should include a timetabled requirement that all Victorian Government buildings meet universal design compliance, and that all government policies, programs and services be developed and monitored through a universal design lens.

Recommendation 9
Transfer responsibility for oversight of the new Plan to the Department of Premier and Cabinet, to reflect that the new Plan will involve whole-of-government and cross-ministerial portfolio responsibility for associated initiatives, policies, priorities and performance.

Recommendation 10
Consider situating the Office for Disability in the Department of Premier and Cabinet to reflect that disability issues and matters require efficient and whole-of-government coordination, actions and accountability.

Topic 5: Strengthening the NDIS and mainstream interface

Question: Where are the gaps between NDIS and mainstream services?

It is Limbs 4 Life's position that the most significant gap between the NDIS and mainstream services is a lack of equitable access to assistive technology and prosthetic services for those who are ineligible for the NDIS and reliant of Victorian government funding instead. In this section we provide significant commentary regarding this matter and offer recommendations for improving outcomes for amputees, and others with disability, who require assistive technology to live a safe, independent and participatory life.

Assistive technology is a human right

Assistive technology is an umbrella term for a device or system that allows a person to perform tasks that they would otherwise be unable to do, or increases the ease and safety with which tasks can be performed.[24] 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." [25] 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.

The World Health Organization's 'Global Cooperation on Assistive Technology' (GATE) is available to assist Member States to improve access to assistive technology with a goal of "improving access to high-quality affordable assistive products globally". The diagram below highlights how the GATE initiative is focusing on five interlinked areas: people, policy, products, provision and personnel.[26]

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.[27] 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.[28]
- 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. [29]

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, and required to enhance a person's safety, independence, and socio-economic participation.

It is Limbs 4 Life's position that access to assistive technology is a human right that enables participation in civil society across a person's life course.[30] 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. Limbs 4 Life has endorsed an ATFA submission and all recommendations made regarding the Victorian Disability Plan 2021 – 2024. For more information, including access to the submission, visit https://assistivetechforall.org.au/

Prosthetics

It is widely reported that the paramount goal for a person with limb loss, in particular lower limb amputees, is to access a prosthesis that aids in replacing what is missing in a functional manner.[31] Indeed, the role of prosthetics and advances in this technology over recent decades provide amputees with a wide range of options that can improve function, assist in preventing further health complications and enable an optimal quality of life.[32]

The type of prosthesis that a person utilises is contingent on the individual; taking account of the cause of amputation,, location of the missing limb/s, any other health considerations, and their desired goals.[33] 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.[34] [35] 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.[36] As these products cost considerably more than the very basic technology developed in the 1950s and 1970s, the introduction of the NDIS has enabled amputee participants to request these products as reasonable, necessary and fit-for-purpose devices which deliver impactful psycho-social-economic outcomes.

Conversely, amputees ineligible for the NDIS and receiving prosthetic funding through the Victorian Artificial Limb Program (VALP), administered by hospitals, are only funded for the

provision of basic 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, which require an exhaustive amount of energy and mental concentration to use. For a lower-limb amputee who needs to be on their feet for lengthy periods, such as those in the workforce or engaging in regular community activities, wearing a standard prosthetic foot or knee, which provide minimal stability and support, can have long-term negative physical, body-biodynamical, mental, social and economic impacts.[37] A person is at a greater risk of falls, back and hip problems, unnecessary stress on their sound limb, poor mental health, and reduced ability to engage in the community if wearing a standard prosthesis that does not meet their individualised needs and lifestyle. For example it is not uncommon for prosthetic feet – such as the SACH foot - to snap if too much force is put through the toe load, leaving the user at risk and unable to ambulate at all.

It is worth noting that funding under the VALP scheme has not been increased for more than two decades and is not reflective of the growing population of older amputees now living in Victoria. It is also not reflective of the fact that a significant number of older amputees receiving VALP funding are still members of the workforce, and provision of an advanced prosthesis would assist them to remain employed.

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 healthcare 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.[38] [39]

Mobility aids

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, scooters, 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.[40]

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.

Home 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.[41]

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.[42]

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.[43] [44]

Because the impact of limb loss is individualised the types of home modifications required can vary greatly. 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. None or inadequate home modification funding puts amputees, and those who live with them, at risk of living in compromised dwellings.

Vehicle modifications

Driving is an important means by which amputees can obtain or regain their independence and 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 foward because it allows the pursuit of social and vocational goals, helps to preserve self-esteem and often represents the ultimate freedom.[45]

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 or 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.

Gaps in funding for 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,

Department of Veterans Affairs (DVA), aged care system, Victorian Artificial Limb Program (VALP) or State-wide Equipment Program (SWEP).

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." [46]

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

Victorian amputees excluded from the NDIS are reliant on the Victorian Artificial Limb Program (VALP) to access prosthetics and the State-Wide Equipment Program (SWEP) to access other forms of assistive technology. Unlike the NDIS, VALP and SWEP deny amputees of 'choice and control', are based on dated funding models, consumers experience delay in receiving their devices, and is creating a community of amputee 'haves' and 'have nots'.

Victorian Artificial Limb Program (VALP)

Amputees ineligible for NDIS funding and instead receiving assistive technology via VALP are primarily provided with basic 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.[47] 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 VALP 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 $45,000, and would require a co-contribution to make up the difference.

It is the recipients of prosthetics through VALP that are being left behind and at a greater risk of losing opportunities to safely and independently participate in the community and labour force. As noted earlier, there are many assistive technology prosthetic devices which can serve to reduce falls in people of any age. It therefore makes sense to ensure that older people are funded for these supports, given they are more susceptive to risks of falls and injury which sees the

healthcare system incur significant and unnecessary costs. Front end loading of VALP funding supports for this cohort would further serve to reduce the overall costs on government, society and the quality of life outcomes for older Victorian amputees.

In addition, amputees funded under VALP are unable to exercise choice and control in relation to their prosthetic provider. They are significantly limited by geography and required to attend clinics in their local area, if available. While this may be suitable for some, others have no access to private providers unless they are willing to cover all out of pocket costs. And, if they don't have a positive experience with their provider there is little or no option to change and seek an alternative solution by attending a different clinics.

In fact, amputees living in Shepparton and surrounding areas are required to travel 2.5 hours to Albury, 1.5 hours to Bendigo or 2.5 hours to Melbourne to access prosthetic services. This is because the only local provider in Shepparton is a private one without access to VALP funding to support amputees under this scheme.

Furthermore, it is important to note that Victoria is the only state that does not have a centralised state-based artificial limb program. Instead, the funding is spread and administed by 13 hospital administration departments. Centralising the program and processes to one single government agency, such as the way in which the State-Wide Equipment Program (SWEP) is managed, would lead to a significant reduction in administration burden and costs.

State-Wide Equipment Program (SWEP)

Amputees ineligible for the NDIS and in need of other forms of assistive technology (e.g. mobility devices, home modifications, vehicle modifications) are generally reliant on SWEP to fund their everyday living devices. Although it must be acknowledged that some amputees in receipt of an Aged Care Package may use some of their package to fund the provision of assistive technology.

Amputees who are NDIS participants can request access to higher-end mobility devices, considerable home modifications, and funding for vehicle modifications. Whereas their older peers reliant on SWEP 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. This can greatly compromise a person's safety and wellbeing, place significant burdens on carers, result in a person entering residential aged care earlier than needed, and increase demands on the healthcare system.

One example of this relates to the provision of wheelchair, which is vital for an amputee's ambulation and safety. Due to SWEP delays, amputees can wait for up to 18 months to receive funding for a basic wheelchair, and funding may be insufficient to cover the full cost of this device. In turn, this means that many amputees are tasked with the burden of paying out of pocket costs to hire a wheelchair and/or co-contribute to receive one once SWEP funding has been provided.

Difficulties in accessing 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. [48]

However, as most Victorian 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 Victorian public prosthetic providers 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.

The provision of prosthetic services is complex and fragmented for people over 65 and/or those who did not have amputations in time to be eligible for NDIS supports. As noted earlier, in Victoria there are 13 prosthetic providers available to service amputees ineligible for the NDIS and reliant on VALP funding. And some of these are also NDIS- registered providers, and therefore service a mix of public and private clients.

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.[49] 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.

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

Question: How do we ensure mainstream services are inclusive of all people with disability?

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability will offer robust, informed and far-reaching recommendations that reflect mechanisms and accountabilities designed to inform disability inclusivity in mainstream services. The Victorian Government should use these to complement feedback and recommendations provided during consultations and submissions into development of the new Plan.

Recommendation 11
That the Victorian Government support the Assistive Technology for All Alliance's call for an intergovernmental agreement to be established to develop a funded national aids, equipment and assistive technology program, including agreement on the process and timeframes for implementing a national program.

Recommendation 12
Strengthen the new Plan by including a separate section devoted to assistive technology, with particular emphasis on meeting the assistive technology needs of people with disability in Victoria who are ineligible for the NDIS.

Recommendation 13
Take immediate action to increase access to prosthetic assistive technology by increasing funding for the Victorian Artificial Limb Program (VALP) to provide a higher subsidy for consumers and to reduce wait times.

Recommendation 14
Take immediate action to establish a centralised body to administer the Victorian Artificial Limb Program VALP, rather than spreading costs and administrative burden across 13 hospitals.

Recommendation 15
Take immediate action to increase access to assistive technology by increasing funding for the Victorian State-wide Equipment Program (SWEP) to provide a higher subsidy for consumers and reduce lengthy wait times.

Recommendation 16
The new Plan should include a commitment to consider and implement recommendations made as part of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability to improve the lives of people with disability and ensure greater inclusivity across public and provide mainstream services.

Topic 6: Strengthening disability inclusion under the Disability Act 2006

Question: What are the most important things that a review of the *Disability Act 2006* should consider? What are the biggest improvements we can make?

While the consultation paper notes that "The introduction of the NDIS has changed the Victorian Government's role in disability. Nearly all specialist disability services are now funded through the

NDIS and provided by non-government and private sector organisations" this is not an accurate description with regards provision of assistive technology to those ineligible for the NDIS.

As noted and described in Topic 5, the provision of assistive technology for those ineligible for the NDIS is largely funded through state-based mechanisms (e.g. VALP, SWEP). All Disability Act 2006 reviews and changes must clarify Victoria's responsibility to provide, fund and account for provision of assistive technology at a state-based level.

Please note, this and related Disability Act 2006 revision matters are discussed in depth in the Assistive Technology for All Alliance (ATFA) submission.[50]

Recommendation 17
Amend Victoria's Disability Act 2006 to resolve and clarify Victoria's responsibilities to provide and fund disability services, especially the provision of assistive technology to people with disability in Victoria who are ineligible for the NDIS.

Topic 7: Responding to coronavirus (COVID-19)

Question: What are some of the most important issues arising from the COVID-19 pandemic for people with disability that we should be thinking about in the next plan?

A United Nation's Policy Brief on person's with Disabilities and COVID-19 stated: "Even under normal circumstances, persons with disabilities are less likely to access health care, education, employment and to participate in the community. They are more likely to live in poverty, experience higher rates of violence, neglect and abuse, and are among the most marginalised in any crisis-affected community. COVID-19 has further compounded this situation, disproportionately impacting persons with disabilities both directly and indirectly." [51]

Amputees, like many other disability groups, have been significantly affected and impacted by the COVID-19 situation and restrictions in Victoria. Limbs 4 Life is aware that amputees were affected by the five key issues identified as part of the consultation.

However, in relation to the experiences of amputees in Victoria, the key issue we would like to raise and focus on is 'safe and accessible services, including health and disability services'.

Difficulty accessing prosthetic providers
One of the most significant impacts that COVID-19 restrictions had on Victorian amputees was the inability for some to access prosthetic providers situated in public hospital settings.

For significant periods during the Victorian lock-down period (and in some cases up to six months plus) prosthetic providers in metropolitan and regional hospitals were closed and unable to service amputees requiring prosthetic maintenance, repairs or replacement. During this time, prosthetic providers in public hospitals would only see clients for their prosthetic needs if it was deemed it would prevent a hospital admission. Given that prosthetic services for those ineligible for the NDIS in Victoria is largely delivered by those providers based in public hospitals this caused a significant impact on our community. Conversely private prosthetic providers were able to remain open and service their amputee clients, who are predominately NDIS participants and compensable insurance clients. Furthermore, most hospital and private prosthetic providers operate between the hours of 8.30am – 4pm or 9am – 5pm, making them inaccessibile for those who work during those hours, particularly those working in the essential services that have been vital during the COVID-19 pandemic. Unfortunately, prosthetic servicing can only be delivered through in-person appointments making telehealth support not an option.

As some hospital-based prosthetic providers are also NDIS registered providers, their closure also affected NDIS participants who use those services. As many private prosthetic providers continued to operate, NDIS funded participants were able to attend their existing provider. And those NDIS participants denied access to their hospital-based provider were in the position to visit an alternate provider instead; something that amputee peers reliant on the Victorian Artificial Limb Program (VALP) were not. This evidenced a significant gap between NDIS and mainstream services during a pandemic crisis.

Border closures and travel restrictions

The impact of closed borders had a significant effect on amputees living in or near borders, and who are reliant on neighbouring states for prosthetic servicing. Accessing cross border services was made very difficult, and in some cases impossible. For example, a significant number of amputees who live in Wangaratta and Wodonga rely on prosthetic services in Albury (NSW). Similarly, amputees who reside in Mildura and Swan Hill travel to Adelaide (South Australia) for prosthetic services.

In addition to border closures, many amputees were impacted by a range of other Victorian COVID-19 restrictions. This included an inability to travel more than 5kms which had an impact on mental health and access to essential services. And for those amputees who travel interstate to see the prosthetic provider of their choice, this was no longer an option and required them to hasily source another provider in Victoria.

Amputees who were unable to access prosthetic servicing experienced a variety of serious impacts, including:

- new amputees who were waiting for their interim (first) prosthesis had their fitting appointments cancelled due to restrictions, leaving them without a limb for extensive periods of time and resulting in loss of muscle tone, the inability to stand or walk and in some cases loss of employment. Please also note, the delay of fitting the interim prosthesis can have a

long-lasting negative impact on a persons ability to re-engage with society, adjust to and accept their prosthesis, and fear.

- wearing or relying on a prosthesis that was damaged
- wearing a prosthetic socket that no longer fitted leading to falls, infections and/or pain which, in some cases, resulted in reduced levels of socio-economic participation, decreased mental health, increased burdens placed on family members and carers, and hospital admissions.
- inability to receive prosthetic liners, a vital component that acts as a suspension system for the prosthesis to be fitted to the residual limb, which require annual replacement and rarely supplied to clients without prosthetic supervision
- reverting to use of a wheelchair, which in some cases was itself unsafe, because their prosthesis was damaged or broken and impacting everyday living (e.g. unable to shop, access medical services such as chemists, attend to family member's and friend's needs).

Access to food and essential supplies

COVID-19 restrictions across the state impacted on amputees' easy access to healthy foods, and led some amputees to revert to poor diet decision-making processes. This resulted in some amputees gaining weight which, in turn, saw these individuals require prosthetic replacement and/or wear a device which no longer fitted properly and compromised their health and wellbeing (e.g. skin breakdowns and infections). In addition, this issue was compounded when exercise options were restricted. Infections, particularly amongst amputees living with comorbidities such as diabetes, can potentially lead to higher level amputations and/or amputation of a second limb.

While supermarkets opened specifically for frontline workers, people with disabilities and the elderly, this was always in the early hours of the morning. People with disabilities (more so those requiring support from external carers and/or poor functional capacity) can take time just to get dressed, let alone be ready by 7am to shop. The panic that was driven by the media was unhelpful and people with disabilities need access to services in a timely and civil manner – they should never be made to 'fight' for goods and services and stand for extended periods of time in queues.

It is critical that in the event of future restrictions that people with disability are supported to more easily access to shops and healthy food to reduce the risk of further health complications.

Access to supports

Many locally based council services ceased during the pandemic. These included essential food and cleaning services, transport services, and daily living activities (e.g. showering, dressing). Provision needs to be made for the frail, elderly and people with disabilities to continue to receive these vital services during any future lockdowns or restrictions.

Increased isolation

The COVID-19 situation in Victoria required Limbs 4 Life to suspend all face-to-face connection touch points. This was not only because of the critical health restrictions but also because many amputees live with other comorbidities (e.g. diabetes) which puts them at greater risk should they

acquire the virus. Consequently, Limbs 4 Life experienced a significant upswing in amputees calling to speak to staff; driven by loneliness and COVID-19 specific fears. We were as nimble as possible in responding to the needs of the amputee community by finding alternate ways of reducing isolation. These included: ensuring phone calls were responded to promptly and giving the person adequate time to discuss issues; sourcing external solutions or supports for those who felt worried or isolated; developing and delivering webinars; online group gatherings; and, providing peer support via phone, internet and social media platforms.

Question: What actions do you think government should be taking to address these issues?

Improve access to prosthetic servicing

The Victorian Government must recognise that amputees who are prosthetic users are severely compromised if they are unable to access prosthetic providers. Lack of access to or compromised prosthetics impact on the individual in various life domains and, in some cases, lead to unnecessary hospital admissions. During a pandemic, or other public health emergency, reducing unnecessary burdens on hospitals is a priority so that the system has the capacity to deal with immediate or anticipated pandemic-related surges.

The Victorian Government now has significant experience in ways of minimising the risk of exposure to the COVID-19 virus through the training, provision of PPE and medical supplies to protect healthcare workers and visitors to hospitals. Equally, the public is now more familiar with their responsibilities in terms of not attending public settings if unwell, accessing virus testing facilities, maintaining good hygiene practices, and sharing personal details to assist in tracing activities.

The Victorian Government must recognise that amputees are vitally reliant on prosthetic providers, and that this can only be done in interpersonal settings (i.e. not via telehealth). And as many amputees across the state have no option but to attend a hospital-based prosthetic clinic (often located on hospital grounds) this must be considered an essential health service and remain accessible during a pandemic.

Improve access to food, essential services and supporters

As people with disabilities and the elderly were limited in ability to visit and access food from supermarkets during early opening hours, it is critical that alternative options are addressed with supermarket chains and owners. Similarly, any carers or support workers (e.g. NDIS support workers, council services) must be available to assist these vulnerable members of the community to either attend shops or pick-up essential foods.

Help to reduce isolation

Recognise that many not-for-profit organisations stepped up to reduce gaps and assist in efforts to reduce the isolation and fears experienced by people with disability during the COVID-19 lock-

down period. Limbs 4 Life is just one such organisation that worked to achieve this. Staff worked exceptionally long hours, developed new skills to deploy new technology and invested in new platforms to meet the needs of the amputee community during that period. We recognised a critical need to provide alternative means of providing peer support, building resilience and reducing long-term physical and mental-health risks amongst the Victorian amputee community. Yet Limbs 4 Life, despite being the only amputee support organisation in Victoria responding to the needs of the largest physical disability group in the state, receives no Victorian Government funding to do so. We are a trusted organisation within the amputee community and can play an important role in supporting the Victorian Government's efforts to share COVID-19 information and create safe environments aimed at reducing isolation.

Recommendation 18
Ensure that Victorian prosthetic provider clinics based in hospital settings are made available to amputees, provided all hygiene and safety practices are observed, during any potential future pandemic-related restrictions or lock-downs.

Recommendation 19
Prosthetic providers are one of the very few allied health providers that do not offer services outside of normal business hours. The Victorian Government must work with this industry, in particular public hospital based providers, to ensure that services are made available at times that meet the needs of working (employed) amputees.

Recommendation 20
Invest in disability organisations who hold a trusted position with unique disability cohorts so that alternative community engagement and resilience building activities can be rolled out to their communities in the event of a future COVID-19 lockdown measure.

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