limbs 4 life

Submission in response to the Draft Report Inquiry into disability care and support

Limbs 4 Life Incorporated

This submission follows our initial submission and is in reply to the draft report.

Preamble

Limbs 4 Life and its stakeholders would like to take this opportunity to congratulate and thank the Commissioners and staff working on the inquiry into Disability Care and Support. The draft report is detailed and concise and we thank the Commissioners for the opportunity to make additional comment.

Introduction

Limbs 4 Life is the national peak body representing Australian amputees. It is our vision to ensure that amputees have access to information, support and resources. Our goal for early intervention is to ensure that no individual goes through the process of limb loss alone and that they can access the organisation for peer support and information pertaining to their situation. Limbs 4 Life facilitates services for the individual, their families and primary care givers. We voice the concerns of amputees within the disability sector through an alliance with government, health care providers and medical professionals. Limbs 4 Life promote social inclusion and work to ensure amputees are given the best possible opportunity to return to independent living.

Overview

As outlined in the draft report (Chapter 4 – Information) *the Commissioners;*

- *consider that the NDIS fund artificial limbs*
- *seeks feedback on the desirability and practicality of this option, and;*

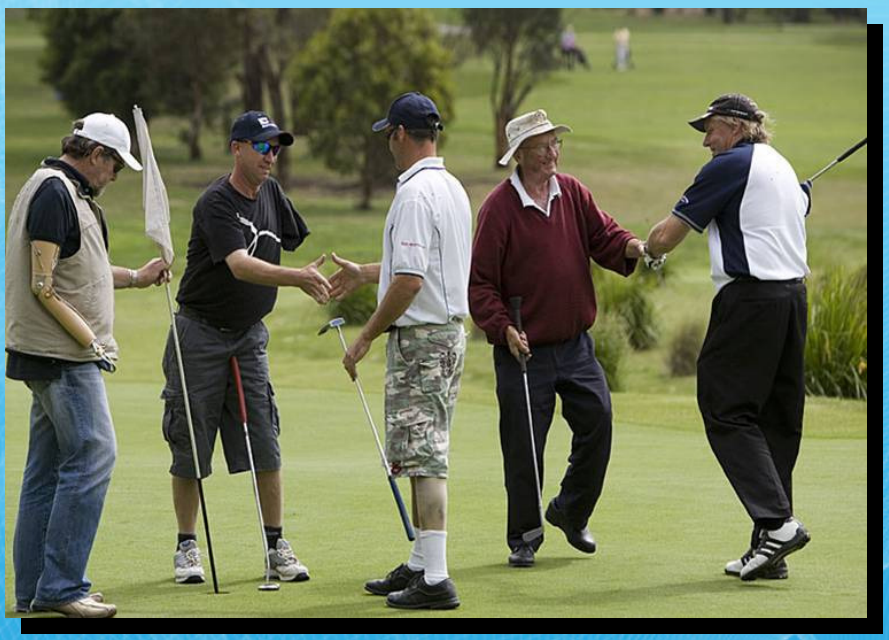
would like to know what items should be included in if the NDIS.

Like many people living with a disability, amputees require long term care and support. Individuals living with limb loss/limb deficiency/amputation have permanent disabilities and should be included under the National Disability Insurance Scheme (NDIS).

As stated in our initial submission; in Australia there are over ten different funding models representing the artificial limb scheme (provision of funding for those living with limb loss). The current model is underfunded, unfair and fragmented and there is no parity between states and territories. The current funding for artificial limbs in Australia does not support developments in prosthetic technology or allow for future developments in technology to support people living with limb loss to regain their mobility and independence. Many products which are currently on the scheme are unresponsive to individual's requirements.

Funding needs to be tailored to meet individual needs. People living with limb loss have permanent mobility issues and can benefit from early intervention processes to enable them to regain independence, balance and confidence. We believe that treatment and care should be person centred and forward driven to ensure that all individuals can achieve ultimate mobility from the prosthetic equipment provided to them; allowing the individual to achieve their full potential in economic and social participation.

Anecdotal evidence from amputees highlights the differences in ability, mobility, balance, activity and fall prevention for those using high end prosthetic equipment. Currently, this equipment is only available to those who individuals who are supported by



compensable insurance programs.

Limbs 4 Life supports a federally funded model to ensure equality for all Australian amputees and to ensure that every amputee is provided with prosthetic equipment (artificial limbs) which will best suit their needs to achieve independence.

Provision of artificial limbs

As stated in our initial submission; in Australia there are a number of different funding models operating around the country. In many cases amputees highlight that the products that they can gain access to greatly depend on geography ie: which state/ territory they reside in. Some states offer a list of products which will be funded; and if a certain product is not 'on the list' access to this product is extremely difficult if not impossible to obtain – irrespective of the individuals choice or wish to trial that particular artificial limb component.

While we appreciate that replacing a human limb can be a complex and costly task; providing the best possible outcome for an individual's chance of regained mobility should not be.

"When prescribing a prosthesis, the goal is to help individuals with lower limb amputation return to their place in society, participating in activities that are important to them. This means finding a prosthesis that is appropriate for their level of activity, ability and weight". [(1)]

In response to the question pertaining to ***'which items should be included'*** all items, products and services which support an amputee's rehabilitation and ability to regain mobility and independence should be included. They include maintenance and repairs of artificial limbs, supporting suspension liner products, stump socks, creams and lotions (where applicable to promote good hygiene and skin care) and the treatment/ support required from a prosthetist, physiotherapist, occupational therapist, orthotist,

and where necessary social workers.

Making allowances to include cosmetic covers where required promote good mental health, support positive body image and general wellbeing for amputees. As outlined by the draft report, in some cases artificial limbs may be replaced with or supported by a wheelchair or assistive devices such as walking aids like crutches, walking frames and or walking sticks.

Artificial limbs used for the purpose of mobility would generally be supplied on a long term basis requiring regular maintenance and when required replacement. The implementation of funding for artificial limbs under the NDIS will provide all Australian amputees with the opportunity to receive equal and fair treatment within the prosthetic health care system.

The impact of underfunding

"A lack of supports in one service area often shifts costs to other service areas. The costs are often exacerbated by the fact that the most appropriate and efficient supports are not being used".

The impact of underfunding has a severe impact on other services; hospital beds, additional surgery due to falls, lack of ability to return to the workforce or community, and other areas including a greater impact on the mental health system. In addition, insufficient funding of artificial limbs directly impacts on an individual's ability to regain confidence and independence and does not support fall prevention, prevent stumbles and in the long term is not cost effective.

"Falling and fear of falling are pervasive among amputees; the risk factors for falling suggest that amputees are vulnerable". [(2)]

Individuals living with limb loss need access to products which will provide them with the best possible opportunity to lead full and active lives, feel safe and have

confidence.

In the article 'Cost-Effectiveness of C-Leg with Non-Microprocessor-controlled knees: A Modelling Approach' these issues are discussed;

"Having to experience a transfemoral (above knee) amputation significantly reduces the patients potential of living an active life. The positive results that we found in QOL when using the C-Leg is also in accordance with previously published articles finding the C-Leg to have positive effect on parameters on gait, speed, energy consumption and cognitive performance, which most likely also contribute to a higher QOL for the patient." [(3)]

Underfunding of sockets and general maintenance can greatly impact amputees' general health. Fluctuations in stump (residual limb) size is an on-going problem. While most amputees try to manage swelling and size changes, funding needs to be available for prosthetic providers to be able to make new sockets ahead of the prescribed time if necessary. Currently sockets are usually replaced every three years, due to funding constraints. However, in some cases the size change can be dramatic and the 'packing of the socket' with foam like products to extend its life can have a detrimental impact on amputees who have skin conditions or are affected by vascular disease or diabetes.

How will it be practical?

Accessing supports can be daunting for new amputees and their families as they are confronted by services administered by local, state and federal governments and delivered by both public and private service providers.

A national system will be practical because it will be replicated throughout every state and territory. It will enable the client to navigate the system with greater ease and promote transparency throughout. Complications lead to confusion in the system which makes it extremely difficult for new amputees and their families to navigate.

Amputees will also find it easier to navigate geographical boundaries when relocating to states which currently operate under different systems.

A national system will also support the collection of data; which is currently not the case in the majority of states and territories. It is difficult to access cost of prosthetics or repairs or the number of amputees treated on an annual basis. Limbs 4 Life hopes that a national system will promote the benchmarking of services throughout the country. Limbs 4 Life promote the development of a consultation process from consumer and user groups in the development of a system to support amputees through the NDIS and welcome the opportunity to contribute, from a user perspective.

"The role of the patient in the process of healthcare itself is of increasing importance. In the Netherlands a law has been issued that states that participation of clients in an advisory board or otherwise is required in healthcare institutions. According to this law, treatment plans have to take patients' wishes and expectations into account. This applies to medical aids". [(4)]

Separation of product and clinical service

Currently, prosthetic service provision is funded exclusively through equipment provision and repairs. There is no funding provided for consultations, reviews, maintenance and associated services. Medicare rebates must be available for the clinical services offered by prosthetists, to ensure the provision of prosthetic devices for amputees.

Qualifications and competency to provide services

It is important that the NDIS adopts best practice guidelines regarding qualifications and competency of health professionals to provide NDIS funded services. In order to obtain NDIS reimbursement, prosthetic prescriptions must be developed in consultation with a qualified prosthetist.

Individual Assessment

We understand the need to reassess people for funded support with a focus on key transition points of the rehabilitative journey, acute hospital care, to rehabilitation, to home and where possible to return to work to community interaction. On-going focus on an individual's level of impairment is necessary to be able to provide the best possible outcomes and supporting devices.

Early intervention

As quoted in the draft report;

'Early intervention, however, could assist in delaying deterioration of their condition and therefore reduce the downstream support needs. Similarly early intervention for those children and young people with congenital disabilities supports improved outcomes and supports families'. [(5)]

There are many examples available which promote early intervention as a priority. Early intervention of an individual's situation is paramount to ensuring their ability to be able to regain independence and re-engage with their community. Limbs 4 Life believe that there are a number of early interventions support which can benefit amputees;

- Access to information
- Access to resources
- Access to a prosthetist prior to surgery (where possible)
- Access to peer to peer support

Early intervention can support long term good mental health and general well being. Anecdotal evidence from the Limbs 4 Life peer support program highlights those benefits; as does the provision of information pertaining to one's health and the

re-instilling empowerment of individual to be able to take a proactive role in the own care, decision making and general well being (where possible).

As stated in the research paper – '*From satisfaction to expectation: The patient's perspective in lower limb prosthetic care';*

Limbs 4 Life – Survey of Australian Amputees – July 2009

Receiving information from another amputee was the single most important factor in my recovery.

Knowledge is power – why did it take me years to access this information about my own disability to be able to fully understand what is right for me?

My prosthetist allowed me to trial a number of feet before making my final selection. I felt informed, and in control for the first time in months.

Knowing that I could access information bought me enormous peace of mind during this life changing journey.

;

"Over the years, many amputees have expressed concern with the lack of information provided to them to enable them to make informed product choices. Usually it is not until after the fact when they begin to self investigate that they feel 'hard done by'; leading to frustration, at times anger and general lack of self esteem" [(4).]

Social isolation

Social isolation affects people with disability and their families at a disproportionally high rate — this was one of the major findings of the Shut Out report (Australian Government 2009a). Survey evidence shows that people with profound core activity limitation were nine times more likely than the general population not to participate in activities outside of home. [(6)]

Like most people living with a disability, social isolation can impact upon amputees,

who can experience difficulty to participate in core activities for a variety of reasons.

Adapting to an artificial limb can take time, and despite being supported in a rehabilitative environment it is often when individuals try to re-engage with their communities that certain barriers and obstacles arise. Energy storing feet and knees like the MPK C-Leg can increase an amputee's ability to confidently re-engage with their communities.

A larger investment in artificial limb componentry can better support an individual's confidence and ability to take part in society.

Following the fitting of the C-Leg the subject reported a 30% increase in confidence. [7]

Internal Vs External

There has been some confusion surrounding the area of internal and external (prosthetics) componentry. We would like to clarify the following; internal prosthetics require a surgical procedure, individuals fitted with an internal prosthetic (hip, knee or shoulder replacement) are not necessarily living with a disability or are necessarily considered disabled.

In addition, because the fitting of an internal prosthesis is a surgical procedure, members of the public have access to funding via the Medicare system. This, however, is not the case with an external prosthetic which in effect replace a limb. There is no option to claim on private health cover for prosthetics or make a financial claim via the Medicare system.

Costs Associated with an Amputation

There are physical, emotional and financial costs associated with an amputation. Financial costs relating to 'non basic equipment' can start from $5,000 to in excess of $80,000 depending on the individuals circumstances. Sadly artificial limbs do not last

for a life time and often require replacement within three to five years.

Other financial costs for amputees which are sometimes overlooked include the cost of transport. Lower limb amputees are sometimes limited to the distance and gradient that they can walk, not to mention the additional expenditure of energy required to mobilise a prosthesis; as a result, many require the use of transport like taxis which over a period of time can become costly. As an example, an amputee may use a taxi to take them a distance of 800 metres or less. For amputees who are employed and unable to drive, a large component of their salary can be expended on travel costs, which, over a period of time can be a expensive outlay.

Individuals living with vascular disease or diabetes need to protect their other foot and limb associated preventative costs in association with this relate to foot health and include podiatry visits, orthotic consultations and the use of orthoses and the cost for suitable shoes which can run into hundreds of dollars.

Lower leg and arm amputees are faced with motor vehicle modifications charges and housing modifications to wet areas (bathroom), occasionally hallways for wheelchair users and ramps at entry points.

Power concessions

The Commission seeks feedback on the arrangements that should apply in relation to higher electricity costs that are unavoidable and arise for some people with disabilities.

The skin is the largest organ of the body and helps to regulate the body temperature. Often amputees will perspire more due to the loss of skin surface area in an attempt to cool or regulate the body's temperature. Residual limbs were not designed to be enclosed in the socket of an artificial limb all day long. Some amputees may have lost a significant amount of surface area (due to missing limbs) which can impair their ability to lose heat. It is therefore more difficult for many amputees to regulate their body temperatures and they therefore require access to air conditioners to assist with the regulations; thus incurring additional electricity and power costs.

Appendix 1.

References

1. The Cochrane Collaboration. Prescription of prosthetic ankle-foot mechanisms after lower limb amputation (review) Hofstad CJ, van der Linde H van Limbeek J, Postema K 2009.
2. The prevalence and risk factors of falling and fear of falling among lower extremity amputees. William C, PhD MSc, OT Mark Speechley. Arch Phys Med Rehabil Vol 82 August 2001.
3. Cost-Effectiveness of C-Leg with Non-Microprocessor-controlled knees: A model ling Approach. Thor-Henrick Broadtkorb, MS, CPO, Martin Henriksson, Ms Kasper Johannesen-Munk CPO, Fredrik Thidell, CPO – Arch Phys Med Rehabil Vol 89, January 2008
4. From satisfaction to expectation: The patient's perspective in lower limb prosthetic care. Harmen Van Der Linde, Cheriel J. Hofstad, Jan H.B. Geertzen, Klass Postema & Jacquest Limbeek – August 2006
5. Victorian Government Productivity Submission 2010 (Sub 537, 18)
6. http://www.fahcsia.gov.au/sa/disability/pubs/policy/community_consult/Pages/default.aspx - Shut Out Report.
7. Safety, Energy Efficiency, and Cost Efficacy of the C-Leg for Transfemoral Ampu tees: A review of the Literature. M.Jason Highsmith, Jason T Kahle, Dennis R. Bongiorni, Bryce S. Sutton, Shirley Groer and Kenton R.Kaufman. Prosthetic and Orthotics International http://poi.sagepub.com/content/34/4/362 Prosthet Orthot Int 2010 34:362