



**Productivity Commission Submission
Inquiry into Disability Care & Support**

August 2010

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Preamble

Limbs 4 Life Incorporated is a non government independent organisation and the national peak body for amputees in Australia. The organisation was developed in 2004 to empower amputees with the provision of information, support and access to resources for all individuals, their families and primary care givers both pre and post amputation. In the five short years since our inception Limbs 4 Life has provided access for support to tens of thousands Australian amputees. We realise the benefit of early intervention as a major priority in a person's recovery, together with the need to obtain suitable functioning prosthetics to ensure an individual can regain their independence. We have engaged our stakeholders during this consultation to truly represent the views of our members and the Australian amputee community.

We welcome the opportunity to provide this submission to the Productivity Commissions Inquiry into a National Disability Care and Support Scheme.

Definition

An amputee is an individual who has undergone the surgical removal of a limb or limbs or partial limbs and or an individual living with congenital limb deficiencies. As an organisation focused on social inclusion; Limbs 4 Life does not discriminate and provides support to any individual who faces life ahead with an amputation.

Overview

In Australia the main cause for limb amputation is diabetes. Other causes include; (in no particular order) vascular disease, cancer, infection and trauma. In 2008 – 2009; 75 Australia children were born with congenital limb deficiencies ⁽¹⁾. The AIHW reported in 2001 that there were approximately 137,000 amputees in Australia or 1/1000 lower extremity leg amputees and or upper extremity arm amputees; however; with the steady rise in diabetic related amputations it is estimated that these figures will show an increase in the overall numbers. ⁽²⁾

In 2007/08 over 9,857 amputations were performed. ⁽³⁾ Further to this in 2008 – 2009 over 3,500 amputations were due to diabetes. ⁽⁴⁾ The Victorian Minister for Health Mr Daniel Andrews stated in May 2009; "The loss of a limb is a personal tragedy and has an enormous impact on the person and their family. About 275 adults develop

diabetes in Australia every day, and within 25 years Australia faces a massive 600 per cent increase in the disease".⁽⁵⁾

Disability

The ability to measure and define severe and profound disability is difficult. Any one individual who has their overall mobility or independence impacted upon is greatly disadvantaged. In a country such as ours it is difficult to accept that there is not enough funding to go around to support the needs of disabled Australians. Disability does not discriminate; neither should the source of the funding. The aim for most amputees with an acquired disability is to regain their independence and to have the ability - where possible, to re-engage with their life, their community, and work. The Industrial relations commission draft in 1990 defined a *disabled* person as a person with one or more of a group of disabilities which had lasted or was likely to last for 6 months or more. These include loss of sight (even when wearing glasses or contact lenses); loss of hearing; speech difficulties in native language; **incomplete use of arms, feet or legs; restriction in physical activity**; long term treatment or medication.

Funding Comparisons

Funding for the supply of equipment and manufacture of prosthetic limbs has not increased since the year 2000 and even then it was minimal. Not only does the current funding not take into account the increase in diabetic related amputations it also does not allow for any trends or advances in prosthetic or related technology. In the past ten years incredible advances have been made in all areas of artificial limbs and the liners that suspend or attach them, though the majority of Australian's are unable to access this equipment. Publically funded Australian amputees continue to be fitted with prosthetic equipment equivalent to that of third world countries - and technology which was initially developed over 50 years ago. This directly impacts upon an individual's ability to contribute to the economy, society and their communities - not to mention the adverse affects on their overall mental health, long term physical health and general wellbeing.

Take, for example, the story of Sarah Hilt. Sarah at the age of 23 lost four limbs after contracting meningococcal disease. Ms Hilt states she could only move on with

her life after spending more than \$50,000 to get superior prosthetic limbs to the basic ones provided by the State Government. She stated; "Why does the health system put so much resources into keeping people alive if they then just throw us on the rubbish heap and expect us to stay home?"⁽⁶⁾ Newcastle rehabilitation specialist Dr Lee Laycock explains that amputees who are publically funded by the State have to wait months to get artificial limbs in Hunter Valley (NSW) hospitals.⁽⁶⁾

In comparison, the difference between funding for internal prosthetics (hip, knee and shoulders) to the funding allocated for external prosthetics (artificial limbs) is extreme. The NSW Health Department estimates that the total cost of a knee replacement is \$23,658 while the cost of a total hip replacement \$24,817.⁽⁷⁾ In addition, they estimate that both units will require replacing within a ten year period. The NSW Health Department provides \$2,850 for a below knee prosthesis and \$4,850 for an above knee prosthesis which is estimated to have a life span of 3 – 5 years.⁽⁸⁾ To compare: In a 50 year period, total hips could cost \$124,085. Whereas a below knee limb every 3-5 years would cost \$28,500 - \$47,499 and a above knee limb every 3-5 years would cost \$48,500 - \$80,833 over 50 years.

The number of joint replacements undertaken in Australia is around 60,000. But the big difference with joint replacement is the rate is increasing dramatically, it goes up between 5% and 10% a year and has done so every year for the last ten years. And it is anticipated to continue to increase at that rate.⁽⁹⁾ Statistics from the National Joint Replacement Registry show that the numbers of hip and knee replacement operations in Australia have shot up in recent years, rising 121 per cent from 32,006 in 1994-95 to 70,796 in 2007-08. There is no question that such procedures are valuable in that they bring untold improvements in quality of life for the patients who benefit from them. In the case of joint replacement, there is even evidence that the procedures may benefit the community in terms of cost effectiveness.⁽¹⁰⁾ It is therefore interesting to note not only the dollar value dedicated to the cost of replacement joints far outweighs that of prosthetic limbs but also the fact that there is very little age restriction placed upon candidates when it comes to fitting internal prosthetics. In many cases, we hear of people in their seventies, eighties and some cases even in their nineties being recipients of joint replacements.⁽¹¹⁾ In Australia, in the financial year 1997/98, Medicare benefits of \$13,500,000 were paid for 17,000 hip and knee replacements.⁽¹¹⁾ This is a far cry from the funding allocated to

Australian amputees. It is safe to say that the financial allocation of funds between internal and external prosthetics differs greatly.

The budget allocation for the prosthetic artificial limb scheme in Queensland in 2009-2010 was 2.4 million dollars. There are currently 6,000 amputees recorded in Queensland with only 3,500 active patients; simply, this equates to an average of \$685.00 per person per year or approximately \$2,055 per person over three years. Due to the shortfall in funding, change over's (replacement limbs/sockets and liners) are only available on a three yearly basis.* When state/s budget or facility budgets (in the case of Victoria) run out of funding amputee services are literally placed on hold. Repairs only are made and individuals are required to wait to access new limbs.

**We are grateful to the assistance of Queensland ALS for supplying these figures*

The cost to supply limb equipment components, socket, liner, fit and manufacture range between \$4,200 to \$5,500 for a below knee amputee and the average cost for an above knee amputee is \$6,800 – 7,200 leading to an ongoing shortfall. ⁽¹²⁾ These costs relate to the most basic form of equipment available and are only beneficial to someone with severely reduced mobility; meaning a person who can transfer from bed to wheelchair and or walk a very short distance. For an individual who wants and needs to work fulltime or be on their feet in any capacity for a normal working day could suffer long term health conditions from wearing basic prosthetic feet or knees which provide minimal energy return and support. The impact on their long term health could be severely compromised. Physical impacts include: back issues and sound side limb stress from compensating for a sub standard prosthetic limb. Mental health issues indirectly affect interaction with peers due to a gap in their physical abilities and identity that is often dependant on them to perform physical occupations.

Compensable Vs Public

There are significant discrepancies between the funding allocated to public amputees versus the funding provided by insurance companies for compensable amputees; for the same level of amputation. Compensable amputees have access to more advanced technologies which supports their ability to retain employment, gain

employment and contribute to the overall economy; not to mention engage in a healthy productive lifestyle and reduce long term health complications. They are better equipped to return to a similar “quality of life” or if they are young amputees, compensable patients can achieve a higher “quality of life” than their counterparts. In comparison, many publically funded amputees are wearing feet with technology developed in the 1950’s, which can lead to long term health conditions and impact on their ability to lead a healthy and fulfilled life. Fitting amputees with second rate equipment not only directly impacts their physical wellbeing; feedback from our consultation suggests that individuals wearing poor fitting and poor performing prosthetics leads to disappointment, frustration, anger and depression. A great deal of focus in health care is placed on prevention of mental health issues, but it seems this is not the case when considering the mental health of amputees. There is no focus on how their physical impairment and resulting prosthesis allows them to participate and find their place in their community / society.

For example; The SACH (Solid Ankle Cushion Heel) foot has long been considered the standard of care for low functioning and elder amputees. First designed in 1958 by Eberhart and Radcliffe, this simple design has a wooden keel enveloped in rubber with a rubber cushioned heel that supposedly absorbs ground reaction forces and permits plantar flexion of the foot. For decades, the SACH foot has been the most commonly prescribed foot and a favourite of clinicians for its simplicity and low cost. (13).

Multi-axial and dynamic response prosthetic feet are routinely fitted in many parts of the world and some states of Australia, and have been for many years. Unlike SACH feet, multi-axial feet allow the wearer to adapt to changes in ground condition and slope. This has great benefits for balance, comfort and stresses on the rest of the body. These feet cost between \$600 and \$900.

Dynamic Response, or energy saving, feet try to compensate for the loss of propulsion that occurs with amputation. Expensive examples of these are used by amputee athletes. It is acknowledged that for everyday activities these feet may not make walking more efficient but they have been shown to reduce the impact stresses that walking puts on a person’s stump, and improve endurance throughout daily activities. Crucially, many of these feet have the capacity to safely absorb very

heavy loads making them incredibly useful, and the safest option, for people in many manual or trade jobs. These feet tend to cost \$800 to \$2500.

Numerous studies suggest that amputees benefit greatly when prescribed more advanced prosthetic systems such as microprocessor knee units and dynamic feet. These devices, which are normally reserved for high activity amputees, can greatly benefit individuals with limited mobility often at only very moderate expense. ⁽¹⁵⁾ Studies concur that amputees have the potential to improve their mobility grade which means the ability to walk on different surfaces at different speeds like crossing the road and walking up and down stairs by one level with a significant improvement in walking quality.

It is well documented that amputees report increased function including walking on stairs and inclines, walking speeds, the ability to multitask, reduced energy expenditure, and greater satisfaction in well being, appearance, social stresses, and frustration when provided with advanced prosthetic systems. It is important to note that there is also a significant reduction in falls. Uncontrolled falls can be reduced through the use of more advanced components, which in turn can lead to fewer injuries and therefore a reduction in long-term health costs, especially in a group with a high level risk, of falls. Although the initial cost of fitting such devices may be higher, these expenses are offset against expenditure in these areas and thus compensated. ⁽¹⁵⁾ SAFETY is a very important by-product of advanced prosthetic devices. These offer higher function for the amputee by creating comfort and stability that improves confidence and trust in the limb, thereby resulting in higher functioning amputees with increased safety (less incidence of falls) at the same time.

Level of Amputation	Public Funding Cost	Private/Compensable Funding Cost
Below Knee Amputee	4,000 – 5,000	8,000 – 10,000
Above Knee Amputee	6,000 – 8,000	15,000 – 70,000
Below Elbow Amputee	4,000 – 5,000	20,000 – 30,000
Above Elbow Amputee	7,000 – 8,000	40,000 – 100,000

**Please note these costs are estimates due to the author being unable to obtain actual costs. In addition all products are impacted by a CPI increase and the funding for the public system does not allow for these increases.*

One of the recommendations from the 1990 Industrial Relations Inquiry states that; *a schedule of fees for each type of standard limb (needs to be defined) and associated services be developed, with patients free to choose more expensive componentry and pay the difference. Standard' limbs comprise basic mechanical components. Amputees may choose more technologically advanced componentry. However, where the use of such components increases the cost above that of a standard limb, amputees must meet the additional cost themselves.* 81% of amputees stated that they would welcome information pertaining to the advances to prosthetics and the technology surrounding them; however an additional 78% suggested that they have never been advised of new products or componentry even though they would welcome their prosthetist sharing these details. 54% of respondents would be happy to contribute to a limb better suited to their lifestyle if they were provided with information to do so and given the opportunity to trial products prior to making an investment. ⁽¹⁷⁾

Amputees' needs, like all individuals, have changed over the past 20 years, especially when considering employment and social needs. Generally people need and want to work. Best products within reason are outside the reimbursement of what the government funding streams will provide and the system in this country does not come close to meet the needs of these individuals. A greater investment at an earlier stage can and will lead to less long term health complications in the future. Prevention and early intervention is paramount.

As part of our consultation process we specifically ask about falls and prevention. It was disappointing to find that so many below knee amputees were not in possession of a water/shower leg. Results found that amputees were hopping to the shower and trying to stand on one leg to wash. In addition to this children who had been supplied a shower leg prior to the age of eighteen were no longer eligible (in some states) for a shower/wet leg once they had turned eighteen. Falls in any capacity are dangerous, and the costs to produce a shower/wet leg of \$2,800 are far outweighed by the cost of lengthy hospital stays and or replacement joints. ⁽¹⁶⁾

Current Funding Models

Across Australia there is disparity in the artificial limb scheme funding system. There are a broad number of different models; and funding for prosthetic limbs differs in each state of Australia even though funding is derived from the Commonwealth. There is not an equitable system across the country and different 'rules' and treatment service programs seem to apply for different amputees in each state and territory. The supply of limb componentry differs from state to state in Australia; there is no consistency in the supply of certain feet, knees, sockets or liners. There needs to be a parity and national consistency and the industry needs to work towards benchmarking services and adopting best practise examples across the country to ensure the best possible system is implemented in each state for each individual amputee.

Currently there are more than ten different funding models to support amputees; Work Cover, Dept of Defence, Department of Veterans Affairs, Motor Transport Insurance (differs in some states), TAC in Victoria, government funded (Victorian Artificial Limb Program) VALP and Government funded (Artificial Limb Scheme) administered by a funding manager in all other states and territories but not necessarily run the same. It is difficult to access data or statistics on very much of the above; unlike our New Zealand cousins who publish their annual reports identifying causes of amputation per person, site of amputation and cost of funding allocated or spend per individual.⁽¹⁹⁾ Data in Australia is more difficult to access. In addition, New Zealand operates an open, equitable system where an amputee living in the North Island can access services in the South Island if required. In Australia an amputee who lost a limb in NSW but was a resident of Western Australia would be required to return to Western Australia to access his/her arm or leg; further adding to the distress placed upon the individual. The other major difference in New Zealand is that the system is entirely equitable. It makes no difference if you have lost a limb due to diabetes, cancer, work place or motor vehicle accident; amputees are fitted with the same componentry which is of a higher standard than used on some public Australian amputees but less than what is afforded to compensable amputees.

The benefit of the Victorian TAC model and a number of Workcover models is that they don't provide a payout for medical costs relating to the inquiry. This allows their

clients to be covered for medical costs relating to the inquiry for the rest of their lives. It is impossible to estimate the increase of charges relating to health care and or the products to support an individual's requirements into the future. We have received numerous letters from people who 20 years ago received a payout and were told to invest those funds. Now 20 years on even with sound financial management those funds have well since expired and individuals are required to fund the cost of their own limbs without the finances to do so. In addition, these individuals are unable to reengage the support needed from the government limb schemes and in some cases due to severity of the injuries are on a pension; and excluded from being able to participate in society. A "lifetime" prosthetic payout from 25 years ago, wouldn't buy one leg in some cases now by "global" standards.

Below are some examples of feedback from our consultation process.

Peter states that; "At the very least, an amputee should have the right to use the funding allocated for their needs to seek the opinions and service from any qualified rehabilitation consultant, prosthetist or physiotherapist that they wish to employ. The funding for my amputee health needs should not be given directly to any centre to use as they see fit, it should be allocated to me, the user, to direct it toward those professionals that can best support me in my quest to lead a healthy full life." ⁽¹⁷⁾

Domenic suggests that; "The current system could be improved by allowing GP's to refer amputees and those living with other disabilities to either private or public clinics depending on where they truly believe the client will receive the best treatment. Those who attend the private clinics should have the costs reimbursed through Medicare, which I believe would be cheaper for the government; rather than having to provide people like me five years of continual treatment with no result. I am on a disability support pension and have a mortgage on the family home so it was difficult to afford the cost of the privately made prostheses, but I now wish I had done it five years ago. During the past five years in the public system I have lost self esteem, was unable to enjoy a social life and could honestly say I felt useless; not to mention the fact that I had to resign from my job." ⁽¹⁷⁾

And from another"Services should work to enable me to achieve financial independence and social inclusion. For instance in the current limbs scheme; rather

than assessing the person for the least cost alternative as is the current case eg: split hook for arm amputations. The most effective support available may include a higher cost limb such as the “i-limb” that the long term allows participation in the employment market and ultimately financial independence. The current practice of prescribing antique technology is ineffective.”⁽¹⁷⁾

Jane believes that a fairer funding system needs to be implemented. Rather than channeling funding through a list of centres as at present there needs to be a panel of qualified individuals including stakeholders to oversee where the funding is actually spent. She goes on to say; “I am able (with some difficulty) to afford to fund a prosthetic limb myself, but others may not be able to do so and may be faced with difficulty finding a centre to provide an effective prosthetic fitting for them.”⁽¹⁷⁾

One amputee states.....“I have had a very unfortunate experience with my service provider of prosthetics in the state I reside and have had to travel to see a private prosthetist in another State to make me a leg that fits. This is a very expensive and time consuming process and far from ideal. I would like to be able to access the money I am eligible for the supply of making a prosthesis given to me; so at least the cost would not fall entirely on my shoulders”⁽¹⁷⁾

Social Impact & waiting times

In assessing the findings from our consultation further comments suggest that; the delay in fitting an artificial limb in Australia continues to increase due to the lack of service providers (who manufacture artificial limbs). Amputees indicate that current waiting times are between 3 – 12 months within the public system, causing lengthy periods without mobility or independence. The waiting time for limb fit, manufacture and supply can have a life-long impact on an individual’s state of mind. It can directly affect their ability to be able to return to work, which in turn impacts upon their financial status, mental wellbeing, independence and ability to contribute to society and the economy in a timely and effective manner.⁽¹⁷⁾

In some cases public patients travel interstate and or visit a private provider and pay for the cost of the limb up to \$20,000 out of their own funds to avoid waiting times even though they are eligible for government funded prosthetics. In cases such as this individuals forego any opportunity for funding support.⁽¹⁷⁾

Aids & Equipment Program

Waiting times for the supply and fit of artificial limbs is not the only area that impacts on an amputee's recovery and return to independent living. The Aids and Equipment program (also funded by the Commonwealth) is plagued by delay and lengthy paperwork. Valuable hospital beds are occupied while individuals wait for approval of funding for wheelchairs, (home modifications) ramps, bathroom aids and other relevant equipment; as allied health care workers try to navigate the paperwork and forms put in place to support an individual's return to independence.

In some states individuals are required to be discharged from a rehabilitation facility for a period of three months prior to obtaining approval for funding for equipment and aids. In the case of an individual faced with a permanent disability, this is an unnecessary delay. In the case where an amputee can afford to purchase a wheelchair (independently) funds are not reimbursed. It would appear that anyone who attempts to move forward faster than the system can accommodate is faced with a personal financial disadvantage.

It seems that there is a myriad of paperwork which requires completion in order to access basic requirements. The paper trail is lengthy and time consuming further straining the services of allied health staff. People with permanent physical disabilities are not going to recover from some of the physical effects that the disability impacts upon them; (eg: a leg will not grow back) however, with support aids at the point of early intervention rather than three months following a hospital discharge there is a better chance that the support aids will in turn support their ability to regain the individual independence, good mental health and general wellbeing. Additionally, these delays cause preventable complications that affect long term limb fit – such as swelling, muscle degeneration, loss of flexibility, flexion contractures and of course mental frustration of a life on hold. And therefore places more unnecessary strain on the health budget.

Rural & Regional Communities

A number of private providers cover rural and regional communities throughout Australia often travelling up to 5+ hours in order to do so; the costs to provide such a service is expensive. A number of amputees living in rural and regional communities

state that the change to the laws has delayed having a limb fitted. "I used to be able to visit my prosthesisist and he would assess my situation (need for a replacement limb/repair etc) now I have a 3 week waiting period just to see my GP in order to gain a referral to see the (qualified) clinician who has always managed my needs. There is already a strain on GP's in rural areas and this kind of bureaucracy is placing more pressure on these regional services.

Roger states, "I live in country Victoria and travel for over two hours to visit my prosthesisist. I am on a disability pension and with the current cost of fuel this is not cost effective; however it is my choice to see the same service provider that I have for the past 20 years so while I could access a local service I want the freedom to be seen by the clinician of my choice. "

Older Australian's

There may be some financial benefits by taking care of older Australians. While we appreciate that boundaries and barriers need to be put in place with regard to the establishment of a National Disability Insurance Scheme, in the long term this could be an area of proportionate disadvantage. Amputees over the age of 65 who are taught to walk properly can remain independent in their own homes; stay healthy from the benefits of being able to walk, be less draining on the system with regard to the costs related to hostels and carers and thus require minimal support from the government and service providers. There should be consideration in some areas to include this group of people who would willingly accept independence over dependence.

"Ageing with a physical disability almost inevitably means that people's bodies will wear out quicker than their able-bodied contemporaries; also, that this process of general 'wear and tear' will often be associated with a variety of more specific physical and health problems such as arthritis, increased pain, reduced energy levels, weight gain, and contractures." ⁽¹⁸⁾

Support and information

Lack of funding is not the only area that needs to be addressed; as a part of the overall healthcare package amputees lack access to information so that they can

make informed choices about prosthetics pre amputation, post amputation and during their journey throughout life with respect to their prosthetic healthcare. It is common knowledge that Australian's are encouraged to make informed decisions and choices in the process of taking control of their health needs. In order for an individual to be able to do so information relating to their condition needs to be easily accessible and readily available. In consulting with our stakeholders many amputees cited the lack of information as one key factor impairing their on-going recovery.

86% report that they would have liked more information to prepare them for amputation and a further 91% stated that they would like to be made aware of new technology with regard to prosthetics and or aids as they became available. A further 70.9% said that they were not given any information either pre or post surgery. And finally 76.8% stated that they would have welcomed printed information and meeting another amputee. ⁽¹⁷⁾

In this sense support also covers mental health and general wellbeing. The benefit of engaging with another amputee during the recovery process has proven to have long term health benefits. Social support plays a very important role in the lives of people who have recently undergone an amputation. Support comes from a range of sources—from family and friends, through health service(s), or from people who fall in between these two groups, support group members (such as yourselves) and peer support volunteers. Research has shown that, even while inpatients, doing rehabilitation in an amputee-specific environment provides important support and reassurance for many recent amputees as, through this, individuals are able to imagine themselves several weeks in the future ⁽²⁰⁾

Peer support volunteers helped recent amputees feel better about their situation, alleviated fears that accompanied the amputation, and responded to worries and concerns. A number of our participants had visits from peer support people around their amputation, which they found beneficial, not only helping them to become aware of what they could do physically after their amputation, but also to help them to come to terms with their loss. Receiving a peer support visit had significant mental health benefits for recent amputees, as these visits allowed them to see that a 'normal' life was possible. For them, this often meant a life not dramatically different from before. This understanding of returning to their normal lives was particularly

important for those who were depressed after their amputation and felt that the amputation was the end of their lives. ⁽²⁰⁾

While rehabilitation specialists can fabricate devices, improve function, appearance and strength, only interaction with other amputees can replace fear of the unknown with information and knowledge. When helplessness, depression and low self esteem are replaced with hopefulness, and the focus on loss evolves into a future vision of quality life with meaning and purpose, then rehabilitation becomes an active collaborative partnership between patients and professionals to reach goals. ⁽²¹⁾

Summary & recommendations

Limbs 4 Life have surveyed over 1,200 amputees in the Australian community for this submission.

One thing that stands out is the disparity between people's circumstances; the ability to obtain functional artificial limbs and the ability to make independent decisions with respect to products and choice of service providers. Amputees would welcome the opportunity to manage their own funding and make choices about who provides and manufactures their limbs. They indicate that they would prefer that funding follow the individual rather than be managed by an external party or rehabilitation centre/facility or external funding manager. The current funding system is not equitable. For a transformational scheme to truly address the needs of people with disability, it needs to be broad, flexible and responsive in order to ensure that individual needs are met at an individual level.

To ensure the best outcomes for amputees the system requires a number of changes. Our stakeholders have indicated that they would like the following areas taken into consideration and Limbs 4 Life supports the following objectives;

- Transparent reporting methods to gather and assess Australian amputee related data (similar to what is accessible from New Zealand)

- To ensure that each and every individual has access to equitable funding; above the current basic prosthetic components
- Individuals have access to equipment to aid their rehabilitation and recovery in a timely manner without lengthy paper trails
- To expedite the provision of aids and equipment for an individual's return home
- To ensure that information relating to an amputee's condition and needs is easily accessible and forthcoming.
- That there is the establishment of a national governance panel which includes stakeholders and consumers together with health care professionals and allied health staff.
- That Prosthetist's be required to meet some minimum accreditation/registration. This should help raise the standards and address some of the poor professionalism which is evident in some of the survey respondents' feedback.

For too many years now amputees have tried to function on equipment equal to that of a third world country. As a nation we are behind the rest of the world in the supply and access of technologically advanced prosthetic equipment. It should not just be available to a lucky few. Our health system should be embarrassed and ashamed with how far behind we have fallen with regards to prosthetic care. 30 years ago, we would have been on par with the rest of the Western world. Today, places like Europe and the US (and NZ) have surpassed Australia by, and in relation to external prosthetics Australia is closer to third world care than they are to their Western counterparts. Practitioners know what is available and are aware of the components and techniques which exist within Australia and the government needs to untie the hands of the providers in order to raise the level of care allotted to amputees.

Just as people's disabilities vary significantly so do those individuals living with limb loss. No one person is the same and neither is their situation. Some amputees' mobility and motor skills are less impacted upon while others require greater levels of care and support from the health system, their family and primary care-givers. It is common knowledge that no two amputees are the same just as no two people are the same. Each patient needs to be treated independently of one another and

provided with state based information relative to their new circumstance; following the loss of a limb/s. Individuals living with a disability in Australia should be provided with the opportunity to be able to access products, services and the supports necessary to allow them to have the best possible opportunity to contribute to their community, live dignified lives as independently as possible. What “quality of life” means, differs for each individual, and so do the costs of limbs for those differing individuals. We should educate and assist amputees and prosthetic providers so that they can make the choices to achieve the level of care that they desire.

In closing; for the benefit of long term health and to reduce the strain on the system amputees need access to better equipment and general care. Information regarding a person’s disability needs to be readily available and easily accessible – currently this is not the case. The majority of amputees indicated that they wanted the opportunity to manage their own health and be in control to manage the funds allocated to them.

We would welcome the opportunity to further consult with the Commission on this matter and provide any additional information that is required.

Acknowledgements

In preparation for this submission Limbs 4 Life developed a survey process (using the short key questions provided by the Commission) which was placed on our website (www.limbs4life.com), sent via email to our members and subscribers and for those without access to internet facilities; posted via hard copy to amputees throughout Australia.

Limbs 4 Life would like to take this opportunity to thank everyone who took the time to contribute to this valuable collection of information and data. The organisation would also like thank AFDO (The Australian Federation of Disability Organisations) who provided financial support to Limbs 4 Life which enabled us to mail/post the survey to a large number of amputees throughout Australia.

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