

Linda McGarvey:

Background:

As a relatively newly disabled individual I have to admit that having worked for a government agency for much of my working life has certainly better equipped me to access support services that have become a necessary part of my life since my cancer diagnosis 8 years ago and subsequent amputations in 2004 and 2005.

I am now a hip-disarticulation amputee.

The important part of this is that as I was an elective amputation I had time to research what that would mean for me. Many people do not have the skills or the time in which to do this. I was able to choose a rehab hospital. Had an appointment with the rehab doctor who discussed prosthetic options with me. I then met with the nurse coordinating transfers. An occupational therapist assessed my home for modifications before surgery thus saving time. I sought peer support and counselling. Having information both about my physical needs but also emotional and psychological support facilitated my recovery. I am relating these events as I consider them to be best practise and as such should be part of any assessment and action plan that is set in place for future amputees where possible.

In reading the draft document I absolutely support the notion of a National Disability Insurance system that would apply to all Australians should they need to access it. However, as amputees require external limb replacement as opposed to internal hips, knees etc that are covered under Medicare I believe that there needs to be a National Limb scheme that is equitable to all amputees regardless of cause or insurance. As you are very aware there are different providers of funding for limbs. If you had a choice you would be 'an insurance job' as only then can you be provided with current componentry that has developed in recent years. The inequity lies in the difference between this and the Artificial Limb Scheme where only certain prescribed parts can be accessed by the prosthetist. It would seem that there has been little change to what is used in the past 15 years. Australian amputees using the ALS receive limbs that are below the standard supplied in other western countries. I believe this is shocking given the advanced technology that would enable amputees to lead more active and productive lives. This may well contribute to better physical and mental well being.

My own particular interest lies in the assessment process, prosthetic and equipment services, and the importance of early intervention.

Important Points

- Pg 7 of key points mentions aids, appliances and home and vehicle modification (including artificial limbs). In my way of thinking an artificial limb is not so different from an artificial knee or hip and falls for me within the category of a replacement body part and should not

be an afterthought but needs to stand alone. Supporting this premise is the nature of our aging population and the increasing levels of diabetes in our country and the unfortunate resulting amputations. I believe that there needs to be best practise policies and procedures put in place that are nationwide so that should amputees relocate from one state to another there is no discrepancy of service. I also would strongly desire that amputees are acknowledged and have their needs incorporated into the NDIS. Additionally, the way in which amputees are assessed would require specialist training.

- National Artificial Limb Scheme (South Australian Limb Scheme manual appears not be have been updated since 90's. There is still reference to wooden sockets!) Additionally there have been little increases in funding for the scheme in the last 15 years. It is therefore not surprising that those not covered by insurance do not have access to modern technology) This must be frustrating to prosthetists who would wish to prescribe componentry that would assist the individual in gaining the best mobility and functionality but are unable to do so. A consequence of this may be seen in an exodus from the industry of 60% of prosthetists within 7 years of graduation.
- Acknowledgement that many prosthetists endeavour to meet the needs of their clients within the constraints of the ALS often with great difficulty.
- Equity, accessibility and respect to all amputees. This is often determined by your own knowledge of the systems.
- Early intervention and planning is crucial to getting amputees back into their communities, lives, families and where appropriate work.
- Amputees to have access to technological advances in componentry that have been developed to best meet the needs of individual amputees. This would obviously necessitate an increase in funding to the ALS or to a new National Limb scheme that covers the needs of all amputees regardless of cause or level of insurance.
- Equipment and home modifications to be supplied or completed in a timely fashion to avoid unnecessary hospital stays-should be part of the early intervention strategies
- The draft refers to the need for greater information. I would urge that this information about the scheme is disseminated in a variety of ways that are practical for those that do not use computer technology.

I can obviously see that some of the issues I have raised are addressed in the draft document. However, I believe that amputees need to be viewed as not only needing equipment and services but that there needs to be a revamping and recosting of the ALS that could be incorporated NDIS. Replacement limbs are body parts not equipment. They are body parts that give function to an

individual. Without this occurring I believe that amputees could still be at a disadvantage of not being able to have limbs that are of the latest technology.

My own personal experience of early intervention, planning and an element of personal control is critical to physical and emotional well-being. As time passes I still am learning how best to get the system that currently is in place to work for me. The supply of my prosthetic limb has been lengthy and has involved personal research into the latest developments here and overseas that are pertinent to myself. I have been fortunate in that my prosthetist has embraced much of what I have researched and attempted to recreate within the constraints of the ALS.

I would encourage that the NDIS become the funding body for artificial limbs and as a consequence will provide equity for all regardless of cause of amputation.

Additionally, as requested by the commission I have endeavoured through internet research to gain some costings involved in the supply and manufacture of limbs that can be compared between what is on offer here and elsewhere in the Western world but personally have found it impossible to gain access to such figures.

In conclusion I would also like to say that I fully endorse submissions made by Limb 4 Life, Otto-Bock, Peter Spooner-Hart, AOPA who have all addressed similar concerns. They have provided detailed information from studies that support this submission. I also fully endorse the suggestion that there should be consumer representation on any advisory board that is established to manage NDIS prosthetic funding. I personally feel that the users of a system are instrumental in shaping future directions.