

# National Disability Insurance Agency – ‘Towards Solutions for Assistive Technology’

## Response to the discussion paper – Limbs 4 Life

February 2015

*Limbs 4 Life aims to provide information, support and access to resources to amputees, their families and primary carers while promoting an inclusive community.*

### **Our Background**

Limbs 4 Life has been instrumental in improving the lives of amputees and their families across Australia over the past ten years. The organisation regularly consults with our stakeholders to gain feedback regarding: their experience living with amputation/s, regaining their independence; and, access to support needs in order to live fulfilled lives.

Limbs 4 Life is the only organisation of its kind in Australia providing practical and emotional support to the amputee community. The organisation achieves this by:

- training amputees as Peer Mentoring Support Volunteers;
- coordinating early intervention Peer Mentoring Support Visits in hospitals and rehabilitation centres;
- offering tailored social and sporting activities;
- delivering professional development training to medical and allied health practitioners;
- disseminating information and resources unique to the amputee community; and,
- responding to health equipment-based enquiries.

### **Our Community**

The community we serve and support is comprised of amputees, carers and family members, and health-care practitioners. Our community, and consequently the need for amputee support, is resulting out of an overall increase in amputations across the Australian population.

Limbs 4 Life welcomes the opportunity to respond to this NDIS discussion paper and have addressed the areas relative to our stakeholder group based on their needs.

**Do you think the participant capacity building framework (Attachment 2) will help participants reach their own decisions and give them better control over choices about assistive technology solutions?**

### **Our Response**

It is Limbs 4 Life’s belief that the ‘participant capacity building framework’ (Attachment 2) will assist amputee participants to reach their own decisions and give them better choice and control over Assistive Technology solutions, if the right kind of support is provided during the engagement phase.

### ***Rationale***

People in Australia face amputation for a variety of reasons: infection, cancer, trauma related injuries, diabetes, and vascular disease and in some cases, as a result of reconstructive surgery/s due to birth deficiencies.

In most cases, a participant who has acquired an amputation would not have prior knowledge of the Assistive Technologies (AT) available and relevant to their needs. Similarly, as a 'novice' just having acquired a disability our stakeholders generally do not know what outcomes-based solutions are available to them and how to access these.

It is our experience that amputees come to learn about and understand what AT equipment and solutions they require through the provision of information that specifically relates to their needs as an amputee. In addition, provision of Peer Mentoring Volunteer Support (such as that offered by Limbs 4 Life) is a sound mechanism by which amputees gather knowledge about AT solutions from peers. The provision of information and Peer Mentoring assists amputees to develop self-confidence and thus make informed decisions about their self-care and AT needs.

As such, it is anticipated that most amputees would begin the process in the 'Novice' category. Over time, through the provision of information from Limbs 4 Life, from 'expert advisors' and personal experience, participants will build capacity and personal understanding to exercise 'choice and control'

### **How useful would it be to have access to peer support people, such as assistive technology mentors?**

#### **Our Response**

Limbs 4 Life currently delivers a 'best practice' early intervention one-on-one Peer Mentoring Support Program to individuals pre or post amputation surgery.

### ***Rationale***

Limbs 4 Life has been successfully operating face-to-face peer support for over ten years. Limbs 4 Life Peer Mentoring Support Volunteers are trained; police checked and have hard earned knowledge of living with a disability. Amputee Peer Mentors can build participant capacity by sharing their very personal experiences, help participants to build confidence and make informed decisions. Peer Mentoring Volunteers understand the needs of new amputees. Limbs 4 Life regularly updates and informs Peer Mentoring Volunteers with information relating to new technology and changes in navigating the healthcare and medical system. Limbs 4 Life's Peer Mentoring Support Volunteers can provide a valuable link to enable participants to have 'choice and control' about Assistive Technology.

Anecdotal evidence shows that Limbs 4 Life's Peer Mentoring Volunteers are useful to individuals who acquire an amputation by:

- building participant (ie. amputee) capacity as a 'trusted other', assisting the novice they are peer supporting to promote and maximise 'choice and control';
- understanding the language relating to Assistive Technology which can be foreign to new participants;

- relaying the processes involved to regain independence;
- reducing the anxiety experienced by those who acquire a permanent disability;
- providing information related to the procurement of Assistive Technologies; and,
- promoting confidence building with 'trusted others' to self-assess.

**How important do you think 'expert advisers' will be in assisting with assistive technology solutions and decision making? What are the main skills and attributes you think they should have?**

**Our Response**

Limbs 4 Life recognise the need of 'expert advisers' to assist with assistive technology solutions in the decision making process. Given that a limb amputation often results in a mix of physical and psycho-social health needs an array of 'expert advisors' covering these areas are critical to the participant being able to determine choice of and control when it comes to assistive technology solutions that suit their individual needs and circumstances.

***Rationale***

To achieve the best assistive technology solutions participants will require support from an 'expert advisor'. 'Expert advisors' can support the decision making process, provide cost effective solutions, and recommend devices to deliver positive participant outcomes and assist them to achieve their goals. 'Expert advisors' can assist a participant to exercise 'choice and control' by supporting them through the trial phase of assistive technologies.

After having supported amputees for over ten years across the Australian community, it is Limbs 4 Life's belief that the following 'expert advisors' should be made available to all amputees (please note that as an amputee moves from being a 'novice' to 'expert' (as outlined in Attachment 2) their need to engage all of the below mentioned experts tends to reduce over time). These expert advisors are:

- Prosthetist
- Physiotherapist
- Occupational therapist
- Social worker

**What do you think about the use of refurbished items (assuming that all appropriate health and safety procedures and necessary safeguards will be in place?)**

**Our Response**

Limbs 4 Life does not support the refurbishment of items regardless of any safeguards and procedures being put in place.

***Rationale***

If the premise of the NDIS is underpinned by 'choice and control', the refurbishment of items will place limitations on items that a participant can select. In addition assistive technologies utilised by amputees fall into two categories: custom made for the individual which is largely because each level and type of amputation differs between each person and off the shelf support items for daily living.

Custom made assistive technologies for amputees include the following (and cannot be shared or transferred due to the Therapeutic Goods Act):

- Prosthetic limbs
- Recreational limbs
- Prosthetic suspension systems (eg: liners)
- Cosmetic covers over prosthetic limbs (cosmesis)
- Specialised shoes

Other assistive technology solutions that fall into the category include permanently fixed products such as:

- Home modifications (eg. Ramps / handrails / wet area devices/grip bars)
- Vehicle modifications (eg. Left foot accelerator, hand controls)

Off-the-shelf assistive technologies often used by amputees include a range of other items. It is important to note that some of these items will have been adapted for individual use and will be required for use throughout the participant's lifetime. These off-the-shelf assistive technologies include:

- Wheelchairs
- Wheelchair cushions
- Crutches
- Walking stick/s
- Home modifications and devices for lower limb amputees (eg. shower stools/anti-skid mats)
- Home modifications and devices for upper limb amputees (eg. spoon/fork/knife, chopping boards)
- IT modifications (eg. one handed keyboards/mouse, specialised computer programs)

Ensuring that amputees have access to customised, off-the-shelf, and modified off-the-shelf items is critical for the individual's social inclusion and economic participation.

The procurement of 'bulk purchases' by the NDIA will place additional limitations on a participant's capacity to exercise 'choice and control' and potentially lead to additional cost burdens for the NDIA.