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09/01/2016

To: The Delegate, National Disability Insurance Agency

Re: [redacted]

I write in support of [redacted] appeal for reconsideration of the report and quote provided for prosthetic services (dated 30/07/2016) requesting provision of a definitive transhumeral myoelectric prosthesis. This report and quote was prepared and submitted following a successful NDIS-funded trial of two myoelectric prosthetic terminal devices. The initial report identifying [redacted] needs and recommending trial of these terminal devices was prepared and submitted on 12/04/2016.

Notification was provided to me of the outcome of the request for a definitive prosthesis on October 24th, 2016. This was a verbal notification offered via a telephone conversation with a local NDIA representative, [redacted]. The conversation was initiated by myself following an absence of communication from the NDIA that an outcome had been reached regarding this request. It was made aware to me in a later email from the NDIA that this decision was reached on 10/10/2016, although I would like to note that the client was not advised of this decision until November 2016.

During the conversation with [redacted], I was advised that the request had been declined as it did not meet the criteria for funding of prosthetic limbs under the following operational guideline:

> *"Upper limb myoelectric prostheses may be approved where the participant is either a bi-lateral amputee or has contralateral overuse syndrome which prevents use of body powered prosthetics and where there is demonstrated commitment and success demonstrated using a training device."*
>
> *NDIA Operational Guidelines – Prosthetic Limbs*

This statement is very problematic when used for the purposes of defining prescription guidelines. The statement does not specify whether the bilateral amputation (or limb difference) must be in the upper limbs. Further, while not explicitly stating that myoelectric prostheses will not be approved to participants without bilateral limb difference or overuse injury, this very much appears to be how it is intended to be read, and is exactly how it has been interpreted by the NDIA in their assessment of [redacted] case. During the two-week community trial of the two terminal devices, [redacted] displayed an extraordinary capacity for learning and integrating this style of prosthesis into his daily function. I would have expected that this *"success demonstrated using a training device"* would have satisfied those who reviewed the request for provision of a definitive prosthesis.

According to an Australian study by Jones & Davidson (1999) *"it is surprising that no one has formally described overuse injuries in the remaining arm of upper limb amputees"* (Prosthetics & Orthotics International, 23, p.57). So how is it that a Commonwealth Government policy require a person with an existing, severely limiting functional impairment (the complete absence of a hand!) must prove themselves even further functionally impaired by way of overuse injury in order to be considered for access to appropriate assistive technology? Shouldn't prevention of injury be the main function of assistive technologies? This specific prosthetic prescription guideline defies current scientific literature, all sense of reasonable logic and, indeed, other aspects of NDIA's prescription policies. I wish to draw

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your attention to the *NDIA Operational Guideline 10 – Planning*, and particularly to *Section 10.9: Other considerations applicable to including supports in a participant's plan:*

> *10.9.1 The principle of "no disadvantage"*
>
> *Governments have made a commitment through the Intergovernmental Agreement for the NDIS that people receiving supports before becoming participants of the NDIS should:*
>
> - *not be disadvantaged by the transition to the NDIS; and*
> - *be able to achieve at least the same outcomes (i.e. achieve at least the same level of social or economic participation or maintain the ability to undertake the same range of activities) in the NDIS as compared to those expected to be achieved by their previously provided support.*

What should have been observed by the NDIA in the formulation of their prosthetic prescription guidelines is that myoelectric technologies have been funded (and continue to be funded to those not yet transitioned to the NDIS) by various state-based funding schemes around the country. Children across various state-based funding schemes have had access to myoelectric technologies for decades irrespective of whether they have a bilateral limb difference or contralateral limb overuse injury. Unfortunately, the NDIA's policy is already disadvantaging those transitioning to the NDIS, as we are seeing here in [redacted] case.

Further to this, the decision to limit access to this technology does not support scientific literature examining the functional benefits of this myoelectric technology over older, body-powered prosthetic technologies. As was identified within [redacted] initial report requesting trial of the myoelectric terminal devices, a myoelectric control system offers significant functional benefits to other control systems. These include:

- Greater functional outcomes through intelligent, proportional control of the terminal device in grasping and maintaining hold of objects, including those of irregular shapes, sizes, and materials;
- Greater functional outcomes through increased independent function of the prosthesis (elimination of contralateral limb intervention for wrist rotation and/or object positioning);
- Greater functional operating "envelope" as operation of the device is not limited by tension (or lack thereof) on the control cable and harness;
- Increased ease of donning and doffing of the prosthesis through elimination of the body harness; and
- Reduced strain on the torso and contralateral shoulder for control of the terminal device, thereby reducing likelihood of onset of overuse injury.

If we examine scientific literature to understand more about upper limb amputees and the role of the prosthesis on function, we find a large volume of evidence to support the use of myoelectric prostheses in upper limb amputees. Myoelectric prostheses are not a new, untested technology. Gaine et al. (1997) state that these prostheses were first developed in the 1960s, with broader public provision beginning in the 1970s. In many European countries today myoelectric technology is a baseline standard for upper limb amputees due to the significant functional benefits it offers the user, while cable activated prostheses are only provided to those unsuitable for myoelectric control. Myoelectric prostheses are no longer at the cutting edge of technology, as Targeted Muscle Reinnervation (TMR) has become increasingly prevalent across many countries in Europe and North America. The decision to restrict access of the upper limb different participant to technology that is, as described by Gaine et al.

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(1997), over 200 years old is not in keeping with the NDIA's governing legislation nor their assistive technology prescription guidelines.

Gaine et al. (1997) examined the functional outcomes of various upper limb amputee groups. Those with a congenital limb difference achieved significantly higher functional outcomes, especially with myoelectric prostheses, than those of traumatic amputees. Functional outcomes were also greater among users who received their prosthesis as a child compared to those who began use of a prosthesis as an adult. The functional benefits of myoelectric prostheses were noted by the authors, with the myoelectric prosthesis being the most accepted style of prosthesis amongst all styles of upper limb prosthetic device (myoelectric, cable-activated, cosmetic, and combinations of those three). Users of myoelectric prostheses reported the highest satisfaction with their prosthesis during social outings due to the combination of acceptable appearance and function. The myoelectric prosthesis was also the most functional style of prosthesis for light manual tasks, office and school work.

In assessing the incidence of overuse injuries within the Australian upper limb amputee population, Jones & Davidson made the following observation:

> *"How much more repetitive work is done by the one-armed person! A prosthesis is at best a tool aiding activities. It is not suitable for the fine sensory work done by the remaining arm. We note the damage done to shoulders, elbows and wrists of the champion sports person with two arms repetitively playing tennis, cricket or golf. These are people in superb physical condition whose bodies respond to overuse with injuries similar to the amputee population. The distribution of the injuries, shoulder impingement, epicondylitis, tenosynovitis and diffuse aching illustrate that the stress may fall on different parts of the body depending on the physical stress. Many of this group of patients unfortunately tried to carry on life as though no injury had occurred to their physical detriment. The rehabilitation implications of this should be noted by those involved in the care of the upper limb amputee. These people should be advised that they are at significant risk of damage to their remaining arm. They are not able to perform at the same level as formerly. This has medicolegal implications."*
>
> Jones & Davidson (1999) *Prosthetics and Orthotics International*: 23, p.57-58.

Within this study, Jones & Davidson also examined the employment status of the Australian upper limb amputee population. It is interesting to note that 73% of employed upper limb amputees wore a prosthesis in daily activities, and that those who did not wear a prosthesis were more likely to be unemployed.

These studies reaffirm the findings documented in [redacted] initial report, as well as the post-trial reports submitted by myself and the assessing Occupational Therapist.

Following examination of relevant scientific literature, it is useful to re-examine the *NDIA Operational Guideline 10 – Planning*:

10.6 Is the support effective and beneficial having regard to current good practice?

> *Before any support is added to a participant's plan the NDIA must also be satisfied that the support will be, or is likely to be effective and beneficial to the participant having regard to current good practice (section 34(1)(d)).*
>
> *The NDIS Act does not define 'effective' or 'beneficial' but they are ordinary words that should be given their ordinary meaning (i.e. effective meaning having a definite or desired effect; efficient and beneficial*

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meaning advantageous; having benefits; improving the health) (see McCutcheon and NDIA [2015] AATA 624 at [34] (link is external)).
The term 'current good practice' means a practice which, even if not widely used, is recognised by numbers of practitioners as being based on sound evidence (see TKCW and NDIA [2014] AATA 501 at [70] link is external)).
When deciding whether a support will be, or is likely to be, effective and beneficial for the participant having regard to current good practice, the NDIA must consider the available evidence of the effectiveness of the support for others in like circumstances.
This evidence may include:

- *published and refereed literature and any consensus of expert opinion (rule 3.2(a) of the Supports for Participants Rules);*
- *the lived experience of the participant or their carers (rule 3.2(b) of the Supports for Participants Rules);*

…

The Supports for Participants Rules do not limit the kinds of evidence that may be relevant, and nor do they suggest that more weight should be given to any kind of evidence over another. However, the Rules do indicate that expert opinion may be particularly relevant.

Also, the participant's lived experience (i.e. their first-hand knowledge, experience and understanding of their conditions and various treatments) will inevitably be subjective, however, this does not mean that it is of limited probative value. How much weight 'lived experience' should be given will depend on all of the available evidence. Where lived experience is consistent with reliable, relevant, independent evidence, it will likely be given a good deal of weight. Where it is at odds with other evidence, it may be given less weight. Where reliable, relevant independent evidence is lacking, evidence of 'lived experience' may be particularly important (see McCutcheon and NDIA [2015] AATA 624 at [86] (link is external)).

Whether or not there is unarguable evidence of the benefits of a proposed support is not the test of whether a support is likely to be effective and beneficial having regard to current good practice. Rather, the NDIA will need to be satisfied that there is evidence, even if anecdotal, from a sufficient number of qualified experts of positive outcomes in a sufficient number of people. Emerging signs of positive outcomes in isolation will not be sufficient (see TKCW and NDIA [2014] AATA 501 at [74] and [75] (link is external)).

A support may be effective and beneficial where the desired effect or benefit achieved is to maintain a participant's level of functioning (as opposed to effecting any long-term change in the disability itself) at a level which enables the person to engage in social and economic activities to the extent they are able to engage (see McCutcheon and NDIA [2015] AATA 624 (link is external)).

So, in reviewing [redacted] case, we find increased reason to support the proposed myoelectric prosthesis. The device has been assessed by multiple experts, all of whom have provided opinion in support of the proposed prosthesis. [redacted] has lived experience with the proposed device, and there is demonstrated evidence that the proposed prosthesis will enable participation at a level which allows engagement in social and economic activities to the extent of his ability. During the NDIS-funded trial, [redacted] was able to achieve exceptionally high levels of function using the proposed prosthesis – levels of function unattainable with body-powered prosthetic technologies – and was able to integrate the prosthesis into his daily function with exceptional ease. His lived experience is consistent with reliable, relevant, and independent evidence explored earlier within this letter.

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In consideration of appeal of this decision, [redacted], his family, and I have revisited the goals identified within his plan, and the potential impact that different types of prosthesis would have upon his life. [redacted] and his family identified that cosmetic and body powered devices have been fitted in the past, though their use was discontinued due to poor functional outcomes. This was identified within the initial request for prosthetic trial, and has been reinforced within [redacted] letter requesting review of this decision.

It is my view, in reviewing all relevant legislation, policies and guidelines, that the recommended prosthetic device remains reasonable and necessary, clinically appropriate, and the most suitable to attainment of [redacted] identified goals and aspirations. In examining the *National Disability Insurance Scheme Act 2013*, we find the following:

3 Objects of Act

(1) The objects of this Act are to:

(g) promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the mainstream community;

4 General principles guiding actions under this Act

(1) People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development.

(2) People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability.

(3) People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime.

(4) People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports.

(5) People with disability should be supported to receive reasonable and necessary supports, including early intervention supports.

(11) Reasonable and necessary supports for people with disability should:

(a) support people with disability to pursue their goals and maximise their independence; and

(b) support people with disability to live independently and to be included in the community as fully participating citizens; and

(c) develop and support the capacity of people with disability to undertake activities that enable them to participate in the mainstream community and in employment.

(15) Innovation, quality, continuous improvement, contemporary best practice and effectiveness in the provision of supports to people with disability are to be promoted.

(16) Positive personal and social development of people with disability, including children and young people, is to be promoted.

17A Principles relating to the participation of people with disability

(3) The National Disability Insurance Scheme is to:

(c) support people with disability to participate in, and contribute to, social and economic life, to the extent of their ability.

31 Principles relating to plans

The preparation, review and replacement of a participant's plan, and the management of the funding for supports under a participant's plan, should so far as reasonably practicable:

(d) where possible, strengthen and build capacity of families and carers to support participants who are children; and

(da) if the participant and the participant's carers agree—strengthen and build the capacity of families and carers to support the participant in adult life; and

(h) advance the inclusion and participation in the community of the participant with the aim of achieving his or her individual aspirations; and

(j) facilitate tailored and flexible responses to the individual goals and needs of the participant

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34 Reasonable and necessary supports

For the purposes of specifying, in a statement of participant supports, the general supports that will be provided, and the reasonable and necessary supports that will be funded, the CEO must be satisfied of all of the following in relation to the funding or provision of each such support:

(a) the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations;

(b) the support will assist the participant to undertake activities, so as to facilitate the participant's social and economic participation

118 Functions of the Agency

(1) The Agency has the following functions:

(a) to deliver the National Disability Insurance Scheme so as to:

(i) support the independence, and social and economic participation, of people with disability; and

(ii) enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports; and

(iii) ensure that the decisions and preferences of people with disability are respected and given appropriate priority; and

(iv) promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and inclusion in the mainstream community;

In examining the highlighted portions from the *NDIS Act 2013*, we find that the legislation governing the NDIA's policies and actions promote:

- Provision of high quality and innovative supports;
- Provision of supports that maximise independence;
- Provision of supports that support inclusion of those with a disability into the mainstream community;
- Provision of supports that enable participants to pursue of their goals;
- Provision of supports that allow a participant to function to the extent of their abilities;
- Strengthening and building capacity of families and carers of participants who are children, and to support these networks into adult life;
- Provision of individualised supports responsive to a participant's circumstances; and
- Provision of supports that meet contemporary best practice.

A large section of the legislation discusses the concepts of what is considered 'reasonable', 'value for money', and the need to ensure the financial sustainability of the NDIS. The definition of what constitutes 'value for money' is found within the *NDIA Operational Guideline 10 – Planning*:

10.5 Does the Support Represent Value for Money?

Before any support is added to a participant's plan the NDIA must *also be satisfied that the support represents value for money in that the costs of the support are reasonable as compared to the benefits achieved and the cost of alternative support (section 34(1)(c)).*

When deciding whether a support represents value for money, the NDIA must consider the following matters:

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- *whether there are comparable supports which would achieve the same outcome at a substantially lower cost (rule 3.1(a) of the Supports for Participants Rules);*
- *whether there is evidence that the support will substantially improve the life stage outcomes for, and be of long-term benefit to, the participant (rule 3.1(b) of the Supports for Participants Rules);*
- *whether funding or provision of the support is likely to reduce the cost of the funding of supports for the participant in the long term. For example, some early intervention supports may be value for money given their potential to avoid or delay reliance on more costly supports (rule 3.1(c) of the Supports for Participants Rules);*
- *for supports that involve the provision of equipment or modifications:*
    - *the comparative cost of purchasing or leasing the equipment or modifications (rule 3.1(d)(i) of the Supports for Participants Rules); and*
    - *whether there are any expected changes in technology or the participant's circumstances in the short term that would make it inappropriate to fund the equipment or modifications (rule 3.1(d)(ii) of the Supports for Participants Rules);*
- *whether the cost of the support is comparable to the cost of supports of the same kind that are provided in the area in which the participant resides (rule 3.1(e) of the Supports for Participants Rules); and*
- *whether the support will increase the participant's independence and reduce the participant's need for other kinds of supports. For example, some home modifications may reduce a participant's need for home care (rule 3.1(f) of the Supports for Participants Rules).*

The NDIA will consider value for money both in the context of the relative expense of different supports available to achieve the same goal, and in the context of whether investments in supports will represent value for money over time.

So, in examining this policy and the *NDIS Act 2013* Section 34 (1) (c), we find the following:

- The recommended prescription is reasonable as it is offers the level of function required for [redacted] to attain the goals and aspirations identified within his plan;
- The recommended prescription provides value for money as it is the lowest cost device available that provides the level of function required for [redacted] to attain his goals;
- Strong, demonstrated evidence exists that the recommended support will substantially improve the daily functional and social outcomes of the participant; and
- The support will increase the participant's independence and reduce his need for other kinds of supports.

Regarding the concept of long-term financial viability of the scheme, it must be recognised that the provision of the proposed prosthesis would dramatically improve [redacted] independence and reduce the need for external supports (including family members). According to the scientific literature explored earlier in this letter, it would also increase his occupational prospects. The NDIS has already borne the costs of fabrication and fitting of a training arm for the purposes of [redacted] trial. Following the trial, the device selected by [redacted] and the supervising clinicians to be the most appropriate for his needs was the lesser of the two trialled devices in terms of final cost. The NDIA was aware of the potential definitive device costs prior to approving the trial, yet it did so on the basis that the proposal was reasonable and necessary. The costs associated with the provision of the proposed definitive prosthesis are considerably less than those of other prosthetic devices funded previously through the NDIS.

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[redacted] has used body-powered and cosmetic prostheses in the past and rejected these due to poor functional outcomes. Despite this, the most recent decision reached by NDIA has effectively forced [redacted] to decide between returning to use of this outdated technology (previously demonstrated to be functionally inferior and inappropriate to meet basic daily functions), or continuing life without a prosthesis. If the NDIA's decision were to remain it would have a devastating impact upon this vulnerable young man. He has demonstrated exceptional functional capacity with this device, and has clear employment goals that would benefit immensely from this prosthesis. Continued application of this poorly worded policy would do more damage to the long-term viability of this scheme than the funding of trials and support of clinically appropriate technologies, such as was performed initially in this case. Participants would be unfairly limited in their functional capacities, thereby harming their social inclusion and employment prospects, and placing increased burden upon the Scheme and wider community for otherwise unrequired supports.

It remains my opinion that the proposed device is reasonable, necessary, and the most clinically appropriate option to meet [redacted] identified goals. Community-based trial of the proposed device proved exceptionally successful. It appears the decision not to support the definitive device rested upon the application of a poorly worded section of policy that does not meet other aspects of the NDIA's policies, the governing legislation, nor what is considered best practice.

Here presents an opportunity to provide this young man with the tools he requires to transition successfully to an independent adult life. [redacted] is a bright, talented individual who has demonstrated to multiple clinical observers that the functional benefits possible with the proposed prosthesis would dramatically improve his quality of life. This device would also provide substantially improved outcomes for those around him through reduced reliance on family and community supports, as well as improved functional capacity for his ongoing community work and long-term employment prospects. This enablement of social inclusion and personal development is, according to the NDIA's own documentation, exactly what the Scheme was set up to facilitate.

Sincerely,

Richard Goward

Prosthetist, Orthotist
Director – Momentum Sports & Rehabilitation Services

References:

Gaine,W., Smart, C., & Bransby-Zachary, M. (1997) *Upper Limb Traumatic Amputees: Review of Prosthetic* Use. Journal of Hand Surgery (British & European Volume), 22B: 1: 73-76.

Jones, L. & Davidson, J., (1999) *Save that Arm: A Study of Problems in the Remaining Arm of Unilateral Upper Limb* Amputees. Prosthetics and Orthotics International, 23: 55-58.

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23/12/2016

To: The Delegate, National Disability Insurance Agency

Re: [redacted]

I write in support of [redacted] appeal for reconsideration of the report and quote provided for prosthetic services (dated 30/07/2016) requesting replacement of her current transfemoral prosthesis. This quote and report was submitted with an AMPPRO functional assessment report which indicates [redacted] current prosthetic functional level. The report examined [redacted] function through objective assessment, identified goals and daily functional needs, as well as her social circumstances.

At this point, I wish to highlight the primary goal identified by [redacted] in her NDIS plan:

> **My First Goal is:** To continue with cycling including mountain bike riding and road cycling and to do bushwalking and hiking.
>
> During this plan I want: To participate in Occupational therapy assessment to investigate solution/ assistive technologies for resting my stump whilst riding, to prevent saddle soreness.
>
> During this plan I want: To liaise with my prosthetist for a prosthetic which enables me to do bushwalking and to walk, up hills, down hills and on uneven terrain.

Following [redacted] assessment it was established that, despite manufacturer ratings compatible with an amputee of [redacted] activity level, her existing prosthetic components do not meet her functional goals nor task-specific functions associated with her recreational goals. As such, recommendation was made for replacement of her existing prosthesis, including all componentry, to improve her safety and function in all aspects of her life.

Written feedback was received from the NDIA, dated 23/11/2016, supporting replacement of [redacted] prosthetic socket, although the replacement of any prosthetic componentry was declined.

Two justifications were provided by the NDIA for the decision regarding [redacted] treatment request. The following is an excerpt taken from the email dated Wednesday, November 23rd 2016, authored by [redacted], on behalf of the NDIA, advising of the outcome of the assessment:

- *"The NDIA will generally fund entry level or standard grade prostheses for participants up to K2 classification and will consider higher prosthesis for people up to K3 and K4 classification.*
- *The NDIS will generally not fund for K4 level, C-legs and computerised components unless reasonable and necessary to do so having regard to the functional benefits expected to be achieved where such benefits can be achieved in other ways.*

  Taking this into consideration the recommended prosthetic limb is not considered standard grade or entry level. The recommended prosthetic limb does not meet reasonable and necessary

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criteria (as per section 34 of the NDIS Act) as it is not considered value for money to provide mobility needs for an ordinary life."

In responding to the feedback provided by [redacted], I would first like to raise issue with the choice of the phrase *"entry level or standard grade prostheses"*. This is a term that does not exist anywhere in scientific literature, general expression within the Prosthetic profession, nor in any documentation publicly available through the NDIA outside of the *Prosthetic Limbs Operational Guideline*. As a provider, I am unsure of what this means, or how to approach future prescriptions that would satisfy this requirement. In spite of this confusing statement, I still believe that the prosthetic recommendation made for [redacted] satisfies the legislation, operational guidelines and other documentation provided by the NDIA.

What has upset both [redacted] and I is the idea that an amputee should not be able to attain their functional potential despite the availability of technology that would enable this. I believe, as would a significant majority of our society, that the ability to safely walk up hills, down hills, and on uneven terrain to be part of the "mobility needs of an ordinary life". I will assume [redacted] was not intending to suggest that these functions are not considered part of an amputee's mobility needs for an ordinary life as this would contravene the *National Disability Act 1992* Section 6 (1) (c).

[redacted] identified goal of safe participation in bushwalking and hiking activities is not an unrealistic aspiration – it is very much achievable with the use of appropriate assistive technology, such as what has been recommended within the report & quote submitted following [redacted] assessment. The fact that [redacted] is decided to include this as the primary goal within her NDIS plan despite already participating in these activities should serve as an indicator that her existing prosthetic componentry is insufficient for her mobility goals. As was outlined within the report submitted to the NDIA, [redacted] is not an "ordinary" amputee, and does not live an "ordinary" life. [redacted] lives alone, and has no family members living locally. Her recreational pursuits are not just an outlet after work, but form a crucial foundation for her social interactions with friends. She participates in a wide variety of sporting activities and is an exceptional athlete. Her ability to perform at a level competitive with "able-bodied" athletes cannot be overlooked when assessing her daily functional requirements.

While [redacted] has previously, and continues currently, to perform her hiking activities on her existing prosthesis, she has reported that nearly all hiking is performed in social isolation due to embarrassment and slow progress with her current prosthesis. [redacted] current componentry is unsafe for the purposes of the hiking activities that she performs, and risks serious injury. This is particularly alarming to me as a provider when considering that the vast majority of these activities are performed alone. The dangers associated with use of a mechanical knee joint during off-road walking was identified within the initial assessment report, and has again been demonstrated in the time since submission of this report with a recent hiking trip. In late November of this year [redacted] travelled to Nepal to complete a demanding nine-day hike to Mt Everest Base Camp. While [redacted] did reach her destination using her existing prosthesis, the lack of appropriate support provided by prosthetic components severely hampered progress and led to multiple falls in dangerous and compromising positions. The terrain on this trek was uneven and rocky which led to inconsistent and unstable behaviour from the prosthesis with every step. It was only through direct assistance from both her guide and porter that she was able to reach the final destination.

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Even with a well-tuned mechanical hydraulic knee unit, a lack of intelligent control compromises the consistency of function (and therefore the safety) of the component on uneven terrain. Further to this, mechanical prosthetic knee joints do not allow the necessary knee flexion or loading stability for a user to negotiate obstacles greater than a single stair in height. Hiking and off-road trekking, by its very nature, encompasses terrain beyond the scope of basic community barriers. These include slopes steeper than the Australian Standard, rocky outcrops, and stairs with a vertical rise larger than the Australian Standard. While traversing these barriers is considered unsafe or impossible on a mechanical knee unit, that would not be the case for a suitably trained K4-level amputee when using a microprocessor knee unit such as that recommended for [redacted].

Earlier this year, [redacted] was selected by a supplier of prosthetic componentry to provide a live demonstration of a new, K4-suitable, water-resistant microprocessor knee unit. During this demonstration [redacted] was able to perform high level functional activities not possible on her existing prosthesis, including unaided descent of ramps steeper than the Australian Standard, step-over-step ascent of stairs, and safe negotiation of uneven terrain and large obstacles which would be expected during typical hiking activities. This serves to prove [redacted] functional capacity to achieve the goals identified within her plan with appropriately supportive assistive technologies. The knee unit trialled during this demonstration day, the Ossur Rheo XC, was examined within the initial report but deemed inappropriate due to lack of suitability in wet or non-freshwater environments, such as could be expected on long hiking expeditions.

In respect of [redacted] demonstrated capacity to achieve safe, functional performance in the prosthetic goals identified on her NDIS plan, I would like to draw attention to the *National Disability Insurance Scheme Act 2013*. Within this piece of legislation, the following points are raised:

4 General principles guiding actions under this Act

> *(1) People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development.*
>
> *(2) People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability.*
>
> *(3) People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime.*
>
> *(4) People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports.*
>
> *(11) Reasonable and necessary supports for people with disability should:*
>
> > *(a) support people with disability to pursue their goals and maximise their independence; and*
> >
> > *(b) support people with disability to live independently and to be included in the community as fully participating citizens; and*
> >
> > *(c) develop and support the capacity of people with disability to undertake activities that enable them to participate in the mainstream community and in employment.*
>
> *(15) Innovation, quality, continuous improvement, contemporary best practice and effectiveness in the provision of supports to people with disability are to be promoted.*
>
> *(16) Positive personal and social development of people with disability, including children and young people, is to be promoted.*

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17A Principles relating to the participation of people with disability

(3) The National Disability Insurance Scheme is to:

(c) support people with disability to participate in, and contribute to, social and economic life, to the extent of their ability.

31 Principles relating to plans

The preparation, review and replacement of a participant's plan, and the management of the funding for supports under a participant's plan, should so far as reasonably practicable:

(h) advance the inclusion and participation in the community of the participant with the aim of achieving his or her individual aspirations; and

(j) facilitate tailored and flexible responses to the individual goals and needs of the participant

34 Reasonable and necessary supports

For the purposes of specifying, in a statement of participant supports, the general supports that will be provided, and the reasonable and necessary supports that will be funded, the CEO must be satisfied of all of the following in relation to the funding or provision of each such support:

(a) the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations;

(b) the support will assist the participant to undertake activities, so as to facilitate the participant's social and economic participation

Further to this legislation, I would like to draw your attention to the recently updated *Assistive Technology Strategy*, found at: https://www.ndis.gov.au/about-us/information-publications-and-reports/assistive-technology-strategy.html. This is the proposed strategy to guide future NDIA policy guidelines regarding assessment and provision of Assistive Technologies. The strategy begins with the following statement:

> *"The National Disability Insurance Scheme (NDIS) was founded on a simple goal – to provide all Australians who are born with or acquire a permanent and significant disability before the age of 65 with the necessary supports to live a better life and one of inclusion. Advancements in technology will be crucial as the Agency works towards achieving this goal."*

Further to this, Priority Two of the *Assistive Technology Strategy* reads as follows:

> *"Strategy Priority 2: Support and stimulate informed, active, participant-led demand by empowering participants to choose technology that best supports their needs."*

In examining the decision regarding [redacted] prosthetic prescription, I believe the NDIA has failed to adhere to the legislation. In declining the proposed prosthesis, [redacted] plan as it stands today:

- Does not support the pursuit of goals identified within her plan;
- Does not support safe participation within her chosen activities;
- Does not facilitate inclusion and participation in the community with the aim of achieving her individual aspirations;
- Does not allow her to contribute to life of her community as a fully participating citizen;
- Does not allow her to contribute to her community to the extent of her ability;
- Does not support positive social and personal development; and

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- Does not promote quality or contemporary best practice in relation to her prosthetic management.

A large section of the legislation discusses the concepts of what is considered 'reasonable', 'value for money', and the need to ensure the financial sustainability of the NDIS. The definition of what constitutes 'value for money' is found within the *NDIA Operational Guideline 10 – Planning*:

> *10.5 Does the Support Represent Value for Money?*
>
> *Before any support is added to a participant's plan the NDIA* must *also be satisfied that the support represents value for money in that the costs of the support are reasonable as compared to the benefits achieved and the cost of alternative support (section 34(1)(c)).*
>
> *When deciding whether a support represents value for money, the NDIA must consider the following matters:*
>
> - *whether there are comparable supports which would achieve the same outcome at a substantially lower cost (rule 3.1(a) of the Supports for Participants Rules);*
> - *whether there is evidence that the support will substantially improve the life stage outcomes for, and be of long-term benefit to, the participant (rule 3.1(b) of the Supports for Participants Rules);*
> - *whether funding or provision of the support is likely to reduce the cost of the funding of supports for the participant in the long term. For example, some early intervention supports may be value for money given their potential to avoid or delay reliance on more costly supports (rule 3.1(c) of the Supports for Participants Rules);*
> - *for supports that involve the provision of equipment or modifications:*
> - *the comparative cost of purchasing or leasing the equipment or modifications (rule 3.1(d)(i) of the Supports for Participants Rules); and*
> - *whether there are any expected changes in technology or the participant's circumstances in the short term that would make it inappropriate to fund the equipment or modifications (rule 3.1(d)(ii) of the Supports for Participants Rules);*
> - *whether the cost of the support is comparable to the cost of supports of the same kind that are provided in the area in which the participant resides (rule 3.1(e) of the Supports for Participants Rules); and*
> - *whether the support will increase the participant's independence and reduce the participant's need for other kinds of supports. For example, some home modifications may reduce a participant's need for home care (rule 3.1(f) of the Supports for Participants Rules).*
>
> *The NDIA will consider value for money both in the context of the relative expense of different supports available to achieve the same goal, and in the context of whether investments in supports will represent value for money over time.*

So, in examining this policy and the *NDIS Act 2013* Section 34 (1) (c), we find the following:

- The recommended prescription is reasonable as there are no alternative supports that would achieve the functional outcomes described;
- The recommended prescription provides value for money as there are no alternative supports that afford comparable function by which to compare price;
- Evidence exists that the recommended support will substantially improve the daily functional and social outcomes of the participant; and
- The support will increase the participant's independence and reduce her need for other kinds of supports.

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Regarding the concept of long-term financial viability of the scheme, I am aware that all the recommended components within [redacted] request have been funded previously through the NDIS on more than one occasion. Regardless of precedence, the recommended support remains the most clinically appropriate prosthetic option for [redacted] needs. She is an exceptionally functional individual who lives under circumstances that appear extraordinary by comparison to most other transfemoral amputees. She requires supports that lie beyond the needs of a limited community ambulator to attain a life that, within her social circles, is considered an "ordinary" life. This enablement of social inclusion and personal development is, according to the NDIA's own documentation, exactly what the Scheme was set up to facilitate.

I would strongly encourage you to reassess [redacted] application against all aspects of the *National Disability Insurance Scheme Act 2013* and applicable Operational Guidelines. During this reconsideration, I hope that you will ensure that her functional potential is realised, and her modest goals and aspirations are not again disregarded.

Sincerely,

Richard Goward

Prosthetist, Orthotist
Director – Momentum Sports & Rehabilitation Services