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Mary Hawkins,
National Disability Insurance Agency,
GPO Box 700,
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engagement@ndis.gov.au

Dear Ms Hawkins,

We appreciate the opportunity to comment on the Assistive Technology Discussion paper.

Post Polio Victoria advocates for assistive technology to enable full social participation, for polio survivors with physical, orthopaedic, respiratory, fatigue, pain and mobility impairments. Many polio also have to deal with post polio syndrome¹ or deterioration in their physical abilities. Every day the polio affected person, with full or partial paralysis, has to use all her/his strength to get through all the ordinary tasks of life.

Participant capacity building framework

The majority of Post Polio Victoria members are experts in determining their assistive technology needs. Our problem is finding technicians with appropriate skills and experience to produce customised devices. The random distribution of polio weakness or paralysis is unique to each affected individual. Uneven muscular development pulls ligaments and bones out of shape. This means equipment such as orthotics, spinal braces and calipers (long orthoses), have to be individually tailored. Often electronic aids, such as powerchairs, also need modification to maximise their usefulness.

A minority of polio survivors, those people who apparently recovered from initial paralysis, find they develop post polio syndrome 40-60 years later. At this later stage they require skilled assessment and assistive devices to maintain living in their communities.

¹ Post-polio syndrome includes new weakness, fatigue, pain, swallowing difficulties and respiratory decline. Jubelt, B., & Agre, J. (2000). Characteristics and Management of Post-polio syndrome. *Journal of the American Medical Association*

Newcomers or immigrants with polio related impairments, also need skilled health professional advice, with consideration of cultural factors, relevant to enhancing their ability to participate in community life.

Assistive Technology Mentors

Post Polio Victoria believes consumer controlled groups and organisations could be funded to provide valuable advice to their members. Some polio groups have invited suppliers to demonstrate products. Post Polio Victoria is a member of Polio Australia² which runs health and Wellness retreats which include some therapy and technology suppliers.

Unless funded to employ health professionals, Post Polio Victoria remains unable to provide health professional level assessment and assistive technology prescriptions.

Expert advisers

Many Post Polio Victoria members find that effective performance, across their life stages and social roles, requires a combination of environmental modifications, assistive devices and personal care. A similar finding was made by Layton³, who researched 100 Victorians with disabilities. While people with long term physical impairments are expert in self management, we need timely access to skilled assessment and new technology to minimise new loss of function and increased disabilities.

Issue of people who are ageing as well as living with after effects of polio

Post Polio Victoria is very concerned that those of us aged more than 64 years, living with polio, are at risk of losing access to prescribed assistive technology. This type of support is essential to maintaining our full participation in community life.

At present limited orthoses and mobility aids are prescribed by the occupational therapist, physiotherapist and orthotist from Polio Services Victoria, or can be purchased privately, at high cost, from external suppliers. We usually co-purchase high cost equipment such as power-chairs, lifting hoists, home modifications through the Victorian Government's State Wide Equipment Program. Co-purchase means the individual may have to pay up to 40% of the item cost.

At this stage of policy development the Commonwealth Home Support Program for older citizens, seems to have extremely limited funding of \$500 p.a. per client⁴. This amount is totally inadequate for people with essential and extensive equipment needs.

² www.polioaustralia.org.au

³ Layton, N. (2012) barriers and Facilitators to Community Mobility for Assistive Technology Users. *Rehabilitation Research & Practice*. <http://dx.doi.org/10.1155/2012/454195>

⁴ Commonwealth Home Support Program P.32

Acquisition and procurement approach

Post Polio Victoria is concerned that this approach may not encompass our members' needs for customised aids and equipment.

Repairs and refurbishment

Orthotics and equipment need to be repaired and replaced. Customised equipment may well be unsuitable for re-use.

Further innovation

Post Polio Victoria recommends:-

- disability support groups and organisations be funded to disseminate non-specific brand advice about the uses of assistive technology.
- NDIA consider investment in local production of assistive devices
- If NDIS does continue to exclude people over the age of 64, then NDIA and the Commonwealth Home Support Program, should establish a well funded assistive technology program responsive to the needs of people who continue to live with long term physical impairments, while they are ageing.

In conclusion, Post Polio Victoria, believes that the acquisition and procurement approach, which includes having a third party entity manage the pricing sourcing and procurement, will not be suitable for post polio survivors. Tailored solutions require accredited therapist prescriptions and committed knowledgeable suppliers to ensue sustainable outcomes.

We are happy to discuss this complex policy area further.

Yours sincerely

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