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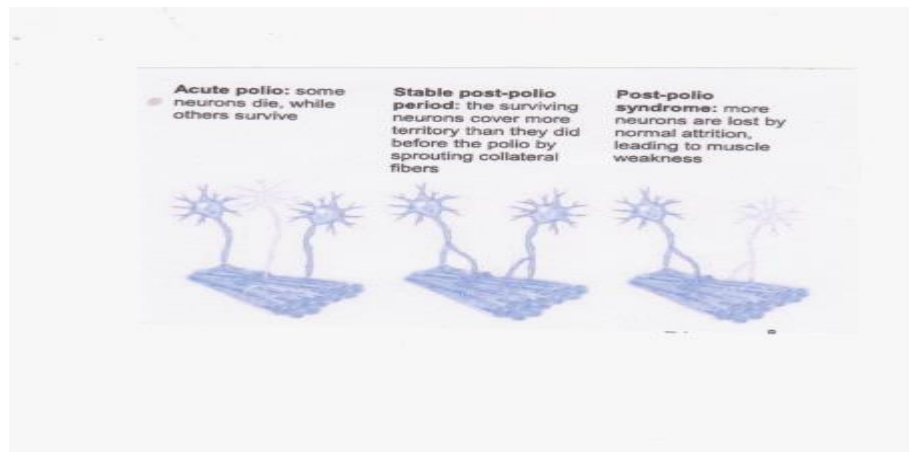
The Executive Officer,  
Family and Community Development Committee,  
Parliament House,  
Spring Street ,  
East Melbourne 3002

Dear Dr. Bush,

Re the Inquiry into Social Inclusion for People with a Disability.

Thank you for the opportunity to comment on social inclusion for people with disabilities. Post Polio Victoria advocates for adequate services, to enable full social participation, for survivors with physical, orthopaedic, respiratory, fatigue, pain and mobility impairments.<sup>1</sup> Post Polio Victoria is concerned both for members who are getting older, while living with post polio syndrome<sup>2</sup>, and a younger immigrant group who have had little or no treatment in their home countries where polio has not been eradicated.

The polio viruses destroy, forever, many spinal nerve cell connections with their muscle cells. The destruction is erratic so that paralysis is uneven and bones may become twisted leading to uneven joint wear. The diagram below demonstrates apparent partial recovery when an unaffected nerve cell connects to more than one muscle cell. Post polio syndrome occurs when the over used nerve cell fails 40-60 years after polio occurs



<sup>1</sup> Polio is a highly contagious gastroenteric virus which causes irreversible paralysis in 1 in 200 patients. [www.who.int](http://www.who.int)

<sup>2</sup> 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*. 284 (4), 412-414

Very many of our older members have thought about the conundrum of social inclusion, over decades of overt and covert discrimination, as we worked to achieve the same goals as non-disabled peers, education, family building and employment. Our members continue to strive hard to maintain work, fulfilling relationships with families and friends, but continue to experience exclusion via attitudinal and physical barriers.

## **Post Polio Victoria's response to the Terms of Reference**

### 2. a. The definition of social inclusion.

Post-Polio Victoria believes social inclusion means that a person with disability feels wanted and valued within our various communities and within Victorian society. We use the term *disability* as defined by the United Nations Convention on the Rights of Persons with Disabilities, *disability* results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society.<sup>3</sup>

We see participation as the end result of inclusion. Many people living with physical, mobility and respiratory impairments need enabling services to assist their participation.

### 2. b. Identify the nature and scale of relative inclusion (exclusion).

There have been many improvements towards social inclusion of Victorians with polio derived disabilities. Post Polio Victoria acknowledges that many of the inclusionary strategies developed by the Victorian government, see 2 c, have been initiated by disability activists and advocacy organisations. Advocacy by people with disabilities remains essential to defining social exclusion and planning inclusionary strategies.

Exclusion of people living with physical impairments, can be seen in the barriers to full participation<sup>4</sup>. Difficulties continue in employment, the provision of assistive technology, public transport infrastructure, eligibility criteria for the National Disability Insurance Scheme and restrictions on the development of Polio Services Victoria.

#### A. Attitudinal barriers

Prejudicial attitudes and the maintenance of social barriers, such as inaccessible buildings, come, in part, from all people with disabilities mistakenly being seen as a burden on the welfare system (Newell & Goggin, 2005)<sup>5</sup> or too costly for inclusionary programs such as access to public transport or buildings. Unless aid, allocated by any level of government, is managed by people with relevant experience in disability, the results are not perceived by the community as positively resulting in the individual being able to participate in the world around them

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<sup>3</sup> United Nations. (2008). Convention on the Rights of Persons with Disabilities. Preamble. clause e.

<sup>4</sup> Cooper, M. & Bigby, C. (2013). Cycles of Adaptive Strategies Over the Life Course. *Journal of Gerontological Social Work* DOI:101080/01634372.2013.875972

<sup>5</sup> Newell, C. & Goggin, G. (2005). *Disability in Australia: Exposing Social Apartheid*. Sydney NSW: University of New South Wales Press.

## B. Employment and Income support

It is difficult for people with physical disabilities to find employment. Employment enables people living with polio to support themselves and their families, and to be integrated into the workforce. The labour force participation for people with disabilities aged 15-64 was 54%, compared with non-disabled of which 83% had jobs.<sup>6</sup> Women are particularly disadvantaged<sup>7</sup>

## C. Assistive technology

Mobility aids and other assistive technology are essential to people, with some level of muscle weakness, so they can be as independent as possible and to carry out their social responsibilities. At present, individuals have to contribute, substantially, to the co-purchase of aids, like wheelchairs, under the State Wide Equipment Program. Those contributions are difficult to make when the person lives on a fixed or minimum income. Waiting times for assistive aids, such as powerchairs, and repairs remain a major problem<sup>8</sup> Post Polio Victoria supports the submission made to this Inquiry by the Aids and Equipment Action Alliance<sup>9</sup>

## D. Rail transport infrastructure

A major issue for Post Polio Victoria is the frustration caused by lack of easy physical access to train stations and fire safe exits. Many of our members use walking aids, manual wheelchairs, power chairs and mobility scooters, They cannot negotiate stairs, steep ramps and escalators. At present there are no fire safe evacuation lifts in the Loop. There doesn't appear to be any plans for such lifts in future underground developments. Post Polio Victoria has not been able to get a positive response from the Ministry of Transport about our concerns.

Fire safe evacuation lifts have been installed in many countries<sup>10</sup>. They are situated within a protected enclosure have an alternate power supply and are able to resist fire for two or more hours.

## E. Eligibility criteria for the National Disability Insurance Scheme

Post Polio Victoria is concerned that the current eligibility criteria excludes polio survivors over the age of 65, although they presently live with some degree of paralysis and are now experiencing additional limitations caused by post polio syndrome.

An unknown number of polio survivors, who believed they had fully recovered, are now finding renewed weakness developing during their fifties and sixties. Their concerns were discussed in a Parliamentary Standing Committee on Health and Ageing paper in

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<sup>6</sup> ABS 4430.0 (2013). Disability Ageing & carers. Summary of findings. 2012

<sup>7</sup> Committee on the Rights of Persons with Disabilities (2013). Concluding observations on the initial report of Australia. Cited in Frohmader, C. (2014). Women With Disabilities Australia Submission to the National Inquiry into Equal Recognition before the Law and Legal Capacity for People with Disability.

<sup>8</sup> Layton, N. (2012). Barriers and Facilitators to Community Mobility for Assistive Technology Users. *Rehabilitation Research & Practice*. Vol. 2012 Article 454195

<sup>9</sup> Willcock, P. (2014). Submission to the Inquiry on Social Inclusion. Aids & Equipment Action Alliance

<sup>10</sup> Sammut, M. & Barber, D. (2009). How can we provide evacuation for all building occupants? Fire Safety Engineering International Conference. Melbourne

2012.<sup>11</sup> This means people who have lived, without using disability services for much of their lives, now require access to specialised disability support at a time when National Disability Insurance Scheme programs may exclude them.

## F. Polio Services Victoria

Polio Services Victoria is funded by the Department of Human Services Ambulatory Care program to replace the services formerly available through Fairfield Infectious Diseases Hospital. It is housed at St Vincent's Hospital. The funding is insufficient to enable the small, dedicated and expert staff to assess and prescribe management strategies such as orthotics, physiotherapy, consultative or educative services, aids and equipment in a timely manner. Neither is Polio Services Victoria funded to provide ongoing programs to maintain the benefits gained. Instead the polio survivor has to rely on local services with which have limited understanding of the unique skills required to manage with polio affected patients.

### 2.c. The impact of Victorian government services.

The Victorian government has introduced helpful measures toward social inclusion of people with polio related physical, mobility and respiratory impairments. They include:-

- Successive legislation and regulations have built up the effectiveness of Victoria's Equal Opportunity Acts and Human Rights commissions.
- The Multi-Purpose Taxi Program to assist mobility impaired people who are unable to access public transport.
- Development of community based housing
- Home and Community Care program
- Individual Support Packages which enable people with severe physical impairments to live at home.
- The establishment of Polio Services Victoria in 1998.
- Local government disability and equity access committees of concerned citizens and local government representatives

### 3.1 What needs to happen to ensure that people's individual disability and experience are accounted for in efforts to increase their social inclusion?

Post Polio Victoria makes the following recommendations:-

A. Attitudinal barriers can best be addressed by better accounting to the public of money and effort spent on people with disabilities. Advocacy organisations should also be funded to assist in developing systemic and individual inclusion strategies.

B. Employment and income support.

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<sup>11</sup> 2012. House of Representatives Standing Committee on Health and Ageing. Discussion paper on the late effects of polio/post polio syndrome.

It is imperative that Victorian and Australian government representatives, in association with the Council of Australian Governments, respond to the parlous state of employment of people with impairments. The Disability Services Act 2006 Objective 4.b and subsequent Principles refers to a whole of government strategy to empower people with disabilities to exercise their rights and responsibilities. The Commonwealth Disability Strategy embodies similar aims.

C. Assistive technology supply and repair be streamlined according to the research done by Aids and Equipment Action Alliance.<sup>12</sup>

D. The ministries involved in rail station and loop developments pay urgent attention to the need for installation of lifts at all train stations that are not situated at level crossings. We also request that all underground stations, present and planned, have at least one fire safe lift.

E. National Disability Insurance Scheme programs should be inclusive of people with post polio with issues such as mobility, physical and respiratory disabilities, regardless of age.

F. Polio Services Victoria be funded to enable the expert staff to provide assessments quickly, orthotics in reasonable time, ongoing physiotherapy, and consultative and educative services to other professionals with polio affected patients

In summary, people living with polio related impairments have strived energetically for social inclusion over decades. Their participation continues to be hindered by inadequate employment, expensive assistive technology, unsafe railway infrastructure, unrealised potential of the Polio Services Victoria model and age related exclusion from the National Disability Insurance Scheme.

Inclusion and participation will be further enabled by government and non-government programs centred around the above recommendations. It will be achieved when the person with a disability has useful aids and equipment, access to disability support care, and they can confidently attend their workplace, a recreation venue, use public transport, and attend a cafe or restaurant knowing that facilities will be fully accessible.

We are happy to discuss this submission further

Margaret Cooper. OAM, Ph.D

On behalf of Jill Pickering, President, Post Polio Victoria



and Maree Jongkryg Vice-President, Post Polio Victoria



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<sup>12</sup> Layton, N. (2012). Executive Summary of the Wait Times Project. Aids & Equipment Action Alliance