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### Submission to the Victoria State Disability Plan 2017-20

Post Polio Victoria is an organisation of volunteers with lived experience of polio. It was formed in 2011 and researches and advises on maintenance and development of adequate services, to enable full social participation of survivors with physical, orthopaedic, respiratory, fatigue, pain and mobility impairments. Our actions centre around:

- requesting the opinions of polio survivors about what assistance they believe is important to maintain their family, friendships, support networks, employment and community involvement;
- representing those opinions and raising awareness about polio survivors to various levels of government, health systems and service providers
- providing information to people with polio concerning provision of health services, government support systems and self management strategies

### Post Polio's Victoria's response to the terms of reference

#### ***Theme 1. Active citizenship***

*Q 1. As an organisation of people with expertise in disability<sup>1</sup> what would make the most difference to you in this area?*

Post Polio Victoria members want to continue participating fully within our various communities and within Victorian society.

However many polio survivors living with physical and respiratory impairments require enabling services to assist participation. We need:

- a. redevelopment of Polio Services Victoria and perhaps Calvary Bethlehem Neurology Unit;

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<sup>1</sup> 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.' United Nations. (2008). Convention on the Rights of Persons with Disabilities. Preamble. clause e.

- b. statewide respiratory health programs;
- c. improved provision of assistive technology;
- d. better access to the built environment particularly housing;
- e. increased information dissemination by advisory organisations controlled by people with disabilities such as Post Polio Victoria. Advocacy by people with disabilities remains essential to defining social exclusion and planning inclusionary strategies.
- f. better access to public and private transport and associated infrastructure

*Q 2. How should we measure progress?*

Progress can only be measured by outcomes consistent with the Convention on the Rights of Disabled Persons and the National Disability Strategy. Outcome design would best be undertaken by partnership between relevant Victorian government departments, information dissemination organisations controlled by people with impairments and key community leaders.

*Q 3. What could government do to make a real difference in this area?*

Re Theme Q 1 a. Polio Services Victoria, Calvary Bethlehem and other appropriate neurology experienced units must be assisted to set up statewide assessment and care protocols aimed at keeping polio survivors active within their communities. The service model developed could include people with other neurological conditions. It should include self management principles.<sup>2</sup>

Re Theme Q 1 b. Partnerships with private and public hospital care systems must be developed in regards to respiratory health for polio survivors. St Vincent's and Austin hospitals are commended for their work in this area however it has not been introduced into other Victorian hospitals.

People living with the after effects of polio often have respiratory conditions which are not recognised by them, or by health professionals. This leads to difficulty in maintaining daily activities and responsibilities, as well as causing significant problems during anaesthesia and rehabilitation.

Development and implementation of a protocol is necessary to alert hospital staff to polio risk factors, as well as including recommendations to mitigate unwanted complications of respiratory decline, collapse and death. Polio survivors need regular assessment and particular care during anaesthesia and recovery periods<sup>3</sup>.

Re Q 1 c.

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<sup>2</sup> Bodenheimer, T, Long, K, Holman, H (2002). Patient self-management of Chronic Disease in Primary Care. *JAMA*. 288(19) 2469-2475 <http://jama.ama-assn.org/cgi/content/full/288/19/2469>

<sup>3</sup> Tobin, A. <http://www.anzca.edu.au/communications/anzca-bulletin/bulletin-release-2014/ANZCA%20Bulletin%20September%202015%20FINAL.pdf> p.42-3

Post Polio recommends that the State Wide Equipment Program and the National Disability Insurance Agency Assistive Technology Strategy work closely to ensure effective, affordable and timely provision of aids and equipment. These are essential to people, with some level of paralysis, so they can be as independent as possible and enabled 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>4</sup>

We recommend that customisation of aids and equipment be investigated. Post Polio Victoria has found that few providers have maintained skilled technicians who can alter equipment to suit individual capacities.

*Q 4. What could the community and business sector do to make a real difference in this area?*

Re Q 1 d & e.

Post Polio Victoria acknowledges that Rotary has made an enormous contribution towards eradication of polio.

However while polio survivors from the Victorian epidemics are ageing, with needs for skilled assessment, skills maintenance and community based assistance, younger people need age and culturally appropriate treatment and mobility aids. Both cohorts need employment and access to the built environment especially housing.

Post Polio Victoria suggests Rotary and other service organisations could sponsor

- an adequate Polio Services Victoria model and
- an information dissemination and advisory organisation controlled by people with lived experience of polio.
- Community education. Social barriers such as inaccessible buildings or lack of acceptance by employers can be changed by polio survivors being perceived as productive economically and socially.

Re Q 1 f.

Post Polio Victoria commends the Victorian government for the construction of wheelchair to train access ramps at some train stations and wheelchair access to tram stops.

We recommend:

- all new train stations eg sky rail and Southlands have lifts installed to give mobility aid using customers equal access. Our members use walking aids, manual wheelchairs, power chairs and mobility scooters, They cannot negotiate stairs, steep ramps and escalators.

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<sup>4</sup> Layton, N. (2012). Barriers and Facilitators to Community Mobility for Assistive Technology Users. *Rehabilitation Research & Practice*. Vol. 2012 Article 454195

- Fire safe evacuation lifts in all underground and sky rail stations. 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>5</sup>. They are situated within a protected enclosure have an alternate power supply and are able to resist fire for two or more hours.
- Redevelopment of the wheelchair access taxi fleet to replace those owners who have surrendered their licences

## **Theme 2. Rights and Equality**

*Q 1. As an organisation of people with expertise in disability what would make the most difference to you in this area?*

Post Polio Victoria requests that polio survivors of any age, culture, place of residence in this state should have access to skilled, safe and affordable health services, assistive technology, public transport, housing and employment.

*Q 2. How should we measure progress?*

Progress can only be measured by outcomes consistent with the Convention on the Rights of Disabled Persons and the National Disability Strategy. Outcome design would best be undertaken by partnership between relevant Victorian government departments, information dissemination organisations controlled by people with impairments and key community leaders.

*Q 3. What could government do to make a real difference in this area*

Post Polio Victoria supports:

- Full rollout of the National Disability Insurance Scheme;
- the Victorian government's initiative in developing Continuity of Support programs for older people who have lived with impairments for decades but who, because of their chronological age, are excluded from the NDIS;
- enactment of the recommendations of the Inquiry into Abuse in Disability Services<sup>6</sup>;
- enactment of the recommendations of the Ombudsman's reports into abuse of persons with disabilities Phase 1<sup>7</sup> and Phase 2<sup>8</sup>
- enactment of the recommendations of the Royal Commission into Family Violence 2016<sup>9</sup>

<sup>5</sup> Sammut, M. & Barber, D. (2009). How can we provide evacuation for all building occupants? Fire Safety Engineering International Conference. Melbourne

<sup>6</sup> Family & Community Development Committee. (August 2015). Inquiry into Abuse in Disability Services. Melbourne: Parliament of Victoria

<sup>7</sup> Glass, D. (2015). Reporting and investigation of allegations of abuse in the disability sector: Phase 1 – the effectiveness of statutory oversight.

[https://ombudsman.vic.gov.au/VO/media/VO/Parliamentary%20Reports/HTML/web\\_VO-Report\\_Disability-P1.html](https://ombudsman.vic.gov.au/VO/media/VO/Parliamentary%20Reports/HTML/web_VO-Report_Disability-P1.html)

<sup>8</sup> <https://www.ombudsman.vic.gov.au/getattachment/45e28c63-24b0-4efd-b313-85f4f6e44d3f>

*Q 4. What could the community and business sector do to make a real difference in this area?*

It is time both the community and business sectors initiated easy access for all to the built environment. Post Polio Victoria supports the Australian Network for Universal Housing Design call for change to the National Construction Code to make at least minimal access to entry points, corridors and one bathroom.<sup>10</sup> This would also assist in the development of housing standards to underpin the 2010-2020 National Disability Strategy.<sup>11</sup> Our members are often unable to visit friends and family members who live in recently built high rise apartment and multi-staired townhouse complexes.

### ***Theme 3. Economic Participation***

*Q 1. What do you think could be done to promote economic participation?*

Post Polio Victoria recommends that polio survivors are enabled to continue to contribute paid and unpaid work to the state economy.

Younger generations of polio survivors, like others with physical disabilities, have difficulty in finding 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 in 2012 aged 15-64 was 52.8%, compared with non-disabled of which 82.5% had jobs.<sup>12</sup> Women are particularly disadvantaged<sup>13</sup>

Many Post Polio Victoria members perform unpaid or voluntary work and care for very young and very old family members. Their efforts are part of the enormous contribution made by volunteers to the state and national economies.<sup>14</sup>

However those aged 65 and over, may not have financial situations equal to their non-disabled peers. Older polio survivors worked and brought up families during decades where there was little government assistance for people with disabilities. Retirement savings were put into provident funds because many people with disabilities were excluded from superannuation until 1991-2.<sup>15</sup>

Enabling strategies include a sliding scale of fees and retention of Victorian and Federal taxation concessions for necessary support services which include personal care, home care, equipment purchase, public and taxi transport and health care.

*Q 3 b. How should we measure progress?*

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<sup>9</sup> <http://www.rcfv.com.au/MediaLibraries/RCFamilyViolence/Reports/Final/RCFV-Summary.pdf>

<sup>10</sup> <http://www.pc.gov.au/inquiries/completed/building/submissions/sub002/sub002.pdf>

<sup>11</sup> Council of Australian Governments (2011). *2010-2020 National Disability Strategy: An Initiative of the Council of Australian Governments*. Commonwealth of Australia: Canberra  
<https://aduhdblog.files.wordpress.com/2016/05/accessibility-in-housing-abcb-proposal-with-insets.pdf>

<sup>12</sup> Australian Human Rights Commission.(2015) Willing to Work.

<https://www.humanrights.gov.au/sites/default/files/document/publication/discussion-paper-disability.pdf>

<sup>13</sup> 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>14</sup> Exploring the economic and social value of present patterns of volunteering in Australia. Social Policy Research Paper no. 28. [https://www.dss.gov.au/sites/default/files/documents/05\\_2012/sprp28.pdf](https://www.dss.gov.au/sites/default/files/documents/05_2012/sprp28.pdf)

<sup>15</sup> [http://www.aph.gov.au/binaries/library/pubs/bn/eco/chron\\_superannuation.pdf](http://www.aph.gov.au/binaries/library/pubs/bn/eco/chron_superannuation.pdf)

Progress can only be measured by outcomes consistent with the Convention on the Rights of Disabled Persons and the National Disability Strategy. Outcome design would best be undertaken by partnership between relevant Victorian government departments, information dissemination organisations controlled by people with impairments and key community leaders.

*Q 3 c. What could government do to make a real difference in this area*

Post Polio Victoria recommends affirmative action by government and the business sector to enable survivors to continue paid and unpaid work.

*Q 3 d. What could the community and business sector do to make a real difference in this area?*

The business and community sector can enable polio survivors, of working age, effective training and job placement.

#### ***Theme 4. Making the most of the NDIS***

*Q 1. What do you think are the most important ways in which the government can assist Victorians to get the most out of the NDIS?*

The NDIS is aimed at enabling people with disabilities to survive and achieve their potential within their communities. Post Polio Victoria recommends that:

- Continuity of Support programs be extended beyond 2019 to allow polio survivors, like their non-impaired chronological peers, to fulfill their roles as paid or unpaid workers and as elders in their family and social networks.

*Q 2. What could the community and business sector do to make a real difference in this area?*

As stated earlier Post Polio Victoria recommends the community and business leaders have to create vastly improved access to the built environment, employment, and fund information dissemination organisations controlled by people with disabilities so they can be independent from government influence.

#### ***Theme 5. About driving outcomes***

Post Polio Victoria recommends funding of information dissemination organisations controlled by people with disabilities, such as polio, to act in or as advisory bodies,

These bodies would assist in providing people with disabilities with advice and with monitoring service providers and relevant government departments.

Progress can only be measured by outcomes consistent with the Convention on the Rights of Disabled Persons and the National Disability Strategy. Outcome design would best be undertaken by partnership between relevant Victorian government departments, information dissemination organisations controlled by people with impairments and key community leaders.

Post Polio Victoria representatives are happy to discuss this submission further.

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