

Polio Australia

Representing polio survivors throughout Australia

Alister Henkens SC MP
Minister for Families,
Communities and Disability Services
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7th July 2021

Dear Minister,

Letter of concern regarding proposed changes to the NDIS

I'm writing to you on behalf of Polio Australia in support of the Australian Federation of Disability's (AFDO) letter of concern regarding the proposed changes to the NDIS.

About Polio Australia

Polio Australia is a peak body organisation representing thousands of Australians with physical disability related to polio and its late effects.

There are two main disability groups in the polio community. The first group is those who acquired polio in the twentieth century in Australia and are now ageing with their disability, many also experiencing significant progression of their condition due to Post-Polio Syndrome/Late Effects of Polio. While most of these people are ineligible for the NDIS due to the age cut-off, there are some NDIS participants in this cohort.

The second group is people who acquired polio internationally before migrating to Australia and now live with some level of disability. These people may be of any age, as there are many parts of the world where polio either still exists or was eliminated only recently. Many of those who are younger now will also experience a progression of their disability later in life.

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Polio Australia's Vision, Values and Purpose

Vision: Polio Australia's vision is that all polio survivors in Australia have access to appropriate health care and the support required to maintain independence and make informed life choices.

Values: Polio Australia represents the needs of the post-polio community and works with passion and professionalism to educate, advocate and achieve recognition for polio survivors.

Purpose:

- Educate and inform polio survivors, their families and carers, and the community at large about the late effects of polio.
- Provide information, education and training to General Practitioners and a range of medical specialists and other health professionals to improve the diagnosis and management of the late effects of polio.
- Facilitate the provision of appropriate and consistent health, disability and aged care support services across all states and territories to improve the treatment and management of the late effects of polio.
- Provide outreach to culturally and linguistically diverse and Aboriginal and Torres Strait Islander polio survivors to ensure their diverse needs are being met in a culturally appropriate way.
- Advise governments on policy development and programs in relation to the late effects of polio.
- Stimulate research into the late effects of polio.
- Assist the state Networks to support polio survivors and their families, friends and carers at the local level.
- Facilitate and encourage the co-ordination and further development of activities within and between the state Networks.
- Support and promote polio immunisation at a national level, and provide assistance to the state Networks to do so at the local level.

Representing people with disability at the Disability Reform Ministers' Meeting

We are asking you to raise the disability community's concerns at the upcoming Disability Reform Ministers' Meeting, and ask NDIS Minister Linda Reynolds to stop the

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proposed changes to the NDIS. Any plans that remain incomplete, lack rigour or are based on little or no consultation with the disability community should not go ahead. Additionally, there should be assurance – based on independent, qualified evaluation – that changes will solve problems and not create them.

People with polio disability have raised concerns about the possibility of a “tick-box” compulsory assessment by an unknown assessor. Many people with polio disability have significant fluctuations in activity levels from day to day, especially in relation to fatigue. Additionally, post-polio conditions such as Late Effects of Polio/Post-Polio Syndrome are progressive in nature, so the level of disability will not be static. Like other progressive neurological and neuromuscular conditions, assessments should be conducted by health professionals with specialised knowledge.

Further, the possibility that results of these assessments might not be able to be challenged or appealed is frightening. We request that the assessment process be transparent, accountable and reviewable, allowing participants to appeal a decision or to provide further information from their healthcare team as required to ensure their needs and goals are central to the process.

Together with AFDO, we urge you not to agree with proposed changes while they are still under development. Any changes made to the NDIS should be carefully considered, based on extensive community consultation, and have people with disability and their needs at the centre.

Yours sincerely,

Stephane Cantrill
Community Programs Manager,
On behalf of Polio Australia

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