



ABRN 142 977 053

POLIO AUSTRALIA INCORPORATED

Representing polio survivors throughout Australia

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Polio Australia Submission

1 February 2013

Inquiry into the National Disability Insurance Scheme Bill 2012



We're Still Here !



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Executive Summary

Polio Australia congratulates the Government on the initiative of establishing an NDIS and welcomes the benefits it will bring to people with a disability in Australia. The fact that the Scheme aims to provide for the needs of all people with disability, regardless of the cause of the disability, is particularly important.

To date there has been little support for those whose disability arose from a disease process. In particular, many, perhaps the majority, of polio survivors have fallen 'through the cracks' of all programs and have had minimal assistance throughout their lives. Polio Australia is deeply concerned that the age-related NDIS eligibility criterion as currently proposed will result in polio survivors continuing to miss out on such assistance.

Each polio survivor experiencing the late effects of polio (LEOP) has a different set of disabilities or limitations and different personal circumstances. There are commonalities, which mean that services need to be provided by personnel who have knowledge of LEOP. Unfortunately this requirement is very often not met. The opportunity to have a personal plan and funding to access appropriate services and to ensure co-ordination between services would be greatly valued by polio survivors.

The specialised coordinated care, which is so necessary for assisting people with LEOP, cannot be provided under standard programs designed for aged care. In fact, there are no specialist LEOP services in the aged care sector for polio survivors aged 65 and over. As the provision of all services that people with the LEOP require are grossly inadequate now, it would be a tragedy if this situation was compounded by an NDIS scheme that excludes polio survivors, one of the largest and most needy disability groups in Australia.

Polio Australia's position is that those with polio-derived disability (being long-standing and permanent) which pre-dates the introduction of the NDIS should not be excluded from participation in the NDIS on the grounds of age because aged care programs demonstrably cannot meet their special needs.

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SUBMISSION FROM POLIO AUSTRALIA 1 February 2013

Background

Polio Australia received an invitation from Mr Ian Holland, Secretary of the Standing Committee on Community Affairs, inviting the organisation to make a submission to this inquiry. As the sole national representative of one of the largest physical disability groups in the community, Polio Australia welcomes this opportunity.

National Disability Insurance Scheme (NDIS)

Polio Australia congratulates the Government on the initiative of establishing an NDIS and welcomes the benefits it will bring to people with a disability in Australia. The fact that the Scheme aims to provide for the needs of all people with disability, regardless of the cause of the disability, is particularly important. We fully support the aim of the NDIS to *"support the independence and social and economic participation of people with a disability"*.

To date there has been little support for those whose disability arose from a disease process or from medical conditions, or for whom the support is inconsistent and often dependent on very specific funding programs.

In particular, many, perhaps the majority, of polio survivors 'fell through the cracks' of all programs and have had minimal assistance throughout their lives. Polio Australia is deeply concerned that the age-related NDIS eligibility criterion as currently proposed will result in polio survivors continuing to miss out on such assistance. Before going on to discuss this in more detail, it is first necessary to present a briefing on the unique issues faced by polio survivors. Further supporting information is provided in Attachment 1.

Polio Australia

Polio Australia is the national body providing for communication between the various state polio organisations and their regional polio-survivor members, and providing for the provision of service programs on a unified national basis. Polio Australia is committed to standardising quality polio information and service provision across Australia for polio survivors. 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 lifestyle choices throughout the whole of their life.

The purpose of Polio Australia is to:

- 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 (LEOP).
-

- 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 LEOP.
- Advise governments on policy development and programs in relation to LEOP.
- Stimulate research into LEOP.
- Assist the state Networks to support polio survivors and their families, friends and carers at the local level.

Poliomyelitis

Poliomyelitis (polio) is a highly infectious disease caused by a virus. It initially invades the gut but may invade the nervous system and the disease can cause total or partial paralysis in a matter of hours. A significant proportion of people who contract the virus have no sign of illness and are never aware that they have been infected.

For around one percent of people who contract the virus the situation is far graver with more severe initial symptoms and possibly permanent disability. Initial symptoms are fever, fatigue, headache, vomiting, stiffness in the neck and pain in the limbs. One in 200 infections leads to irreversible paralysis (usually in the legs). Amongst those paralysed, 5%-10% die when their breathing muscles become immobilised. Others only survived because of mechanical breathing devices such as the iron lung.

Polio can strike at any age but a high proportion of those infected are young children. Polio is often regarded as having three stages:

- Acute Illness: As described above.
- Recovery period: The period during which the person regains function.
- Period of maximum recovery: The years from when the person has regained as much strength as possible.

For some polio survivors the residual effects of their illness have imposed continuing restrictions on their lives, with varying degrees of severity. These effects can include partial or complete quadriplegia or paraplegia, severe scoliosis, shortened or withered limbs, breathing problems and the need to use aids and appliances such as wheelchairs, callipers, orthopaedic shoes and crutches or walking sticks. Others appear to have recovered completely, leading physically active lives until new symptoms become apparent. A further group of people appear to escape this development. Up to seventy per cent of people who contract paralytic and non-paralytic polio develop new problems known as the Late Effects of Polio (LEOP), and possibly Post-Polio Syndrome (PPS), usually in their forties and fifties.

The Late Effects of Polio (LEOP)

LEOP is a term applied to a range of difficulties experienced by polio survivors. These difficulties are generally regarded as those which develop from living with residual paralysis and from problems arising from weakened muscles and deformed limbs or joints. For example:

- Muscles, which appear normal, may have been weakened by polio and, after some years, the activities of daily living and of physical pursuits take their toll and the muscles become more obviously weak.
- Overuse and unbalanced use of joints and muscles through the need to use crutches, walking sticks, manual wheelchairs, strain on arms when they are used to compensate for weak legs (such as in pushing out of chairs or pulling up stairs by the hand rail).

- Excessive strain caused by, for example, awkward gaits from shortened or weakened limbs. These problems can result in joint problems, degenerative arthritis and pain from nerve entrapment, such as carpal tunnel syndrome.

Post-Polio Syndrome (PPS) is now considered to be a sub-set of LEOP when neurological factors are involved. Following the initial polio illness the nerve cells send out extra branches to replace those that have been damaged. This enables the person to regain some movement and strength. It is thought that PPS is caused by the deterioration of these weaker and over-used nerve cells.

The most common symptoms of PPS are fatigue, muscle weakness, and muscle and joint pain. There are a range of other symptoms which people may experience. These include atrophy, cramping or twitching in muscles, new or increased difficulty in breathing or swallowing, changes in voice, sleep problems, and increased sensitivity to cold.

Over the years the state organisations supporting polio survivors have undertaken a number of surveys of their members – one such survey was published in New South Wales in 2007 ^[1]. Attachment 2 presents a table from that survey showing the percentage of respondents who experience each of these symptoms. It can be seen that muscle weakness and general fatigue are experienced by around 90% of respondents, and muscle pain and joint pain by around 75%. Attachment 3 highlights some other key findings from the survey, related to the activities of daily living.

It has been found that people who contracted the virus but were not paralysed, and perhaps were not even aware of having had polio, can experience some or many of these late effects. This means that the potential number of people with polio-derived problems may far exceed the number recorded as having contracted polio.

Ageing with the Late Effects of Polio

As many polio survivors have grown older, they have joined a new and growing cohort of the Australian ageing population, those who have lived for decades with long-term disabilities (AIHW, 2000 ^[2]; ABS, 2010 ^[3]).

People ageing with physical disabilities ^[4] want to continue to live in their communities and realise their vocational, recreational, family and social potential. To achieve this, people with LEOP have to contend with the legacy of polio, which often leaves them with a range of physical and psychological challenges decades after contracting the disease. The attitude of polio survivors to the cards that life has handed them is clearly displayed in a recent survey ^[1] of polio survivors:

- the need to be 'normal' has been a significant factor in the lives of many respondents;
- an approach to life which embraces learning to live with one's physical limitations and make the most of life;
- a lack of willingness to accept help or even to acknowledge the need for it;
- a view of life which puts responsibility on oneself; and
- optimism to deal with future problems.

[1] *Polio: The Living Legacy*. Post-Polio Network (NSW) Inc – 2007 [ISBN: 9780646480558]

[2] Australian Institute of Health and Welfare. (2000). *Disability and ageing. Australian population patterns and implications*. Canberra: AIHW Cat. no. dis. 19.

[3] Australian Bureau of Statistics. (2010). *Disability, Ageing and Carers Australia: Summary of findings*. Catalogue 4430.

[4] Disability is defined here in the same sense as the UN Convention on the Rights of Persons with Disabilities: *An evolving concept and results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society*.

People living with LEOP, as well as ageing, face four additional problems:

- progression of the impairments, leading to Post-Polio Syndrome (PPS);
- age related health conditions;
- lack of expert advice; and
- **potential exclusion from the National Disability Insurance Scheme.**

The increasing problems of LEOP, and the neurological problems which lead to PPS, are considered to occur around 30-40 years after the initial illness. Those who were only young children at the time of the initial illness have been experiencing these additional problems since a relatively young age, perhaps only in their 30s or 40s - well before age 65, and these problems cannot be regarded as related to normal ageing.

Federal Parliamentary Recognition of the Late Effects of Polio

On 30 March 2012 representatives from Polio Australia and State Polio Networks participated in a *Roundtable Forum on the Late Effects of Polio / Post-Polio Syndrome* conducted by the Federal House of Representatives *Standing Committee on Health and Ageing*. The Committee's unanimous cross-party Report to the House of Representatives presented cogent arguments on the urgent need for comprehensive, consistent, adequately-funded health, disability and peer support services for **all** Australian polio survivors. (See page 7 of this submission for the Report's recommendations.)

Relevance of the NDIS to Polio Survivors

The key aspects of the NDIS bill that are of particular relevance to people with the LEOP are summed up in the following phrases:

- *Participants develop a personal, goal-based plan with the Agency, and how reasonable and necessary supports will be assured to participants.*
- *Will fund reasonable and necessary services and supports directly related to an eligible person's individual ongoing disability support needs;*
- *Will enable people with disability to exercise more choice and control in their lives, through a person-centred, self-directed approach, with individualised funding.*

Each polio survivor has a different set of disabilities or limitations and different personal circumstances. There are commonalities, which mean that services need to be provided by personnel who have knowledge of LEOP. Unfortunately this factor is often not met. The opportunity to have a personal plan and funding to access appropriate services and to ensure co-ordination between services would be greatly valued by polio survivors.

The specialised coordinated care, which is so necessary for assisting people with LEOP, cannot be provided under standard programs designed for aged care. At present, Victoria is the only state with a specialised service for polio survivors. The coordinated assistance which the NDIS should be able to provide would be ideal for polio survivors. So many medical and allied professionals have very little idea of LEOP and can in fact provide services which are counter-productive, or exacerbate the person's problems, or even counter each other.

The funding provided under the NDIS could assist those who have high costs with mobility and other aids. A pair of orthopaedic shoes costs over \$1,000 at a minimum. Callipers can cost anything from \$1,000 to \$10,000 let alone the cost of, for example, electric wheelchairs and car and home modifications. Such costs are prohibitive for a retired person or pensioner and state-based services are grossly inadequate.

Polio Survivors' Lack of Eligibility for the NDIS

The summary statement for Chapter 2 of the Explanatory Memorandum clearly states that "*Chapter 2 sets out the general supports and assistance, including funding, that the Agency can provide to **all** people with disability and other individuals and organisations to enable them to support people with disability*". Unfortunately for many polio survivors the concept of **all** people with disability is a misnomer as the eligibility requirements will rule out almost all people with LEOP for any assistance. A very serious concern for Polio Australia and the state-based Polio Networks is that polio survivors will not be eligible for NDIS provisions on the grounds of age.

To be eligible for assistance during the launch phase a person has to be born by 1948, which will rule out most polio survivors. By 2021, three years after the proposed launch date of the NDIS, no one in Australia who survived the great polio epidemics of the 1930's, 1940's and early 1950's will be eligible for assistance as 2021 is the 65th anniversary of the introduction in Australia of the Salk Vaccine in 1956. The only groups who will meet this restrictive eligibility requirement are:

- The relatively small number who contracted polio during the epidemics in the mid-to-late 1950's, or individual cases after the introduction of the polio vaccine in 1956;
- The isolated cases of those who have migrated to Australia from countries where polio is still rife, or was so after it had been eliminated from Australia.

Additionally, only a relatively small percentage of polio survivors are in the geographical areas covered by the trial NDIS programs.

It is acknowledged that in the design of the NDIS it was considered that aged care programs would meet the needs of those aged 65 and over. It can also be assumed that it was considered that disabilities, which are specifically related to ageing, might be more appropriately provided for under aged care programs. Polio Australia has been told that after 65 years of age, people with the LEOP can then access services in the aged care sector. The problem with this is that currently **there are no specialist LEOP services in the aged care sector for polio survivors aged 65 and over**. As the provision of services that people with the LEOP require over the age of 65 are grossly inadequate now, it would be a tragedy if this situation was compounded by an NDIS scheme that excludes polio survivors, one of the largest and most needy disability groups in Australia.

With very little assistance, most polio survivors have achieved the NDIS aim of independence and social and economic participation of people with a disability but often at great physical, emotional and financial costs to themselves and their parents initially and later spouses and children. Surely as their level of disability and associated costs increase over time, they should not be excluded from assistance just because they have lived with their disability for longer. They have funded their own mobility and other special aids; they have survived in a world which did not make provisions for people with disability; their families have suffered deprivations to be able to afford help or aids.

Recommendation

It is our key recommendation that the NDIS age limit be considered selectively for people whose disabilities result from various causes.

We consider that **polio survivors should be eligible regardless of age** because:

- many or even most polio survivors have been living with a disability or at least some level of impairment since their initial illness, which for many was in infancy or early childhood;
- the need for services by polio survivors will increase greatly as they age because the rate of deterioration for people with LEOP varies between two and five percent per annum and this is driven largely by the level of appropriate care and management of the condition; and
- the prevailing attitude of the medical profession and society in general to those recovering from acute polio was to get on with life and try to overcome all obstacles and try to be 'normal'. Children were encouraged to get rid of crutches, callipers, etc even though we now know that this may have been counter-productive in terms of their later condition.

Conclusion

The NDIS aims to prevent people experiencing the problems and deprivations that these people have either endured or overcome to the best extent they could with little or no assistance. The NDIS should enable people with a disability from now on to have a greater chance of a fulfilling life.

Polio survivors meet the eligibility requirements in that their disability is permanent and their support needs are *"likely to continue for the person's lifetime"*.

Polio Australia's position is that those with polio-derived disability (being long-standing and permanent) which pre-dates the introduction of the NDIS should not be excluded from participation in the NDIS on the grounds of age because aged care programs demonstrably cannot meet their special needs.

ATTACHMENT 1 - SUPPORTING INFORMATION

History of Polio in Australia

While polio has been known to exist for at least three millennia it is only in the period from around 1880 to 1960 that its impact is recorded as being devastating. In Australia, the first recordings were around 1880 to 1895 with sporadic incidences until the late 1930's when there was the first major epidemic. In terms of the proportion of the population affected, 1937 was perhaps Australia's most significant epidemic. It was an epidemic which was at its worst in Victoria. It was said to be five times greater than the previous epidemic. There were extraordinary measures. Many schools were closed and children from them were not permitted to transfer to other schools. One hundred police were stationed along the border to check if cars entering New South Wales carried children who had been exposed to the infection or had attended one of the closed schools. (*Australia through Time 1993*).

In terms of actual people affected by the epidemics, it is thought that up to 40,000 people contracted polio which progressed to its paralytic form in the period from the 1930s to 1960s and the number with non-paralytic polio is likely to have been ten times that number (400,000), leaving Australia with up to half a million Australians with significant disability as a legacy of the polio virus. Additional to this is a much larger group who had also had a brush with the poliovirus, which is likely to have left them with long-term impairment to some part of the body.

Federal Parliamentary recognition of the Late Effects of Polio

On 4 July 2012 the Federal House of Representatives Standing Committee on Health and Ageing Committee tabled a Discussion Paper resulting from the evidence taken during a Roundtable Forum held on 30 March 2012. In an unusual step the Committee made the following recommendations:

Recommendation 1

The Committee recommends that the Australian Bureau of Statistics and/or the Australian Institute of Health and Welfare establish mechanisms through inclusion of appropriate questions in existing health and/or disability surveys to estimate and report on the size of the population of polio survivors living in Australia, and the proportion of that population experiencing the late effects of polio/post-polio syndrome.

Recommendation 2

The Committee recommends that the relevant National Boards, in consultation with key stakeholders including peak professional bodies, medical/health educators and training providers, seek to ensure curricula for students includes information on the late effects of polio/post-polio syndrome, to raise awareness of the condition as a possible diagnostic outcome and of best practice for treatment and management.

Recommendation 3

The Committee recommends that Medicare Locals actively engage with Polio Australia and the state-based post-polio associations, with state and territory government departments of health, and with general practitioners to promote activities which will raise awareness of the late effects of polio/post-polio syndrome:

- among practicing health professionals through continuing professional development; and
- in the community through patient education, noting the need to tailor communication to enhance engagement with specific population groups taking into account demographic factors such as age and cultural background.

ATTACHMENT 2**Late Effects of Polio Symptoms –
Differentiated by Continuing, Increased and New Symptoms**

	CONTINUING PROBLEM		NEW SYMPTOM	OTHER	TOTAL	TOTAL PERCENT
	NOT INCR'D	INCR'D SEVERITY	_____	_____	_____	_____
Muscle pain	103	187	75		365	74.9
Joint pain	85	201	77	1	364	74.7
Muscle weakness	99	269	80	2	450	92.4
Fatigue	98	244	88	1	431	88.5
Muscle atrophy/wasting	139	138	40		317	65.1
Muscle twitching	107	94	67	2	270	55.4
Muscle cramps	134	122	54	2	312	64.1
Breathing difficulties	64	92	50	1	207	42.5
Headaches	81	68	26	3	178	36.6
Sensitivity to cold	129	152	39	1	321	65.9
Tendency to fall	103	136	72	3	314	64.5
Sleep problems	97	131	82	4	314	64.5
Swallowing difficulties	58	58	70	1	187	38.4
Problems finding words	46	107	121		274	56.3
Change in voice	39	58	82	2	183	37.6
Nil Response					2	
Total Participants					488	

ATTACHMENT 3 – Activities of Daily Living**Nature of Appliances Used****Number of Participants: 488**

	NO. OF AIDS USED		PERIOD OF USE				TOTAL USAGE		NUMBER WITH INC'D USE
	ONE	TWO	A	B	C	#	TOTAL NO. USING AID	% of 488	
Special shoes	101	75	109	34	28	26	197	40.4	37
In-shoe orthosis	56	88	34	43	59	32	167	34.2	41
Ankle-foot orthosis	38	12	16	12	22	10	60	12.3	14
Walking stick(s)	139	21	18	54	94	33	199	40.8	84
Crutches	19	49	34	16	25	9	84	17.2	28
Walking frame			6	11	39	2	58	11.9	23
Knee brace/ Bandage	30	13	5	14	26	9	54	11.1	17
Arm support	10	3	5	2	8	2	17	3.4	6
Wrist support	16	8	6	4	19	4	33	6.7	12
Calliper(s) /half	39	6	24	12	9	6	51	10.5	5
Calliper(s) /full	58	23	65	10	2	6	83	17.0	7
Corset			24	6	4	1	35	7.2	7
Manual w'chair			14	19	50	4	87	17.8	41
Electric w'chair			2	8	21	5	36	7.4	22
Elec. Scooter			1	17	41	2	61	12.5	28
Breathing help (day)			4	4	12	4	24	4.9	14
Breathing help (night)			4	9	23	4	40	8.2	18
Iron lung *			5						
Other							21		
Nil appliances							81	16.6	

The following tables show responses in relation to aspects of daily living.

The questions asked people to respond in relation to their level of difficult with the task:

Please indicate your level of difficulty with the following activities:

- Write down the appropriate number and letter in the first column.
- Tick the second box if it has become more difficult in the last ten years.

1 do not cause you any problem

2 can be managed alone but with difficulty

*If you answer '2' to this question please ALSO add an additional letter **S** if this is a slight difficulty; **M** if it is moderate difficulty or **H** if it is a high difficulty*

3 can be managed with help from others

4 are impossible for you

Walking Ability

Number of Participants: 488

ACTIVITY	LEVEL OF DIFFICULTY 4 is highest difficulty												N R	INCR'D DIFFIC'Y	
	1	%	2 *	2 S	2 M	2 H	All 2	%	3	%	4	%			%
Walking – level surfaces	197	40	5	77	76	15	173	35	9	2	41	8	68	249	51
Walking – uneven surface	72	14	16	91	105	64	276	57	34	7	54	11	52	320	66
Walking – short distances	196	40	2	63	65	24	154	32	20	4	46	9	72	222	46
Walking more than 200 m	138	28	8	55	63	57	183	28	18	4	83	17	66	262	54
Climbing stairs	75	15	10	58	95	90	253	52	29	6	80	16	51	317	65

Household Tasks by Level of Difficulty

Number of Participants: 488

	LEVEL OF DIFFICULTY: 4 is most difficult													No resp
	1	%	2*	2S	2M	2H	All 2s %	3	%	4	%	N/A		
Light tasks washing up	322	66	7	51	42	7	22	8	2	6	1	3	42	
Heavy tasks vacuuming	102	21	7	80	73	49	43	19	4	104	21	5	49	
Light gardening	103	21	8	70	78	38	40	32	7	92	19	10	57	
Heavy gardening	39	8	3	26	46	40	24	25	5	219	45	23	67	
Cooking: Snacks	314	64	5	47	32	8	19	13	3	14	3	4	51	
Cooking Full meals	268	55	7	59	38	17	25	20	4	26	5	4	49	
Shopping: Small	259	53	7	59	43	13	25	35	7	21	4	6	45	
Shopping: Major	148	30	3	67	58	40	34	67	14	51	10	9	45	

Personal Care by Level of Difficulty**Number of Participants: 488**

ACTIVITY	LEVEL OF DIFFICULTY: 4 is highest difficulty											INCR'D DIFFIC'Y [% of 488]	
	1	%	2*	2S	2M	2H	All 2s %	3	%	4	%	No.	%
Grooming	385	79	5	41	18	5	14	3	0.6	1	0.2	116	24
Getting dressed	313	64	5	74	40	3	25	18	3.7	4	0.8	171	35
Getting in/ out of bed	305	63	9	66	50	7	27	13	2.7	6	1.2	188	39
Feeding yourself	411	84	2	26	12		8	4	0.8		0	78	16
Taking a bath/shower	278	57	12	66	55	12	30	23	4.7	7	1.4	194	40
Using the toilet	340	70	10	47	42	8	22	5	1.0	1	0.2	126	26
Writing by hand	341	70	12	44	39	12	22	2	0.4	2	0.4	147	30