

Polio Australia

Representing polio survivors throughout Australia

National Patron: Dr John Tierney PhD OAM, Federal Senator for NSW 1991 – 2005

NDIA

'Towards Solutions for Assistive Technology' – Discussion Paper Response from Polio Australia Inc

Background

Polio Australia is the national organisation of which the members are the state organisations representing polio survivors. The organisational structures vary between states but in essence each organisation is a voluntary self-help association of polio survivors with their families and carers providing information and support to their fellow survivors. While polio survivors are the largest group of people with physical disabilities in Australia, in most instances, the support organisations (including Polio Australia) have no government funding, and indeed there are few government services.

Polio is also one of only two or three diseases which, in colloquial terms, has "a second go at you". Many survivors thought they had completely overcome the disease and were active in all aspects of life. Others had residual disabilities but still led independent and productive lives. In fact the independence and determination developed in order to rehabilitate has led polio survivors to be known as a driven, independent and stubborn group of "over-achievers". In some cases the residual disability was extremely severe with more limited active community involvement but the same determination to survive and succeed.

Some years after the initial illness, generally between 25 and 40 but perhaps as few as 15 years, new problems develop known as the Late Effects of Polio, including the more specifically named Post-Polio Syndrome. These problems are not age related but are exacerbated by ageing. Many of the symptoms such as muscle weakness, muscle fatigue, joint and muscle pain and breathing problems may require the use of assistive technologies in order to continue to live successfully in the community.

Use of assistive technologies

The stereotypical view of a polio survivor during and in the years following the major epidemics, especially in the 1950s, is of a little child with callipers on one or both legs. This highlights the importance of assistive technologies to the polio survivor even though it shows a limited understanding of the range of disabilities involved and the range of technologies required.

The attached extract is from the report published in 2007 of a survey undertaken the previous year by Polio NSW Inc (then known as the Post Polio Network (NSW) Inc). The report involved analysis of 488 complex 12-page questionnaires from polio survivors who were members of the Network. This represented around 57% of all members. It can be seen that only around 16% use no appliances and over 12% of respondents use 6 -10 appliances.

No attempt was made in this survey to assess how many would use (nor the number they would use) of aids and appliances of the nature that would fall into the lowest level of the hierarchy pyramid such as kitchen utensils and shower chairs. Many polio survivors would use from a few to perhaps dozens of such items. In this lowest level of the hierarchy they also use fairly standard mobility aids such as walking sticks, walking frames and crutches as shown in the table. Additionally they may also use items in the second lowest category such as adjustable beds, standard wheelchairs and scooters.

A significant number, however, require more individual and complex aids which would be in the top two hierarchy categories.

Current provision

Information is not available on assistive technologies used by polio survivors other than those listed in the table, the majority of which are mobility related or appliances for disabilities of the arm and back. It is highly likely that some may use, for example, technologies which assist with computer or telephone use, building adaptations and countless other aids to daily living. In the NSW survey 10% had vehicle modifications or scooter lifts in their cars.

Statistical data is not available on the sources of the appliances and technologies used nor on the costs to the individual. It is known that some use disability services such as those provided by the Northcott Society in New South Wales.

Others use government services such as Enable in New South Wales and its predecessor, PADP, to fund purchases from private suppliers. The limitations of such programs which apply to all people with disabilities impacted on polio survivors. Examples include that the most appropriate technology may be more expensive and could be declined and that there are referrals to providers with less-appropriate or lower-standard appliances. Restrictions to, for example, one pair of shoes could mean a person had nothing to wear while the one pair is repaired. In some instances during the PADP days the Network wrote letters of support for members. Specific instances include a person who was no longer able to walk other than very short distances and did not drive who was told that she had to wait at least two years for the loan of a second-hand mobility scooter. Another person who had only one pair of orthopaedic shoes which were in an advanced state of disrepair and who had been advised to change to boots for greater support was told it would be 18 months before she could get a pair of boots. It is acknowledged that these problems are not as serious as they used to be and most items are supplied within about six months but nonetheless the avoidance of such problems is essential in the development of new provisions.

Anecdotal information indicates that the costs bear very heavily on many polio survivors. In trying to live "normal" independent lives they have been self-reliant and either pay the full cost of any assistive device or the full cost minus the relatively small proportion which is refunded by private health funds. The polio survivor preparing the initial draft of this submission predominantly uses mobility devices but also requires an adjustable bed and specially selected items such as office chairs. The cost of the mobility aids alone is considerable in order to cover hand-made individually-designed orthopaedic shoes, in-shoe orthoses, carbon fibre callipers for both legs, mobility scooter and in-car hoist. To replace all at once, even with only one pair of shoes involved would be in excess of \$10,000 and these callipers are simpler than many complex styles which might cost close to \$10,000. The total health fund rebate is only a maximum of \$500 per year for shoes, orthoses and callipers combined and nothing for the scooter and hoist. Polio NSW recently learnt of one person who has some metal work skills who makes his own calliper because he was quoted \$3,000 for a professional one. The home-made one is heavy, cumbersome and of dubious appropriateness for his mobility.

Many see little point in applying for services such as Enable. Their independence may mean they are not pensioners or only have a part-pension which frequently puts them lower on priority lists even though their superannuation might not readily cover such expenses.

Assistive technology provisions for polio survivors under the new proposals

The provision of assistive technologies to polio survivors has to be considered in three phases as there are three categories of people: those not eligible for the NDIS but not covered by aged care; those eligible for NDIS; those covered by aged services.

Polio survivors not covered by NDIS due to age restrictions

As it is nearing 60 years since the last major outbreak of polio in Australia there are few polio survivors who were born in Australia, the UK, North America or most European countries who are not over the age of 65 or will reach that age by the time the NDIS is fully rolled out. **The majority of these people are not eligible for NDIS on age grounds** although there are a few who apparently might be accepted because of their previous inclusion within disability provisions. All of those who have survived, had gainful employment and contributed to the community despite their disability, often with physical, emotional and financial hardship for them and their families, are not able to now have the assistance of the system which is supposed to cover ALL people with a disability. Polio Australia has made representations on this matter pointing out that it is understood that it would be prohibitive to cover all age-related disabilities but for those whose disability dates from perhaps 60 years ago, many since early childhood, some even less than one year of age, the NDIS should provide cover.

It is a major concern that these people will not have access to any assistance with AT. The specific concerns are:

- Under the NDIS, responsibility for disability services, including those from whom assistive technology is provided, will transfer to the Commonwealth. State-based services are supposed to continue until the full roll-out but some are pulling out of such provisions now even though it is some years until the full roll-out. This results in a loss of services for the intervening years even for those who will eventually be covered by the NDIS.
- Once there is full roll-out, any remaining services from which there is funding assistance will be closed down leaving those polio survivors excluded from the NDIS with no such services at all.
- There is an inadequate supply of trained and skilled people in many areas such as orthoses, especially callipers, and orthopaedic shoes – even considering about only one (but relatively common) need area for polio survivors. When you find someone who has the specialised knowledge to assist you then your need is to continue with that provider and not have to search at inconvenience and cost for another provider, even if a suitable one does exist and that is definitely not certain. Many of these providers are small services, possibly with only one professional person. It is doubtful that they would wish or even have the time, as they are usually stretched to their limits, to apply to be an approved provider. If many of their clients are forced by financial need to change to a new, and possibly less competent, provider or one with fewer resources because they can only use their entitlements with an approved provider then the ones who are not an approved provider may be forced out of business leaving polio survivors without anyone to meet their special needs.
- Many polio survivors are already concerned that their assistive technology provider is ageing and there are insufficient younger skilled people to take their place and few training programs. They will be even more stressed if they have these services taken away from them.
- They would not be eligible for the assessor or mentor services which are proposed even if these were considered desirable. Should they be of value such services are not generally available on a fee-for-service basis either.

- The above points indicate that many polio survivors could be left with no appropriate service or inferior services and no financial assistance. This hardly represents the NDIS goals of total coverage of services and your own choice of provider.

Polio survivors covered by the NDIS

The situation for these people is in many respects akin to all people covered by the NDIS and the concerns raised about the proposals are likely to also be considered in other submissions. These include:

- The NDIA desires feedback on the discussion paper and proposals but it is so complex and not user-friendly that many of the people who should respond would find it difficult to do so.
- The introduction note states that the aim is to achieve "*individualised, participant empowered and sustainable approach for assistive technology service delivery*" and that a core objective is to "*maximise participant choice and control*" but so much in the proposal appears to be limiting participant choice and control. In fact the procurement model and preferred supplier systems recommended seem to be totally contrary to these aims. It seems incomprehensible that reducing the number of suppliers and pursuing bulk procurement can be regarded as providing participant choice and control and the tailored individual service that the NDIS was supposed to provide.
- With those items of AT which are in the higher two tiers of the pyramid, provision is very specialised. To use complex callipers and leg braces as an example, there are very few suppliers and even fewer highly-experienced orthotists who are to give the advice, fitting and support essential for selection and use of such technologies. It is essential that the client has not only this specialised help but also a good rapport with the professional. Without freedom to select one's own supplier someone could well waste many thousands of either their own or taxpayer dollars with inappropriate selection. Even with the simpler item of orthopaedic footwear members of our organisations have had to start all over again and use of inappropriate items can exacerbate already severe physical problems and add to emotional stress.
- There is the suggestion that panel procurement might improve the range and perhaps lead to discounting for some items. However, there are concerns that it could also lead to loss of suppliers, especially within local areas; restrictions to the specific items covered because approval may be more forthcoming for them; and retailers who select the items they stock on economic or turn-over grounds rather than to provide good services, especially those with space limitations who may only stock higher turn-over items.
- To respond to some of the questions listed:
 - Capacity building: There are some worthwhile ideas contained in this proposal. Most polio survivors would be in the expert category or perhaps developing if there are changes in their lifestyle or new physical difficulties as their late effects of polio symptoms increase BUT this whole system is only of relevance to the small proportion of polio survivors who are eligible for the NDIS. These are predominantly younger people from countries where polio has not been or was more recently eradicated.
 - Peer support mentors might have a role in encouraging people in the use of complex technologies but it is doubtful they would have the expertise to advise on the nature of purchases.
 - Similarly, expert advisers are unlikely to have the requisite knowledge to provide adequate assistance in determining appropriate technology except in some specific areas such as computer technology.

- The question of ownership of the product and the issue of the use of refurbishments cannot be applied universally. There may be some items (e.g. computer equipment and maybe items in the lowest tier of the pyramidal hierarchy), that are appropriate for ownership by the organisation rather than the individual and also for re-use but in the polio survivor context so many items such as orthoses are so individual in style, purpose and size that the idea of re-use is almost ludicrous.

The **additional concern** is that, owing to the shortage of providers with specialised knowledge of the needs of polio survivors and as their needs are so diverse and individual, it is highly unlikely that an approved provider will be available to meet their needs. They would then be no better off than the polio survivors who are not eligible for the NDIS. The comments above about specialised assistance then become relevant for this group.

Polio survivors covered by aged care services

The theory behind making the NDIS cut out at 65 was that there is a significant proportion of older people who may need assistive technologies because of age-related disabilities. It was considered preferable that these needs be met through aged care provisions. The fact that a person has reached the age of 65 does not mean that they need residential or nursing home care. In fact many live independently into their 90s. The increase in the age for entitlement to the aged pension and changes to retirement age notions attest to the independence and capability of older people. Consequently the issues raised above regarding polio survivors not covered by the NDIS are relevant. Where a person does have some eligibility for general assistance with in-home living, the availability and appropriateness of assistive technologies, as discussed, are applicable.

If the NDIS, aged care funding programs and, for example, Veterans Affairs, join in procurement programs then all the issues raised above, both in respect of those covered by NDIS and those who are not, will become relevant to all older Australians with any level of disability and technology needs.

For those who do need residential care the question must be asked whether there is any provision for specialised assistive technology. The paper suggests that aged care providers would be able to source equipment through the same approved providers as under NDIS. We have serious doubt that many residential care providers would include funding for such equipment as part of their care and, even if they did, whether the equipment available would be suitable to the person's special needs. If funding were not available then they would be in the same position as all others not eligible under NDIS. These concerns are highlighted by a simple example. If a nursing home keeps a stock of walking frames they might expect all residents to use the same style whereas people with unusual and difficult gaits may need a special type of frame. These can cost, say, \$800 compared with the standard \$100.

Conclusion

We trust that you will consider all responses to the discussion paper and, from the perspective of Polio Australia, we hope that the special needs of polio survivors will be addressed in your further deliberations.