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This submission is written on behalf of Post Polio Victoria Inc (PPV) which has over 200 members who have had polio. The aim of PPV is to ensure that people with a history of polio receive appropriate and informed health care and have full access to the services they need for greater inclusion and participation in work, home and community life.

PPV's members are people who contracted polio both in the epidemics in Australia that ended soon after the introduction of the Salk vaccine in 1956 and also in countries such as India, Vietnam and the Middle East where the disease has been endemic until more recently. Therefore the age of our members range from people in their eighties to some in their forties.

Victoria responded to the epidemic by providing rehabilitation services staffed by Government funded doctors and physiotherapists. In 1998 that service was largely withdrawn. What remains now is a service that provides people with polio an assessment and referral to generalist services in the community, which patients must either fund themselves, or for the "lucky" ones, attend as NDIS recipients.

**This submission is concerned with the inequality of the support provided to people with disabilities. People with disabilities over the age of sixty-five are not given the same access to funding to meet their support, rehabilitation and assistive technology needs as is received by their younger counter parts, who are eligible for the National Disability Insurance Scheme.**

We will provide three case studies to illustrate.

#### **Ron Bell**

Ron contracted polio in 1952, at the age of fourteen, leaving him with paralyzed leg muscles mainly on one side. He wore a full leg caliper made of iron and with leather straps and buckles, the only available brace at the time. Following long and difficult hospitalisations he regained strength and learned to walk again. He lived an active life, working in community services, raising a family, volunteering in the community and managing his small rural property. He retired and receives the Aged Pension, still volunteering and living independently on his rural property.

In 2005, his old calipers well worn out, Ron was the first Australian to be fitted with a new brace called a "Stance Control". Made of aluminum it was lighter, and had a mechanism that "sensed" the movement of the knee and the hip so that it locked at the point of the stance that prevented a fall, and enabled a natural gait. As the only funding available to people with disabilities such as Ron was \$2200 through the State Wide Equipment Program (SWEP), which fell well short of the more than \$10,000 it cost at the time, it was paid for by a donation from the Lion's Club that Ron belonged to.

Ron did well with this, generously promoting the benefits of the brace to others on videos and in public talks, until recently when this brace required replacing and he needed one for his other leg as well due to muscle weakness caused by the effects of post polio. The cost of the Stance Control twelve years later was \$15,000. Ron needed two, and so needed to pay \$30,000.

Ron has been assessed as Level 2 under My Aged Care, receiving around \$15,000 per year, less the \$6700 for mandatory Case and funds management fees, equalling \$8300 per year, provided in monthly deposits of \$845.00. These funds have been allocated for home and garden maintenance, with no funding allocated for assistive technology, despite the essential role this plays in his life. It is not listed in the Level 2 guidelines as included.

Ron was unable to walk for almost a year as he had no way of funding the two new braces. He used a wheelchair and crutches. At this time Ron was the primary carer at home as his wife by now had back and hip conditions requiring surgery, and was herself in a wheelchair most of the time, and was relying on Ron.

The State Wide Equipment Program still only provided a little over \$2200. His orthotist contacted people for spare parts to help lower the cost. Eventually Ron received a personal donation from a church member which enabled him to get the two Stance Control braces he required.

### **Peter F.**

At the age of six in 1955 Peter had polio, paralysing both legs permanently, contracting both hip flexors, forcing him into a forward leaning position, and preventing him from being able to stand and walk upright. To enable walking Peter has worn two full length calipers and used elbow crutches since then. This forward leaning position means half of his body weight is supported on his arms which makes for precarious balance and increased risk of falls, and has increased pressure on his shoulders. In more recent years he therefore also uses a wheelchair.

Peter says "When the Polio Unit (run by the Victorian Health Department) was disbanded in the 1990s the Kennett government promised that support would be continued through regional rehabilitation centres. However, those were geared to short-term rehabilitation programs of six weeks' duration. Over time I attended three different rehabilitation centres weekly for stretching and assistance with

walking, and paid a fee each time. The centres each in turn kept me on for a while, but then discontinued treatment, until finally I was left with no regular assistance at all."

He has made occasional visits to physiotherapists at his own expense, but even with private health cover, given the treatment required, the cost was prohibitive.

Peter leads an active and productive life, and like many people with polio, has had to deal with the added difficulties created by lack of support for his disability throughout his career. "Despite all this, I completed a double degree in Law and Arts at Melbourne University, followed by an MA at Monash University. I worked as a university tutor at Monash and later at Melbourne University. Subsequently I obtained a PHD at the University of Paris, living independently in student accommodation for 4 years. Upon returning to Melbourne in 1984 I joined the Victorian Bar and have worked as a barrister and legal translator. My disability has definitely impacted my career as I was often discriminated against by clerks who wouldn't give me cases because of my crutches."

Peter has been assessed as a Level 2 under the Aged Care system, pending approval of Level 3, for which there will be a considerable wait. The level 2 package is capped at \$15,000 out of which provider charges are \$5000. Peter is a self funded retiree and means testing means that his co-payment is assessed at \$10,000. He therefore receives no financial assistance at all!

Asked what assistance he needs Peter says "My three main needs are assistance with aids and equipment and repairs. My wheelchair is 20 years old and my calipers are 48 years old. I also need on-going Physiotherapy for maintenance of movements and stretching contracted muscles. And I need transport to medical appointments and other destinations. Without those resources, I am at risk of injury at any time, essentially taking away my capacity to function independently at all."

If Peter was on the NDIS he would receive all that he needs and he would be encouraged and enabled to continue his active life as safely and comfortably as possible for as long as he possibly can.

### **Liz Telford**

Liz contracted polio in 1956, just missing out on the vaccine. Like Ron, she was mainly affected on one side and required a long leg caliper which she wore until she was seventeen, receiving treatment from the physiotherapists through the Polio Unit. Then she "graduated" into a short leg brace as she had gained enough strength over her growing up years. Then no further treatment (or funding for assistive devices) was provided. She studied, worked as a Social Worker, pursued further training, raised a family and built a practice as a psychotherapist. Like Ron and Peter, she lead an active life. The impacts of post polio became stronger in her late forties and by the time she was in her fifties she required a long leg brace for many activities, a scooter for long distances and was using crutches consistently. She developed significant degeneration from her uneven walking pattern over the years

and painful muscles and tendons. Pain increased as her working muscles struggled to compensate for the polio affected ones that were wearing out. Her use of private physiotherapy and other pain management programs was increasing. Due to pain, fatigue and weakness, she was forced to reduce her work much earlier than she wanted and then to retire a number of years before planned.

Liz is now sixty-three and requires a scooter for distances, upgrading of her brace to a long leg light weight carbon fibre model costing about \$8000, domestic support in the home and garden (approximately \$15,000 per year), on going rehabilitation in the form of a weekly physiotherapist lead exercise and hydrotherapy sessions (approximately \$7000 per year). As an NDIS participant, all of this is covered. In addition, \$30 a week is paid for transport costs. Liz also wants to trial an alternative to her scooter and hire will be paid for, with the intention that if successful, the new device will be funded next Plan.

The NDIS is not means tested, there are no administration fees as Liz is self managed and the requirements were decided at the annual review based on Liz's individual requirements. She will remain on the NDIS as long as she chooses.

### **Conclusion**

Ron, Peter and Liz all have a similar disability caused through contracting polio within a few years of each other. They are active people who wish to remain so. Assistive technology is essential for their independence. Therapies are needed for on-going movement, strength, and pain management. They may need increasing levels of support in and around the home, and to access the community. Only Liz will receive the funding to meet these needs, simply because she is a few years younger than Peter and Ron.

These are just three examples. There are thousands of people who have a history of polio in Australia. Many have survived the epidemic and are now in their sixties and above. They have a disability. This needs attending to first. The Aged Care System does not meet the needs of people with a disability as the NDIS does.

This is not a rational and fair approach to providing disability services.

### **Recommendations:**

1. Review the exemption to the NDIS for people with disability aged over 65
2. As a minimum, remove means testing and capping of aged care funding for older Australians living with disability, or develop an NDIS-funded safety net to cover the gaps in funding for this cohort
3. Invest in training in disability and progressive neurological conditions for those involved in assessment and provision of aged care services
4. Significantly increase the number of home care packages available – we recommend an additional 30,000 additional packages within the next 12 months

5. Ensure there are consistent, transparent avenues for funding assistive technology that do not leave older Australians with disability out of pocket for vital aids and equipment
6. Ensure that no older Australians living with disability need to choose between assistive technology and services due to limited funding support