



Polio Australia
Representing polio survivors throughout Australia

Royal Commission Into Aged Care Safety and Quality

AUGUST 2019



Our Mission

Polio Australia is committed to standardising quality polio information and service provision across Australia for polio survivors.

Our 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 lifestyle choices.

Our 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.

Our 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 programmes 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.

Key Issues and Recommendations – An Overview

Issue 1: Aged care funding is insufficient for the complex needs of older Australians living with a disability

Recommendations:

- a) Review the need and legality of the continued exemption under the Age Discrimination Act sought by the NDIS to exclude people over the age of 65 from the NDIS and consider removing this exemption; and
- b) For the complex needs of older Australians living with a disability, aged care funding aligns with NDIS funding, i.e. is not means-tested or capped; or
- c) As a minimum, the NDIS develops a safety net model that provides funding to address needs not met by aged care; and
- d) Tax offsets for medical expenses be reinstated where public and private health insurance and government subsidies do not adequately contribute to the costs for people with disabilities.

Issue 2: Lack of recognition of disability and the disability-related needs of older people within the aged care system

Recommendations:

- a) The Department of Health develop targeted action plans to address barriers to accessing safe, equitable and quality aged care for those over 65 living with disability; and
- b) An integrated care model focused on health, function and participation is adopted by the Department of Health to adequately address the disability needs and support of older Australians.

Issue 3: Inappropriate and inadequate level of assessment for people with disability and specific health conditions

Recommendations:

- a) Comprehensive, thorough initial assessments conducted by trained health professionals for people who have progressive neurological conditions; and
- b) Investment in training packages for the aged care sector workforce that address disease-specific and disability-related needs of older Australians.

Issue 4: Lack of available support and funding for assessed care needs

Recommendations:

- a) Investment within residential aged care facilities to compensate for the additional needs of older Australians living with disability requiring residential care; and
- b) Investment of 30,000 additional home care packages within the next 12 months to support polio survivors and other Australians waiting for home care packages to continue to live at home.

Issue 5: Lack of funding, and funding consistency, in relation to assistive technology

Recommendations:

- a) Consistent and transparent funding avenues be made available for the prescription and provision of assistive technology; and
- b) Assistive technology funding is made available in addition to home support funding within HCP and CHSP programmes to ensure polio survivors 65 years and over living

with a disability can maintain their independence, quality of life and community access; and

- c) State and federal governments develop a long-term, sustainable solution to the equitable provision of assistive technology to all Australians, regardless of age.

Issue 6: Lack of knowledge and/or training by aged care workers regarding disability and specific health conditions

Recommendation:

- a) Investment in disease-specific training packages for the aged care sector workforce that address the disability needs of polio survivors over the age of 65.

Issue 7: There is inconsistency in the level of care available between different geographical regions

Recommendation:

- a) Investment in programmes to support health infrastructure and employment retention in regional and remote Australia.

Introduction

Polio Australia, the national peak body for survivors of polio living in Australia, welcomes this opportunity to provide a submission to the Royal Commission into Aged Care Safety and Quality ("the Royal Commission").

During the mid-20th century, from the 1930s to the 1960s, approximately 40,000 cases of paralytic poliomyelitis were reported in Australia. There were also unspecified numbers of unreported or misdiagnosed cases, many due to the stigma attached to having 'polio'. There have additionally been many people migrating to Australia having survived polio in their country of birth. There is, therefore, no consistent information on the exact numbers of polio survivors living in Australia, although the figure can be confidently assumed to be in the thousands.

While people who contract polio may go on to make a full or partial recovery, the Late Effects of Polio can manifest 15 or more years after the initial infection and lead to new or increasing impairment or disability. The Late Effects of Polio (LEoP) includes the diagnosable neurological condition known as Post-Polio Syndrome, and can include symptoms such as debilitating fatigue, progressive muscle weakness, chronic muscle and joint pain, breathing and sleep issues, poor thermoregulation, and speech and swallowing disorders. The LEoP also includes high rates of osteoporosis/osteopenia, osteoarthritis and postural abnormalities such as scoliosis or kyphosis as a result of muscle weakness and prolonged compensatory postures and movements.

The majority of polio survivors in Australia are now aged 65 and over. Currently there is inequity in government support of people living with polio-related disability or the Late Effects of Polio. People under the age of 65 diagnosed with a progressive neurological condition such as Post-Polio Syndrome are eligible for the National Disability Insurance Scheme (NDIS) to access supports that meet their individual needs. However, when the National Disability Insurance Scheme was enacted in 2013 it included an exemption of the NDIS to the Age Discrimination Act 2004. This allows for the restriction, or ineligibility, to the NDIS for people aged 65 years and over.

Unfortunately, there has not been a review of this exemption to age discrimination after two years of the NDIS Act, as recommended by the Parliamentary Joint Committee on Human Rights, Examination of legislation in accordance with the Human Rights (Parliamentary Scrutiny) Act 2011 recommended in 2013¹. Therefore, when the NDIS was made available in their area, polio survivors aged over 65 were ineligible for the system designed to support people with disability. This is despite most polio survivors living with their disability from a young age, and having paid, or made significant co-contributions, to support their disability-related needs. Unlike the NDIS, the aged care system is capped, means tested and designed to address ageing and not disability. This inequity has the likely effect of causing significant financial hardship, reducing choice and control, or forcing people to move into residential aged care prematurely.

¹ Bills Digest no. 72 2012–13. http://www.austlii.edu.au/cgi-bin/viewdoc/au/legis/cth/digest/ndisb2012351/ndisb2012351.html?context=1;query=disability;mask_path=au/legis/cth/digest

Additionally, inadequate assessment for people with the Late Effects of Polio has led to problems with the level of care recommended. This leads to delays in recommendations for appropriate levels of support. Therefore, polio survivors may have longer wait times, increased financial burden and stress, and an inappropriate level of care. This increases stress to their current function and the capacity for family, friends and health care providers to support their functional needs. Further, the recommended level of care often fails to take into account the ongoing needs for assistive technology, which may be highly-customised and expensive.

Appropriate funding in aged care is required to support people to remain in their homes if they choose to do so, or to incorporate their disability-related needs in residential care. Funding should also be provided for assistive technology, education and training for interdisciplinary teams to understand and manage older Australians living with a disability, and supports to allow people to participate in community life.

Terms of Reference

Polio Australia's submission relates to the following terms of reference of the Royal Commission:

- a) the quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response;
- b) how best to deliver aged care services to:
 - i. people with disabilities residing in aged care facilities, including younger people;
- c) the future challenges and opportunities for delivering accessible, affordable and high quality aged care services in Australia, including:
 - i. in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and
 - ii. in remote, rural and regional Australia;
- d) what the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe;
- e) how to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters;
- f) how best to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure.

Data Collection for this Submission

Polio Australia has worked with polio survivors over the past ten years, and over this time has gathered information, case studies and stories from polio survivors. For this submission, Polio Australia has collected information and data through:

- in-depth discussion with over 20 polio survivors
- feedback and comments from polio survivors through email, phone and social media
- informal focus groups about My Aged Care (at annual Polio Health and Wellness Retreats)
- written accounts / personal stories from polio survivors

Key Issues and Recommendations

1. Aged care funding is insufficient for the complex needs of older Australians living with a disability

There are thousands of older Australians living with disability, including those with the Late Effects of Polio. The recent introduction of the NDIS provides a framework to support people with disabilities, but due to an exemption to the Age Discrimination Act it does not include people with a disability over the age of 65. The aged care system, unlike the NDIS, has not been designed to support the needs of people with disabilities. Instead, the focus of support is on needs related to ageing. The level of care and funding eligibility to support independence is not based on the needs of individuals with complex, progressive disabilities. This can lead to financial hardship, stress and an inappropriate level of care.

Unlike the NDIS, aged care funding is capped and means-tested, often leading to grossly inadequate funding allocations for those with complex needs due to disability. There are often significant out-of-pocket expenses for an older person with a disability, due to the increased need for assistive technology, specialist medical and other healthcare appointments, surgeries and medications. This is in addition to the accepted higher medical costs associated with ageing. Polio survivors over the age of 65 will often have reduced disposable income due to early retirement or having worked reduced hours, creating financial strain in dealing with these costs.

While the increased out-of-pocket expenses for people with disability are acknowledged and supported through the NDIS, people over the age of 65 years do not have financial support for their increased medical and equipment costs. State disability support programmes provide some money to the cost of equipment, but often do not cover the costs of equipment, leaving significant gap fees.

In recognition of increased medical expenses, during the financial years 2015/2016-2018/2019 there were net medical tax offsets available for medical expenses incurred, less any refunds from NDIS or private health insurers. From 1 July 2019, this offset will no longer be available. The removal of this tax offset, at the time of the NDIS rollout, is another financial hit to people with a disability over the age of 65.

Paul (NT), polio survivor: "I had a my aged care assessment after I had a fall and fractured my femur. My femur healed with a slight bend which meant my KAFO no longer fitted and a new one was required to enable me to get back on my feet. I am not eligible for NDIS because of age nor aged or disability pension through Centrelink because my wife earns too much. We are not rich and the \$10,000 to get new orthotics hurts. Not good being caught in the middle."

Gillian (NSW), polio survivor: *"I am very disappointed to have lived with a serious disability, contributed substantially to the tax system and received very little help when I really need it."*

RECOMMENDATIONS:

1. Review the need and legality of the continued exemption under the Age Discrimination Act sought by the NDIS to exclude people over the age of 65 from the NDIS and consider removing this exemption; and
2. For the complex needs of older Australians living with a disability, aged care funding aligns with NDIS funding, i.e. is not means-tested or capped; or
3. As a minimum, the NDIS develops a safety net model that provides funding to address needs not met by aged care; and
4. Tax offsets for medical expenses be reinstated where public and private health insurance and government subsidies do not adequately contribute to the costs for people with disabilities.

2. Lack of recognition of disability and the disability-related needs of older people within the aged care system

In December 2017, the Department of Health released the Aged Care Diversity Framework. The framework aims to "...embed diversity in the design and delivery of aged care; and support action to address perceived or actual barriers to consumers accessing safe, equitable and quality aged care..."²

Polio Australia commends the development of targeted action plans to respond to the needs of Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds and people who identify as Lesbian, Gay, Bisexual, Trans, Gender Diverse and Intersex. However, given the complexity and unique circumstances that are experienced by Australians over the age of 65 who have a permanent and severe disability, Polio Australia calls for the Department of Health to also commit to developing an action plan to also address the specific needs of this vulnerable cohort. It is important to recognise that the needs of older people with disabilities are often more complex than those of others seeking support through aged care.

The appropriate level of care in the aged care setting is not being met, partly due to assessment and care being based on a medical model. A holistic approach that considers ongoing disability and the needs of people to complete activities and participate in communities is required. This framework is consistent with the principles that underpin current disability policy landscape (including the NDIS) where assessment and support looks beyond just disability. By focusing solely on a medical model, people will not receive an appropriate level of care.

² Aged Care Sector Committee Diversity Sub-group (2017) "Aged Care Diversity Framework (Publications Number: 12028)" accessed 15 August 2018 <https://agedcare.health.gov.au/support-services/people-from-diverse-backgrounds/aged-care-diversity-framework>

A holistic approach would ensure clients' needs are met, both on a medical and disability model. The risk otherwise remains, that a client with assistive technology is viewed as able, whereas they would not be able to function without their aids and equipment, and they would not receive the appropriate plan or package. This risk can be overcome by taking into account their ongoing disability and need for assistive technology in order to complete daily activities.

A person with Post-Polio Syndrome may be independent with their domestic activities of daily living while wearing their customised lower-limb orthosis. They may not be able to walk safely without the orthosis, and therefore be at significant risk of falls. The orthosis may require regular maintenance, and may need to be replaced on a 5-yearly basis due to the person's progressive condition. An uninformed assessment, using a medical model, may determine that this person is independent and recommend a low level of funding for services, or no services at all, not taking into account their inability to function safely without the orthosis or the need for funding assistance for maintenance and upgrading of equipment.

RECOMMENDATIONS:

1. The Department of Health develop targeted action plans to address barriers to accessing safe, equitable and quality aged care for those over 65 living with disability; and
2. An integrated care model focused on health, function and participation is adopted by the Department of Health to adequately address the disability needs and support of older Australians.

3. Inappropriate and inadequate level of assessment for people with disability and specific health conditions

The initial screening of referrals and subsequent assessment by aged care assessment services should be undertaken by health professionals who are appropriately trained in progressive neurological conditions. Currently, a referral is triaged to either the Regional Assessment Service (RAS) or Aged Care Assessment Team / Service (ACAT/ACAS). Based on an initial review of a polio survivor's current capacity, referrals are often made to the RAS for a Commonwealth Home Support Package (CHSP). These assessments are often conducted by a staff member without a health-related qualification to determine the ongoing support needs of someone with a progressive neurological disability to live independently. The level of support recommended within an assessment may not consider the resultant fatigue that can occur for someone to perform activities independently and thus, their true capacity to consistently perform these tasks.

If the RAS assessor does identify risk factors that would require additional support beyond the level of a CHSP, the polio survivor can be penalised with increased waiting time to be referred again for an assessment and re-allocated an initial assessment with the ACAT/ACAS for a Home Care Package (HCP). This separation of assessment creates

inefficiency that could be avoided if a thorough and comprehensive assessment was initially conducted that considers disability.

The ACAT/ACAS teams are comprised of allied health or nursing qualified health professionals. They are skilled to work in ageing and frailty; however, they may not have an understanding of neurological conditions. The recommendations often provided by these teams to reduce the effects of ageing can in fact accelerate and exacerbate signs and symptoms of the Late Effects of Polio.

Appropriate screening and assessment by health professionals trained in understanding neurological conditions, risk factors and the supports that are often required for people living with a progressive neurological condition will ensure people have adequate support in place. This should include consideration that support may need to be increased on a flexible or long-term basis.

An assessment for someone with a long-term, progressive disability should include the following elements:

- Symptom variability that can affect someone's need for support, and caregivers' capacity to contribute to this support
- Assistive technology (especially aids and equipment)
- Flexible respite options (for both the person with the condition and their carer/s)
- Appropriate therapy/health service supports with the level of hours of support adequate to ensure a person can remain at home
- Support for the primary caregiver and family to return to their own personal pursuits and roles

It would be beneficial to ensure that assessors determining eligibility and appropriateness of care have an appropriate professional health background (e.g. a Nurse or Occupational Therapist with knowledge and training in neurological conditions). Additional training in managing specific complex disabilities could also be provided to aged care providers, state health services, palliative care organisations and by peak support organisations, such as Polio Australia.

Fran (VIC), polio survivor: "I no longer expect anyone to know about Post Polio Syndrome so spend time describing the problems and providing written material for the individual and organisation."

Sally (VIC), polio survivor: "Four months after my application, I am finally on a waiting list for a scooter." Sally requires a scooter to undertake her everyday activities, however the unpredictability of a waiting list does not reassure her. "I asked for a smaller scooter than they assigned me so I could manage it better but they denied my request." Sally echoes the experience of many polio survivors, "I know what my needs are better than anyone but they don't listen."

RECOMMENDATIONS:

1. Comprehensive, thorough initial assessments conducted by trained health professionals for people who have progressive neurological conditions; and
2. Investment in training packages for the aged care sector workforce that address disease-specific and disability-related needs of older Australians.

4. Lack of available support and funding for assessed care needs

The unmet need for home care packages and accessible home accommodation options is leading to increased disability, health impacts and undue stress on older Australians and their families. Polio Australia recognises and congratulates the Australian Government on the recent release of an additional 10,000 level 3 and level 4 home care packages. However, the wait times and demand for support are still too high. Polio Australia supports the Council on the Ageing (COTA) recommendation for at least 30,000 additional packages to ensure older Australians never have to wait longer than three months.³ The delays in assessment and delivery of support services for people with a progressive neuromuscular condition results in the risk of implementing recommended services that no longer reflect the person's current support needs.

The wait times do not reflect the true extent of the problem as people wait for an assessed high level package and are offered a lower level package after waiting months, or over a year, for support. A lower level package does not provide the assessed support needs but often is accepted as it becomes increasingly difficult to remain at home with declining health and function and without the financial assistance required to remain living independently.

Long wait times, without adequate support to enable someone to remain living at home, increase the risk of admission to residential care before it otherwise would have been necessary. For people with a disability looking for residential care, there are limited options and this can lead to further declines in health that could be avoided with appropriate and timely care and intervention.

Gillian (SA), polio survivor: "I was assessed at Level 2 because I shower myself, organise shopping, cook for myself. That was last July 2018 and despite enquiries I haven't heard from them since. The home care supposed package waiting time is a disaster... perhaps if I got it I could actually afford to get out now and then."

Anon polio survivor (SA): "Took me 14 months and having my name down at several homes before getting a bed. Only happened then as I ended up in hospital chronically ill and refused to leave until bed in nursing home was found."

³ COTA Australia Position Paper. Keep fixing Australia's aged care system. September 2018, p.8. <https://www.cota.org.au/publication/keep-fixing-australias-aged-care-system/>

RECOMMENDATIONS:

1. Investment within residential aged care facilities to compensate for the additional needs of older Australians living with disability requiring residential care; and
2. Investment of 30,000 additional home care packages within the next 12 months to support polio survivors and other Australians waiting for home care packages to continue to live at home.

5. Lack of funding, and funding consistency, in relation to assistive technology

The two main programmes for supporting Australians over the age of 65 (CHSP and HCP) do not have clear funding structures to address the assistive technology needs of people living with a disability. As discussed above, when the NDIS was established, those living with a disability over the age of 65 years were ineligible for inclusion. State-subsidised funding for some aids and equipment (e.g. Enable in NSW, SWEP in Victoria, CAEP in WA, etc) provides some assistance with the costs of items such as customised footwear, orthoses, scooters and wheelchairs. However, there is inconsistency between states as to whether this funding continues upon the commencement of aged care funding, particularly HCP. There is limited coverage under some private health insurance.

The federal government has identified the ongoing need for subsidised equipment for people over the age of 65, however the certainty and funding arrangements are unclear. The current arrangements are for existing clients of state disability services to access a similar level of support under CHSP funding and state government subsidies. Alternatively, funding may be available via the Continuity of Support (CoS) Programme or HCP. As the NDIS becomes established, it is unclear how state services will be funded and continue to operate. The recent federal budget released confirmation of funding for CHSP until 2022, however the long-term funding of the CHSP and CoS beyond this date is unclear. The CoS programme commenced in December 2016 and is yet to have had a full review of the framework and support services it is designed to deliver.

The current funding arrangement for CoS does not recognise that an existing client of state disability services would need further support. Rather, it only allows the person to continue with a similar level of funding. This does not recognise the progressive nature of some disabilities, like Post-Polio Syndrome, where equipment needs, and costs, will increase over time. Secondly, the CoS programme is limited in its funding and does not adequately allow for assistive technology, which plays a vital role in supporting a person with a disability not just to remain at home but to participate meaningfully in their community (please see above under point 2 regarding the aged care system not recognising disability needs of older Australians). Lastly, the needs of an ageing population are most likely going to increase with age. If the CoS will not cover this, it places additional need for more comprehensive funding within aged care packages for assistive technology and care.

Assistive technology enables polio survivors to manage muscle weakness/paresis, fatigue and pain. While these symptoms often occur irrespective of age, polio survivors 65 years and over are grouped with people acquiring a disability due to the ageing process and/or experiencing frailty. All needs are important and should be addressed, regardless of age or disability. Polio Australia wish to emphasise the financial burden and

out-of-pocket expense polio survivors have had, living with their disability to pay for aids and equipment throughout their lifetime. This has led to polio survivors being unable to meet the costs of assistive technology and forgo the benefits of this assistance due to financial barriers, particularly as they no longer have an income to afford expensive items. Assistive technology has been poorly subsidised or not subsidised at all which has affected a polio survivor's capacity to accumulate wealth and to have funds available in later years for ongoing, and often increasing, assistive technology expenses.

Polio Australia supports The Assistive Technology for Older People (ATOP) Alliance in calling on the Australian Government to develop a National Assistive Technology Programme. We believe the Disability Reform Council should be engaged to explore the benefits of establishing a national aids and equipment programme for people with a disability over 65.

Polio Australia is calling for Commonwealth and state governments to resolve assistive technology funding for older Australians with disability.

Bruce (WA), polio survivor, had an OT assessment and was recommended a wheeled shower commode and electric hospital bed. *"As I am 84 years old I am unable to access any support through NDIS. My Home Care Plan does not have the money in it to be able to afford such items."*

Margaret (NSW), polio survivor: *"Level of care is not in proportion to my needs. For now I am fairly low care but confined to Electric Wheelchair which I had to purchase myself. So far I have had to fund my own equipment. There has not been any offer of help in that direction. I am very disappointed that there is no funding for essential equipment as I am not eligible for NDIS."*

Reginald (NSW), polio survivor, was approved for a Level 4 package 2.5 years ago and was offered a lower level package while he waited. He declined as the lower level packages were inadequate for his care needs, and has since been on a Commonwealth Home Support Package for domestic assistance and daily personal care. This is enough for now, but his needs are likely to increase. His complex and expensive equipment needs (hoist, power wheelchair) have, until now, been funded by the state government's Enable NSW programme. Now that Reginald's Level 4 package is available, he's facing a dilemma. It might provide him a higher level of care, but who will fund his assistive technology into the future when he's ineligible for state funding? *"I'm ok with equipment for now. But if I go to the package now, I can't go back."*

RECOMMENDATIONS:

1. Consistent and transparent funding avenues be made available for the prescription and provision of assistive technology; and
2. Assistive technology funding is made available in addition to home support funding within HCP and CHSP programmes to ensure polio survivors 65 years and over living with a disability can maintain their independence, quality of life and community access; and
3. State and federal governments develop a long-term, sustainable solution to the equitable provision of assistive technology to all Australians, regardless of age.

6. Lack of knowledge and/or training by aged care workers regarding disability and specific health conditions

Polio Australia recognise and thank health, disability and aged care professionals for their treatment, management and support with polio survivors. There have, however, been instances too frequently reported to us regarding limited knowledge on recognising, testing and treating the specific symptoms characteristic of the disability polio survivors experience. A solution to this gap in knowledge is for the aged care sector, and relevant health and disability providers, to invest in training packages to support staff working with progressive neuromuscular conditions, such as the Late Effects of Polio. Short courses that explain the condition, symptoms, common treatment and management techniques, and important safety advice regarding falls prevention and maintaining physical function, are needed to prevent further disability and increased costs related to hospitalisation and rehabilitation. There is a lack of understanding in the workforce regarding the effects of disability separate to the ageing process, which is causing accelerated declines in function and reduced quality of life.

Anon polio survivor (SA): "Physios have no understanding of appropriate exercises around pain/fatigue issues... Carers not remembering about issues around limb placement/movement range."

Gillian (NSW), a polio survivor diagnosed with Post-Polio Syndrome, sustained a fall that resulted in a double-fracture of her pelvis. This occurred while being supported by a domestic worker unfamiliar with neurological limb weakness. Gillian is now looking at her options in aged care. "Because of this fall, I have completely lost my independence, cannot rely on paid help and am lucky to have kind friends. I did receive help but no longer have any confidence in the provider after the terrible fall. After a lifetime on crutches and a calliper plus a very weakened right leg to boot I wish to remain at home as long possible.... If only one could find a reliable and informed person who understands the situation and does not lump one in with 'old age'. Awareness and training of polio and its implications is really missing."

Bruce (WA), polio survivor: *"The workers who are my carers acknowledge that they have no training in assisting people with disabilities which include paralysis and the subsequent mobility and support issues. I am fortunate in that most of the time I have the same carers who know my needs and are able to deal with my showering needs. However, it is a concern when relief staff have to fill in as they are not aware of what is needed and I am concerned that I might have a fall while in their care. Often I am the first person with paralysis that they have ever had to care for."*

RECOMMENDATION:

1. Investment in disease-specific training packages for the aged care sector workforce that address the disability needs of polio survivors over the age of 65.

7. There is inconsistency in the level of care available between different geographical regions

Polio Australia supports and acknowledges clinical and support workers across health, disability and aged care. There is genuine concern regarding the health disparity of Australians living in regional and remote locations compared to cities. The health interface between aged care and access to GPs and allied health professionals is crucial to the effective management of complex health conditions and disability. Access to GPs and the costs of health care providers, especially relative to the income of people living in regional and remote Australia, is important to consider if we are to support Australians who are ageing.

There is an increased need for appropriately trained and experienced health and medical professionals in regional locations given they often have a greater proportion of older Australians⁴. Polio Australia encourages continuing development of programmes to facilitate remote and regional health infrastructure and training and development in line with the funding in metropolitan areas to support the health of older Australians. Polio Australia also acknowledge the need for measures to support the retention of the health, disability and aged care workforce in regional Australia. This may involve extension of programmes that offer employment opportunities and career pathways to ensure wage parity across the industry (e.g. the difference between a Registered Nurse in an aged care facility versus a hospital) and higher living costs in regional towns compared to metropolitan centres⁵.

⁴ Australian Institute of Health and Welfare (2018). Australia's health 2018. Australia's health series no. 16. AUS 221. Canberra: AIHW

⁵ Australian Council of Social Services (2015). Inequality in Australia. Sydney: ACOSS. p50.
https://www.acoss.org.au/wpcontent/uploads/2015/06/Inequality_in_Australia_FINAL.pdf

Margaret polio survivor (NSW): *"I had to answer on the day of contact between a choice of 3 residential establishments to live as I could not live independently. Access to the capital city Rehabilitation Specialist is extremely difficult [12 ½ hr drive]. I have limited access to a G.P."*

RECOMMENDATION:

1. Investment in programmes to support health infrastructure and employment retention in regional and remote Australia.

Conclusion

The aged care system is designed to address the needs of people who are ageing. It unfortunately does not meet the needs of people living with a disability. The aged care system requires further assistance for people living with a disability such as the Late Effects of Polio to meet the considerable needs of assistive technology. There also needs to be greater awareness related to disability and neurodegenerative conditions, including an understanding of how symptoms differ from ageing and the progressive nature of such conditions, requiring increasing levels of support and funding.