

**New Aged Care Act Rules consultation – Release 2a –
Funding for Support at Home program**

Spinal Cord Injuries Australia
Submission December 2024

About SCIA

SCIA is a for-purpose organisation working for people living with spinal cord injury (SCI) and other neurological and physical disabilities. SCIA was founded by people with SCI over fifty years ago; people with disability make up over 35% of our staff, 25% have an immediate family member with disability and the majority of our Board live with SCI.

SCIA is national and member-focussed, serving over 3,000 members made up of people living with disability, their family, carers, researchers, and other professionals in the sector. SCIA's Systemic and Representative Advocacy Team work closely with our members to understand their aspirations and concerns and to promote full inclusion for our members living with disability.

About Spinal Cord Injuries

A spinal cord injury (SCI) is a complex and permanent disability. At least one new SCI happens every day in Australia, making an approximate total of 20,800 Australians with a SCI¹. Accidents such as SCI can happen to anyone at any time and 40% of new SCI's are in people who are aged 60 and above – parents and grandparents entering retirement.

People who acquire disability under the age of 65 have access to needs assessed support in the National Disability Insurance Scheme (NDIS) however, those who acquire disability at or after 65 are, by legislation, excluded from the NDIS and directed to My Aged Care. Many such people, if it were not for their disability, would not need to access aged care services for many years.

People who are on the cusp of retirement deserve to be supported in the same manner as their 64-year-old peers.

Introduction

The Aged Care Bill and associated changes including the new Support at Home program, offered a once in a decade opportunity to redress the inequity for people who acquire permanent and complex disability after the age of 64. Unfortunately, with the Legislation and associated rules, including the Support at Home levels being capped of \$78,000, co-contributions, capped home modifications and capped assistive technology, we continue the policy of inequity.

The Aged Care Royal Commission recognised this inequity and, in recommendation 72 entitled "Equity for people with disability receiving aged care" stated: "By 1 July 2024, every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person under the age of 65 years with the same or substantially similar conditions²".

SCIA understands that in this current fiscal environment, such equity is unlikely, and in this submission, we make a number of specific and targeted recommendations to improve outcomes for

¹ SpinalCure Impact Report 2022

² Royal Commission into Aged Care Quality and Safety (2021). Final Report: Care, Dignity and Respect

those with disability who are adversely impacted by the proposed funding arrangements. We also attach our Policy Brief as Appendix A below, written before the passing of the Legislation because it remains illustrative of the personal circumstances of many of the people with complex and permanent disability who rely on Support at Home funding.

Member Consultation

SCIA has been working with our engaged group of members aged 65 and over to discuss their *My Aged Care* questions, concerns and recommendations. Our submission and Policy Brief are based on feedback and recommendations through this consultation process.

In our submission we will focus on the issues particularly relevant to the members impacted by the changes to Support at Home funding including: the subsidies for home support, assistive technology and home modifications as well as the co-contribution process.

Chapter 7—Funding of aged care services—Commonwealth contributions

Part 2—Subsidy for home support

The detail in this chapter outlines the Support at Home ‘levels’ which have a maximum amount set at level 8 of \$78,000 per annum, made up of \$192.33 per day (with 10% Care Management Costs) for all at home supports including, clinical (such as nursing), independence (such as personal care) and everyday living (such as gardening and cleaning).

Part 3—Subsidy for assistive technology

Persons with a diagnosis that includes one of the listed disabilities: cerebral palsy, epilepsy, Huntington’s disease, motor neurone disease, multiple sclerosis, Parkinson’s disease, polio, spinal cord injury, spinal muscular atrophy, stroke, other acquired brain injury, muscular dystrophy or muscular atrophy are eligible for Assistive Technology under three levels with a maximum amount of \$15,000.

Part 4—Subsidy for home modifications

All older persons have access to three levels of funding for Home Modifications with a maximum amount of \$15,000.

Chapter 8 —Funding of aged care services—Individual fees and contributions

Part 2—Means testing

(Division 1 - In a home or community setting)

Older persons utilising Support at Home services are required to make a means tested co-contribution in some circumstances. Clinical care is fully funded. Independence (personal care) requires a 5% co-contribution for a full pensioner and up to a 50% co-contribution for a self-funded retiree. Everyday living, as a less essential service, begins with a 17.5% co-contribution for pensioners and an 80% co-contribution for a self-funded retiree. A lifetime cap of \$130,000 is applied to co-contributions.

Impact on people with complex and permanent disability

SCIA welcomes the separation of home care support, AT and Home Modifications in the Legislation, yet we remain concerned that they are insufficient to enable people with complex physical disability to 'age in place' without significant personal savings. Most people with a complex condition such as quadriplegia will, at a minimum, require 2 hours personal care in the morning and evening (4 hours in total) to ensure basic activities of daily living such as getting out of and into bed, showering and toileting. This is a minimum amount, and many people will require additional supports for food preparation, cleaning etc.

Currently, with a capped amount of \$78,000 per annum a person receiving Support at Home will only be able to access 18 hours of care per week, 10 hours short of the minimum 28 hours care. Thus, for a person with quadriplegia it is not possible to 'age in place' without personal savings to make up the minimum short fall of 10 hours per week. The additional co-contribution of between 5% and 50% further reduces the support available.

Similarly, whilst the higher and separate provisions for Home Modifications and Assistive Technology are welcome, the \$15,000 falls short of the amount needed when adjusting to a SCI. Custom power wheelchairs, hospital grade beds and hoists, essential for a person with SCI cost in excess of this amount – again meaning that 'aging in place' for a person with a complex physical disability is not an option without a team of family assistants and personal savings.

Recommendations

Much of the costs outlined above are required whether a person be in residential aged care or in their family home. For example, a power wheelchair is essential Assistive Technology to enable a person with complex physical disability such as quadriplegia to mobilise and participate in an aged care facility as well as in the community. Similarly, care at home, and care a residential aged care facility both have financial implications. Therefore, there are several financial levers that could be utilised to better support people with complex physical disability to 'age in place'.

Recommendation 1: As outlined in the Policy Brief below, SCIA still calls for a 'needs assessed supplement' for those receiving Support at Home to bring them up to the level of those 64 and under supported through the NDIS.

However, if this is not adopted, we propose the additional and alternative recommendations below that will advance the support for those 65 and over within the framework of the new Aged Care Act Rules giving them an improved opportunity to 'age in place' until such time as their reasons for entering residential aged care are age related (not disability related).

Recommendation 2: at a minimum the Commonwealth must adopt a 'no worse off' principle by enabling anyone better supported through a Home Care Package to retain that level of support for life. Many people over 65 have been eagerly awaiting the new legislation anticipating equitable, or at least improved supports, these people are already disappointed. If, for example, a self-funded retiree finds that their level of supports is reduced under Support at Home, they should not be further disadvantaged and should be able to remain on their existing Home Care Package.

Recommendation 3: Consideration should be given to waiving the co-contribution for people in the disability categories listed in Division 2, section 211B. This would – without increasing

commonwealth spending – offer increased financial assistance by way of reduced contributions that may allow a subset of those with permanent and complex disability to ‘age in place’.

Recommendation 4: utilising the 2022 (yet to be published) Deloitte Study comparing the cost of home care with the cost of residential aged care, consideration be given to a ‘needs assessed’ supplement for people who prefer to ‘age in place’. This amount would not necessarily need to exceed the total comparative cost that would otherwise be required to support this person in residential aged care. Safety concerns notwithstanding, dignity of risk for an older person who, were it not for their disability, would require no aged care support should enable such a choice – indeed currently many people receiving a Home Care Package are already making such a choice.

Recommendation 5: an additional annual supplement, of up to \$50,000 could be paid to those in the disability categories listed in Division 2, section 211B to bring them in line with their NDIS counterparts.

Conclusion

As so well-articulated by the Hon Anika Wells, Minister for Aged Care, “Older Australians who have contributed so much to Australian society rightly expect to be well supported in their frailer years”³. The current Aged Care Act Rules do not allow this for those 65 and over with permanent and complex disability.

SCIA remains committed to eradicating the age discrimination that leads to unequal supports for people 65 and over. No one should need to enter a residential aged care facility solely because of disability. We call on the Commonwealth Government to implement Recommendation 72 from the Aged Care Royal Commission.

However, we also believe that any measure that enables more people with complex and permanent disability such as SCI to ‘age in place’ should be considered in the interim. Therefore, we ask that the Department give due consideration to recommendations 2-4 in this submission to create a better future for the older person, parents and grandparents, who have already had their lives disrupted by permanent and complex disability.

Appendix A – SCIA Policy Brief, Achieving equity for those aged 65 and over.

³ A New Program for In-Home Aged Care, Discussion Paper, 2022

POLICY BRIEF

Achieving equity for people who acquire disability at 65 or older.

If you acquire a disability such as Spinal Cord Injury (SCI) at age 64 you will receive tailored supports that enable you to participate in your community. If you acquire a disability such as SCI at age 65, you will not have access to disability supports. This glaring inequity needs our urgent attention.

Introduction

Acquiring a complex and permanent disability, has lifelong effects. However, with appropriate support people with disability such as Spinal Cord Injury (SCI) or Acquired Brain Injury (ABI) can continue to live fulfilling lives.

People who acquire disability under the age of 65 have access to needs assessed support in the National Disability Insurance Scheme (NDIS) however, those who acquire disability at or after 65 are, by legislation, excluded from the NDIS and directed to My Aged Care. Many such people if it were not for their disability, would not need to access aged care services for many years.

At least one new SCI happens every day in Australia, making an approximate total of 20,800 Australians with a SCI¹. It is estimated that one in forty-five Australians has an Acquired Brain Injury (ABI)². Data about significant acquired disabilities such as SCI and ABI collected over the past decade shows that people are increasingly having their injuries later in life. In 2023, 40% of Australians who acquired a SCI did so when over the age of 65³ and people over 65 are twice as likely to have an ABI that limits their ability to participate in the community.

The Hon Anika Wells, Minister for Aged Care stated, “Older Australians who have contributed so much to Australian society rightly expect to be well supported in their frailer years”⁴.

¹ SpinalCure Impact Report 2022

² Australian institute of Health and Welfare, Disability in Australia: acquired brain injury, Bulletin 55, December 2007

³ Data provided on request by the NSW Agency for Clinical Innovation.

⁴ A New Program for In-Home Aged Care, Discussion Paper, 2022

Unfortunately, this does not apply for older Australians with disability because My Aged Care is designed for the frail aged and offers inadequate support to those with complex disability.

The Aged Care Royal Commission recognised this inequity and, in recommendation 72 entitled “Equity for people with disability receiving aged care” stated: “By 1 July 2024, every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person under the age of 65 years with the same or substantially similar conditions⁵”.

Recommendation 72 has not been adequately acknowledged. The new Aged Care Legislation references Australia’s obligations under the UN convention on the Rights of Persons with Disabilities (CRPD) once⁶ and otherwise solely refers to “frail and aged” persons. Consequently, aged care supports are not funded or tailored to meet the needs of older persons with complex disability.

People aged 65 years or over who acquire a permanent complex disability and who have insufficient personal funds to supplement their assistive technology, home modifications and ongoing care needs at home are forced into residential aged care.

Once in residential aged care, older Australians often face the added injustice that personal care and nursing supports otherwise targeted for the “frail and aged” are insufficient due to their complex disability.

SCIA members call on the Australian Government to immediately address the arbitrary inequity faced by those 65 and older who acquire a permanent and complex disability.

Disability Supports in the Community

People over 65 who have complex and permanent disability do not have access to disability supports in the community.

The comparative figures provide a stark picture:

- The average payment for a participant of the NDIS with an SCI in 2022/23 was \$150,600⁷.
- The cost of supporting a person with a severe SCI, quadriplegia, living in the community is approximately \$200,000 annually⁸.
- The new Aged Care Legislation and associated Support at Home funded *levels* increases the maximum amount of funding for personal care from \$60,000 to \$78,000 per annum. Whilst this is a welcome increase, it still falls far short of the supports offered to NDIS participants.
- Translated into care hours the additional funding amounts to 4 hours per week, insufficient for a person with permanent and complex disability to remain at home.

⁵ Royal Commission into Aged Care Quality and Safety (2021). Final Report: Care, Dignity and Respect

⁶ Exposure Draft, Aged Care Bill 2023, Part 1, Section 5

⁷ NDIS Spinal Cord Injury Summary Insights, June 23

⁸ Comparing Aged Care and NDIS Support, A funding analysis, Leading Age Services Australia, January 2021

Those 65 and over with permanent complex disability and their loved ones are faced with heartbreaking decisions to finance basic personal care needs, such as toileting and transferring to and from bed, including:

- selling their homes;
- partners returning to paid employment following retirement;
- moving into residential aged care; and
- relying on elderly partners or family for complex personal care needs

Alternatives such as these place extreme strain on individuals and their families.

A 2021 study conducted by Leading Age Services Australia found that “There is a substantial difference in support between aged care and NDIS programs. This appears to reflect differences in the hours of care available, though differences also exist in the level of support for reablement, social engagement, behaviour support, care management and assistive technology”⁹.

Shauna and her husband Steve are both active members of their community who worked until retirement age saving for a shared future. Shauna sustained C4 quadriplegia following a cycling accident. Shauna’s disability means her legs are paralysed, her bowel and bladder functions are impaired, and she has limited use of her arms and hands, otherwise, she is mentally fit and active. Because Shauna is over 65, she is supported through My Aged Care (something she would not need to access were it not for her disability) with a Level 4 Home Care Package. Shauna’s package only covers her morning care for six mornings a week. There is nothing remaining in the package to cover the seventh morning, evening care, nursing, respite, allied health, or equipment. Most of her care is provided by Steve, who is 85 years old, or purchased at their own expense. As Steve ages, Shauna’s only alternative will be to move into residential aged care. Steve and Shauna have been advocating for adequate support for over 10 years and feel utterly disregarded following a lifetime of hard work and contribution.

**Names in case studies have been changed to respect privacy of members.*

Assistive Technology and Home Modifications

People over 65 who have complex and permanent disability do not currently have access to sufficient Assistive Technology (AT) or Home Modifications.

Australia’s Disability Strategy 2021-2031 requires that: “People with disability have access to a range of supports to assist them to live independently and engage in their communities.” This is outlined in Priority 4, that says, “people with disability are supported to access assistive technology”¹⁰.

⁹ Comparing Aged Care and NDIS Support, A funding analysis, Leading Age Services Australia, January 2021

¹⁰ Australia Disability Strategy 2021-2031 The Strategy and supporting documents | Disability Gateway

Under the NDIS people are funded for low, medium, and high-cost AT according to their needs. A welcome change in the new Support at Home program is the separation of AT from the daily package amount. People 65 and over now have access to a separate total of \$15,000 for AT. Whilst this is an increase from the previous Home Care Package amount, with major items such as wheelchairs and hospital grade beds, people 65 and over still require personal funds to meet their AT needs or must use outdated equipment that risks further injuries. Lack of proper assessments and training further compounds their challenges, perpetuating a cycle of disadvantage and marginalization. SCIA members explain that commonly either elderly partners or children who may live some distance away are forced to provide support that, if appropriate AT had been provided, an individual could manage independently.

AT not only supports the individual but also saves on long term health costs. A 2020 Review of Assistive Technology Programs in Australia found that for every \$1 spent on assistive technology, there is a \$2 saving related to the potential cost of paid carers, support services, and medical services. An annual spend of \$16 billion dollars can save \$32 billion dollars¹¹.

Edward is a 77-year-old with quadriplegia who lives alone. Edward is supported by his son and through a Home Care Package. Edward tries not to rely too much on his son who has a young family and a full-time job. Edward requires a power wheelchair to access the community independently, however within his Home Care Package he does not have sufficient funds to upgrade his 10-year-old power chair. Edward during his early life had a high paid executive job. Following a brief break for rehabilitation he took on less challenging customer service work and maintained a steady income until retirement at 65. It is accurate to say that Edward has been a contributor all his life. He could not have foreseen, nor planned for, the quadriplegia he acquired in an accident 30 years ago. Edward now remains isolated in his home most days, experiencing depression and not wanting to be a burden on the community he once actively participated in.

Disability Supports in Residential Aged Care

People in residential aged care with permanent and complex disability require a level of support often unavailable in aged care facilities.

In 2020, the average annualised support in residential aged care for those with high needs was approximately \$104,000 with a maximum capped amount (inclusive of personal contributions and government contributions) of \$139,000 a year¹². This compares to the average high level specialist disability accommodation NDIS funding of \$199,601 with the amount for the highest impairment category having an average of \$493,170 a year¹³. People with permanent complex disability in residential aged care require specialist bowel and pressure care to avoid complications associated with their disability that is not available in many residential aged care facilities, or where it is available, there is, in many cases, a lack of knowledge about disability. Consequently, they are often either turned away from local and preferred facilities due to a lack

¹¹ Australian Healthcare Associates. Review of Assistive Technology Programs in Australia: Final Report and Supplementary Technical Report for the Australian Government Department of Health. Canberra: Department of Health. June 2020

¹² Comparing Aged Care and NDIS Support, A funding analysis, Leading Age Services Australia, January 2021

¹³ *ibid*

of nursing support or admitted but suffer medical complications such as pressure areas that can limit quality of life, or in severe cases lead to hospitalisation.

Roger developed Parkinsons in his 70's. He lived comfortably at home until a fall caused a spinal injury, leaving him in excruciating pain and leading him to a decided to move to residential aged care. The aged care facility Roger moved to had inadequate disability supports. Roger was not assessed by an Occupational Therapist for suitable equipment such as a tailored cushion for sitting, a wheelchair or an air mattress. Roger spent almost all the daytime in his room, in pain and seated in a standard chair. Within six months Roger had developed pressure sores on his back, his buttocks, and his lower spine which remained untreated for some time and ultimately caused a severe infection, nearly costing Roger his life.

Urgent Change is Required

In 2011, the Productivity Commission recommended the establishment of two schemes: the National Disability Insurance Scheme (NDIS) and the National Injury Insurance Scheme (NIIS). However, the NIIS scheme, was only partially established. Failing to deliver the completed NIIS has been a contributing factor in the increased costs of the NDIS¹⁴ and left those with complex permanent disability acquired at 65 and over inadequately supported through My Aged Care. SCIA members call on the Government to urgently address this inequity through the following actions.

ACTION: Specific reference to disability in all Aged Care Legislation (unless suitable alternative provisions such as inclusion in the NDIS or establishment of the NIIS are implemented).

ACTION: Provision of fair needs assessed supports for people with permanent and complex disability acquired at or after 65 years of age that:

- is sufficient to allow the choice of living independently in the community;
- includes sufficient morning and evening personal care and nursing as required; and
- includes a needs-assessed AT and Home Modification program.

This can be through an uncapped needs assessed supplement for those in My Aged Care who would qualify for NDIS support if under 65. It may be administered either by a specialist team within the aged care sector or contracted to the relevant NDIS team. Longer term, consideration should be given to complete establishment of the National Injury Insurance scheme separating those who acquire disability into this separately funded scheme.

ACTION: Mandated inclusion of assessments from Occupational Therapists trained in disability support for all people with disability who elect to enter residential aged care.

ACTION: Mandated training for aged care nursing staff and other workers to understand the daily physical support needs of people with disability.

ACTION: Provision of needs assessed AT to enable active participation for those with disability in residential aged care.

¹⁴ Completing the National Injury Insurance Scheme, A Key Sustainability Measure for the NDIS, Submission to the NDIS Review, Young People in Nursing Homes National Alliance, 2023.

This could be you, your Mother, Father or Grandparent. People 65 and over who have already had their retirement plans shattered by acquired complex and permanent disability have been continuously overlooked by repeated reforms and inquiries. The two-tier system we have created amounts to age discrimination and should be immediately addressed by implementation of the above actions.

Contact:

SCIA Policy and Advocacy Team, [REDACTED]

Appendix A, Additional Case Studies

Barry's Story

Barry, a 79-year-old quadriplegic who lives alone has found that when he is unable to get the support he needs "when I signed up, I was told that if I needed something and I saved up for it, I could have it. That worked for about 3-4 years but recently nothing is approved. My OT suggested I ask for a Thermomix because I am finding it hard to cook but it was rejected. I don't know why."

Grayson's Story

Grayson, an 80-year-old who is finding it hard to remain at home, is looking for a suitable aged care facility. He has visited several in his local area, but his power chair does not fit in the bathroom. Grayson feels trapped unable to remain at home and unable to find a suitable aged care facility to meet his needs. As Grayson explains "If I go to the spinal ward they know how to look after me. They can get me a special bed. If I go to my local hospital through general admissions, they don't know about SCI. The same goes for nursing homes, they won't know how to treat me. If there was a spinal aged care facility, I would sign up tomorrow".

Phillip's Story

Phillip acquired a SCI from a medical procedure. The \$60,000 Home Care Package did not cover the necessary home modifications, nor the \$120,000 required for his care annually. Phillip was fit and healthy at the time of his accident but at 67, was two years too old to access the NDIS. Ultimately after receiving informal care from his wife, Phillip moved into the only accessible and available aged care facility, over an hour's drive away from his wife and family. Phillip says "I just don't feel that because I am over 65 my life is worth less than someone who is 20. I feel like I am in prison in the aged care facility. Everyone around me has age related issues and I have only a physical disability - but I am unable to do anything. I want to be with my family and my dog".

Christine (Phillip's Wife's) Story

Because Phillip was in a wheelchair, he could not access the family home. However, paradoxically, to have the Home Care Package assessment that would fund home modifications, Phillip was required to be at home. Christine, at her own expense, modified the

house to bring her husband home for the assessment. Unfortunately, the \$60,000 did not cover Phillip's care requirements and Christine trained herself to be an informal carer, helping Phillip with his complex care needs, including toileting and transferring. Two years after the accident and after much stress, Christine had a heart attack and could not carry out her role as a carer. Phillip moved into respite, and later an aged care facility. Now, if Christine wants to see her husband, it requires a 2-hour round trip. If he wants to come home to see his family, it becomes a 4-hour trip for Christine. It is likely that the outcome would have been considerably different for this family if the accident had occurred when Phillip was eligible for NDIS support.

Iris's Story

Iris has paraplegia (acquired over the age of 65), her husband has Alzheimer's disease. Iris manages their Support at Home packages. Iris says, "I am FURIOUS about the way my government is treating me, expecting me to spend my life savings on transport, equipment, physio, etc. I received no home modifications apart from two ramps and a shower hose. Not one sink has been made accessible".

Iris also discusses the supports her friends in the NDIS receive, such as auto-opening curtains and custom wheelchair cushions, which she believes would significantly help her with daily activities. Iris raises another critical issue saying when she searches online for assistive technology and mentions that her funding is through My Aged Care, the suppliers will not reply. Iris would like to see the tighter controls in the NDIS so that funds can be spent on those over 65. She explains "Currently, I feel overwhelmed most of the time".