



ACT Disability Strategy 2022-2032

Summer Foundation submission to the ACT Disability
Reference Group

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The Summer Foundation acknowledges and thanks all staff and storytellers for their contributions to this submission.

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Introduction

The Summer Foundation welcomes the opportunity to make a submission to the ACT Disability Reference Group on the ACT Disability Strategy. It is crucial that the ACT Disability Strategy ensures an accessible community that improves the lives of more than 80,000 people with disability living in Canberra. To achieve this, it must strengthen the rights and choices of Canberrans with disability and build their capacity to live a good life.

The Federal Government developed [Australia's Disability Strategy 2021-2031](#) in line with Australia's commitments under the [United Nations Convention on the Rights of Persons with Disabilities](#) (UNCRPD). The strategy plays a vital role in protecting, promoting and realising the human rights of Australians with disability. It recognises that governments, leaders and citizens have a shared responsibility to build a society in which people with disability can participate as equal members with equal opportunities to fulfil their potential.

It is crucial that the ACT Disability Strategy:

- Provides statewide leadership towards greater inclusion of people with disability
- Guides public policy activity to be inclusive and responsive to people with disability
- Drives mainstream and disability-specific services and systems to improve outcomes for people with disability
- Engages and involves the whole community in achieving a more inclusive society
- Is co-designed by people with disability

The Summer Foundation is pleased to support the ACT Government to implement inclusive actions and activities that strengthen and consolidate the ACT's commitment to Australia's Disability Strategy and the UNCRPD. This will ensure Canberrans with disability are sufficiently supported to live the life they want.

Background

The Summer Foundation is committed to ensuring younger people with complex and significant disability (aged under 65) are able to live in high quality, age-appropriate housing that meets their needs. We do this by building the capacity of younger people, their families, supporters, government and the sector.

There are currently 10 younger people living in residential aged care (RAC) across Canberra.¹ Although this figure seems small, younger people with disability across the country enter RAC each month, mostly via hospital due to interface issues between the health and disability systems. Once a younger person enters RAC it becomes increasingly difficult for them to leave due to inadequate support to transition back into the community.

Canberrans with disability are getting stuck in hospital despite being clinically fit for discharge. Many require funding for housing and other supports to meet their complex ongoing needs and enable them to return to community living. Yet there are system inefficiencies that prevent Canberrans with disability from accessing these supports and services in a timely manner.

¹ Current as at 31 December 2021. See: Australian Institute of Health and Welfare (2022) 'GEN Aged Care data on younger people in residential aged care'. Link [here](#).

What a good life looks like

The right to live a good life is enshrined in the UNCRPD, which recognises the equal right of all people with disability to live in the community, with choices equal to others.² The UNCRPD requires signatories to take effective and appropriate measures to ensure people with disability realise their right to full inclusion and participation in society. Although a ‘good life’ means different things to different people, the UNCRPD suggests that a good life for people with disability is one where they have the same opportunities and ability to make choices as people without disability.

The National Disability Insurance Scheme (NDIS) was created to empower people with permanent and significant disability to live a good life, in keeping with Australia’s human rights obligations under the UNCRPD. The National Disability Insurance Agency (NDIA) uses an ‘ordinary life’ to describe the right of people with disability to live well in the community. An ordinary life in the context of the NDIS involves supporting participants to:

- Have and maintain good relationships
- Belong and participate in their community
- Be involved in making choices about their own lives.³

For people not eligible for the NDIS, there is often a disconnect in how they experience access to supports and therefore a good life. More can be done by both the ACT Government and the NDIS Information Linkages and Capacity building (ILC) framework, previously known as Tier 2, to better engage and support people with disability.

The ACT Disability Strategy must enable Canberrans with disability to explore and create a good life. The ACT Disability Strategy should outline how state-based policies and systems will contribute to dismantling the systemic barriers that prevent Canberrans with disability from participating and living well in the community. This should include information that assists Canberrans to navigate disability supports and service systems, extending to the NDIS, to ensure access to all systems is possible regardless of who funds or delivers it.

Efficient and reliable support systems have a profound effect on health and wellbeing. Measures that are co-developed with the purpose of facilitating day-to-day social inclusion, independence, choice and control will help people with disability realise a good life.

“I am fully sound of mind and I am able to think for myself, so having independence is really, I feel like, the only option for me.”

Connor - ACT resident

Recommendation 1: The ACT Disability Strategy must clarify that a ‘good life’ is synonymous with social inclusion and community participation. Policy measures taken to enable a good life need to consider and dismantle barriers to community living.

² See [Article 19](#) of the UNCRPD

³ National Disability Insurance Agency (2021) ‘How we think about an ordinary life when deciding on supports to include’. Link [here](#).

What are the challenges to having a good life?

Inadequate and inefficient provision of supports

Some people with disability may not know their rights around decision-making or have access to information that may assist them to live a good life.⁴ Despite easy English explainers, many people with disability find information regarding the NDIS, state funded housing and support options, and their rights and protections to be inaccessible and far too complex.⁵

Not all people with disability understand or realise the full benefits (NDIS and ACT based) available to them, and their experiences and outcomes are not as good as they could be. The NDIA provides little guidance regarding supports and services through the NDIS. The ACT Government should proactively enable Canberrans with disability to have access to information and resources. Without this, the effectiveness and efficiency of supports and services is severely limited.

Where people with disability are unable to access the right funding through the NDIS, the ACT Government will be under pressure to fill the gap for Canberrans. There are clear mandates that step out the responsibilities of each system and government. However, these are at a high level and are often misunderstood where support needs intersect different systems.⁶ This confusion often impacts the lives of people with disability, across quality of life, independence, community participation and capacity.

“Unfortunately when I finally got my [NDIS] package, I realised it didn’t even meet my basic needs. And because of that it left me with no other option than to enter aged care once again.”

Michael - ACT resident

System interface issues

There are complexities in navigating the interface between the NDIS, disability, health and housing sectors.⁷ Decisions relating to NDIS housing and support outcomes are particularly lengthy and unpredictable. This is often also true of access to state funding for housing or other disability support.

The pathway from hospital to the community for people with disability is characterised by delayed discharges. People with disability experience further health complications and are left to live in hospital, or are discharged into RAC or other unsafe settings due to the challenges associated with securing supports to re-enter the community.^{8,9} Discharge delays also have financial and patient flow implications for hospitals and state health systems.

⁴ Summer Foundation (2021) ‘Submission to the NDIA on Support for Decision Making’ p5. Link [here](#).

⁵ Summer Foundation (2022) ‘A more inclusive and just society for people with disability’ p23-24. Link [here](#).

⁶ Summer Foundation (2022) ‘Current Scheme Implementation and Forecasting for the NDIS’ p11. Link [here](#).

⁷ La Trobe University and Summer Foundation (2022) ‘Evaluating the discharge planning process: Barriers, challenges, and facilitators of timely and effective discharge for people with disability and complex needs’. Link [here](#).

⁸ Summer Foundation (2022) ‘Current Scheme Implementation and Forecasting for the NDIS’. Link [here](#).

⁹ Summer Foundation (2022) ‘A more inclusive and just society for people with disability’. Link [here](#).

Current housing stock fails to meet the needs of Australians with disability and demand for accessible housing is anticipated to almost double over the next 40 years.¹⁰ Many Australians with disability are living in housing that does not meet their needs yet they are unable to move because of the lack of better, affordable alternatives. This is no different for Canberrans with disability.

“The Department of Housing built a bungalow for me. But they didn’t know what my needs were and they ended up building something that I couldn’t access or use...Because of this I ended up getting very sick and ended up in hospital. Even then I still couldn’t get any supports to return back home.”

Michael - ACT resident

How to make it easier for people with disability to live the life they want to live

Strengthening mainstream services and NDIS interfaces

Strengthening mainstream services and supports to be more inclusive will ensure that obtaining supports through the NDIS is not the only avenue for people with disability to live a good life. Regardless of NDIS eligibility or funding, improved links between different service systems (including health, housing and aged care) to support the varying needs of people with disability, their families and carers is crucial.

Governments at all levels should collaborate to overcome boundary issues, including identifying service gaps and barriers to accessing disability and mainstream services for people with disability. Updates must be made to the [Applied Principles and Tables of Support](#), the NDIA’s [Guidelines](#), [Mainstream and community supports guideline](#) and [Participant Service Charter](#) to ensure accountability, transparency and ease of understanding for everyone.

Recommendation 2: The ACT Disability Strategy must deliver collaboration across states and with the Federal Government to achieve better holistic outcomes for Canberrans with a disability.

Recommendation 3: The ACT Disability Strategy must ensure transparent and timely processes to access support through the ACT Government or service sector. Additionally, where possible, it should provide clarity and information where this is lacking through the NDIS.

¹⁰ Wellecke C, D’Cruz K, Winkler D, Douglas J, Goodwin I, Davis E and Mulherin P, ‘Accessible design features and home modifications to improve physical housing accessibility: A mixed-methods survey of occupational therapists’. Disability and Health Journal, 15 February 2022. Link [here](#).

Accessible housing for all Canberrans

The provision of accessible housing for people with disability requires coordination between all levels of government and the NDIS.¹¹¹²¹³ It is critical that the ACT Government:

- Ensures housing policy enables community engagement and participation, and improves the range and scale of community-based housing
- Develops specific social, public and private housing targets to ensure accessibility for people with disability who require [Livable Housing Design Guidelines](#) (LHDG) Silver, Gold and Platinum level housing
- Audits current social and public housing occupied by Canberrans with disability to determine whether it meets residents' diverse accessibility needs and current design standards, and update or rebuild as required
- Ensures wider inclusion of hospital-based NDIS leads and supports the capacity building of health services to work alongside support coordinators, mainstream and community services to support people with disability
- Incorporates a priority approach around people with disability within hospital internal systems and processes, which includes information sharing with the NDIA for effective use and implementation.

"I am really looking forward to my independence. My apartment will provide me with what most people deserve."

Connor - ACT resident

Recommendation 4: The ACT Disability Strategy must include commitments to improve housing accessibility across the social, public and private housing markets for people with disability. These must be co-designed by people with disability to ensure they meet the needs of people with disability.

Recommendation 5: The ACT Disability Strategy must reduce the barrier to understanding and accessing services through the NDIS by increasing education, training and capacity building for the health sector to support timely and accurate decision-making on Home and Living supports.

¹¹ La Trobe University and Summer Foundation (2022) 'Evaluating the discharge planning process: Barriers, challenges, and facilitators of timely and effective discharge for people with disability and complex needs'. Link [here](#).

¹² Summer Foundation (2021) 'Hospital discharge of NDIS Participants with high and complex needs'. Link [here](#).

¹³ Summer Foundation (2022) 'Current Scheme Implementation and Forecasting for the NDIS'. Link [here](#).

Strengthened disability workforce

The disability workforce is instrumental in supporting people with disability to live a good life. Yet finding skilled and experienced workers who can work with people with complex needs has been identified as a current challenge by people with disability and their supporters.¹⁴ The ACT Government must strengthen the disability sector by investing in disability education, training and postgraduate studies, ensuring more skilled workers and a more adaptive workforce.

Recommendation 6: The ACT Disability Strategy must invest in education and TAFE systems to deliver adequate training to grow a professional disability workforce. Training should be designed with Canberrans with disability to ensure it is purposeful in shaping a workforce that is responsive to the needs of people with disability, in and outside of the NDIS.

Conclusion

Community living is essential to improved health and wellbeing as well as maximised independence and quality of life. An effective ACT Disability Strategy must facilitate social inclusion and community involvement, thereby enabling the realisation of a good life.

People with disability often require access to a wide range of services across mainstream systems and the NDIS to live a good life. To be effective, the ACT Disability Strategy must require all levels of government and the NDIA to work together to support Canberrans with disability. Systems change is required to ensure people with disability have access to the supports they need, when they need them.

The provision of supports and services must directly align with the needs and goals of people with disability. The ability to exercise choice and control in daily living is synonymous with a good life. In order to reach their full potential, people with disability must be in charge of their lives, with support if required.

¹⁴ Summer Foundation (2022) 'A more inclusive and just society for people with disability' p22. Link [here](#).

About the Summer Foundation

The Summer Foundation exists to permanently stop young people with disability from being forced into residential aged care, ensuring people with disability have access to the support required to be in control of where, how and with whom they live.

The Summer Foundation works to influence, challenge and build capacity of the systems, policies and markets that need to change; to permanently eliminate the need for young people with disability to live in aged care.

We focus on unique, high impact interventions that complement the efforts of government, relevant sectors, markets and other organisations. We use a range of tools including:



EVIDENCE BASE

Our research informs the development and evaluation of potential solutions, resources and tools.



EXPERT KNOWLEDGE FROM LIVED EXPERIENCE

We build on the expert knowledge from those with lived experience of the issue of young people in aged care to inform, co-design and evaluate our resources, tools and interventions.



KNOWLEDGE OF GOVERNMENT AGENDA AND DRIVERS

We leverage our knowledge of government drivers to establish best practice policy, to facilitate understanding and implementation of policy and inform government agenda.



CLINICAL EXPERIENCE

We use clinical experience that tells us what is happening on the ground to develop and share resources and tools designed to build the capacity of the system and market users.



DEMONSTRATION PROJECTS OR SOCIAL ENTERPRISES

We design, test, evaluate and improve potential solutions and market interventions to develop social enterprises.