



The issue of young people in aged care

AROUND

AUSTRALIANS UNDER
65 ENTER AGED CARE
EVERY MONTH*

*BETWEEN JAN AND DEC 2022

www.gen-agedcaredata.gov.au/Resources/ Younger-people-in-residential-aged-care In Australia, more than 1,743 NDIS participants under 65 are living in aged care. The issue is complex and crosses multiple sectors, including hospitals, housing, disability and primary health.

People under 65 end up in aged care when disability and health services don't work together in a timely way.

They are living with people in their 80s, they rarely see family or friends and it is common for young people in aged care to lose skills and independence.

The issue of young people in aged care will be resolved when the systems, policy settings and markets consistently enable people with disability to live where, how and with whom they choose; experiencing choice and control equal to people without disability.

People with disability must have access to the support they need to be in control of where and how they live and who they live with.

This means we need to take a multi-faceted approach – to empower people with disability in their housing searches; to build the capacity of those providing services; and to influence the governments making the critical systems and funding decisions.

Our goals

In 2006, the Summer Foundation was established to stop young people with disability being forced to live in aged care.

We are changing systems to ensure people with disability and complex support needs live where and with whom they choose, with access to high quality housing and support options that enhance health, wellbeing and participation.

Our goal will be achieved when these outcomes across 4 strategic priorities are realised.





PRIORITY 1: Stop the flow in

No one under 65 admitted to aged care



PRIORITY 2: Leaving residential aged care

All young people with disability in aged care have made an informed choice on where they want to live and the support they will receive



PRIORITY 3: Access to quality housing

NDIS participants with complex support needs can readily access a range of home and living supports, which means people can live where and how they wish



PRIORITY 4: An effective NDIS for our cohort

A re-designed NDIS that works well for participants with complex support needs

How we work

To achieve our goals as detailed in our strategic priorities, we use 5 key levers.

We generate evidence such as published research and lived experience as a basis for all our work, and innovate through the co-design of new solutions and services.

We work with government and influence people on the inside. Our systems advocacy work sees us apply pressure from the outside by harnessing public support. Where necessary, we use a legal lever and support people to fight for their rights.





EVIDENCE: We use lived experience, peer reviewed and public research to inform the development and evaluation of potential solutions, resources and tools



INNOVATION: We build on the expert knowledge from those with lived experience of the issue to inform, co-design and evaluate new services, solutions, resources and tools



INSIDE: We define, promote and advocate for best practice to influence and inform government policy and agendas



OUTSIDE: We publicly campaign to elevate the stories of people with lived experience to build public support and motivate politicians to act



LEGAL: We support people to fight for their rights and hold the government to account

Our research

The Research team is made up professionals with experience across clinical and academic settings.

Our team investigates the pathways and factors that lead to people with disability ending up in residential aged care, as well as related issues such as the quality of support, NDIS processes, support costs in different housing models, outcomes for specialist disability accommodation (SDA) tenants, and supply and demand in the SDA market.

Three key principles underpin the Summer Foundation's approach to research:

- Engagement of end-users, particularly people with complex support needs who live in, or are at risk of entry to, aged care; as well as community organisations, mainstream services and policy makers
- Impact on policy, practice and systems change is central to the purpose and design of our work
- Knowledge translation and real world impact

We use a range of methodologies to develop the breadth of evidence needed to inform policy and practice around the issue of people with disability and complex needs:

- Literature reviews and environmental scans help us understand the problem and build on previous local and international work
- Analysis of administrative data helps unlock the full potential of existing data
- Primary research involves the collection of information about the needs, preferences and outcomes of people with disability, as well as the impact of the NDIS
- The Summer Foundation La Trobe University
 research partnership uses research to improve the lives
 of people with disability and understand the issue of
 young people in aged care and the associated systems
 and pathways. By researching the issues at each stage
 of the critical pathways that lead young people to aged
 care, we can provide the evidence needed to create
 system change that will help to solve this problem.

Find out more: ## summerfoundation.org.au/research



Government relations and policy

The Government Relations and Policy team works to bring the voice of people with disability to government.

We do this through providing policy advice, direction, influence and solutions to government and by collaborating with the sector to build understanding around key issues and challenges. We actively collaborate with government to find and implement solutions for people with disability with complex support needs. The work that happens across the organisation feeds into our policy work by informing us about what is happening with participants, providers and other networks. Both challenges, successes and everything in between are critical to informing the policy environment and enabling good outcomes for people with disability under the age of 65.

What we do:

 We work 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 residential aged care

- We draw on a strong evidence base from the Research and Co-design teams to identify and promote innovative, high impact interventions that complement the efforts of government and relevant sectors, and serve the rights and interests of people with disability
- The methods we use to influence government include writing policy position statements, engaging in law reform processes, responding to government inquiries, building relationships with key stakeholders, engaging directly with government ministers and MPs, holding events, using storytelling videos from people with lived experience of disability and leveraging media coverage

To find out more:

summerfoundation.org.au/policy



Co-design

The Summer Foundation's purposeful inclusion of lived experience has evolved over the past 15 years, bearing testament to the importance of it as a key tool in our work.

We have developed a niche expertise for creating the environment and methodologies for successfully working with people who have the most complex support needs to enable them to contribute to solutions in a purposeful and authentic way.

By honing design skills to suit people with cognitive and communicative disabilities, a set of methodologies has evolved. These methodologies are transferable across a broad range of disabilities, and also apply to people who do not necessarily have a disability, but have lived experience of the various stakeholder groups relevant to issue of young people in residential aged care.

While the Co-design team furthers the Summer Foundation's commitment to bring lived experience into the way the organisation responds to tackling the problem of young people in aged care, the services of the Co-design team are being increasingly applied outside the Summer Foundation

A range of external organisations has engaged the Summer Foundation's ability to translate lived experience into illustrating, informing and designing solutions.

The Summer Foundation will continue to offer the services of the Co-design team to external customers on a fee-for-service basis. It offers a range of capacity building training services, along with lived experience facilitation to illustrate, inform and design solutions to support the work of other organisations.

Email: livedexperience@summerfoundation.org.au



Hospital to Home service

The Hospital to Home program was established to support the discharge of people with disability from hospital to housing that aligns with their housing needs and preferences.

Our specialists have expertise in navigating both the NDIS and the hospital system and works alongside people with disability who are stuck in hospital to help find suitable housing. We work collaboratively with the person and their existing support network. This includes:

- Hospital allied health teams
- Support coordinators
- Guardians
- Other stakeholders who make up the person's support team

We use our expertise to assist teams to:

- Support a person with disability to articulate their housing needs and preferences
- Understand the different housing pathways available, both SDA and non-SDA
- Navigate NDIS processes, including reviewing reports and evidence to consider the likelihood of SDA eligibility

- Complete an innovative housing search using the Housing Hub and other platforms
- Present a range of housing options, connecting people with disability to housing providers to facilitate offers for housing
- Use a rights-based approach and incorporate principles of choice, control and inclusion for people with disability

Outcomes of our service:

- People with disability have increased choice and control about their housing and support
- Increased capacity of hospital staff and support coordinators to navigate the NDIS and housing sector to access interim and long-term housing for people with disability
- Demand data that identifies gaps and informs the development of new interim and long-term housing options

To find out more:

summerfoundation.org.au/hospital-to-home



Summer Foundation information service

Navigating the interface between the NDIS and other sectors such as health and aged care is often complex for people with disability, their close others and providers.

The Summer Foundation information service responds to our stakeholders who are seeking information and guidance.

We often hear from people looking for support to address individual challenges they are experiencing with

- Navigating the NDIS
- Achieving effective NDIS plans
- Avoiding entry to residential aged care

Information service consultants work with people to receive timely and relevant advice and referrals.

Our response is based on individual circumstances and context, which can include information and resources to support them to address their individual challenges, and connect the person further within Summer Foundation.

The insights from the service are routinely fed back into the organisation to inform our work.



Email: info@summerfoundation.org.au

Phone: **1300 626 560**

Housing Hub Find the home that's right for you

The Housing Hub was established in 2017 to connect people with disability to suitable housing. Housing providers can list their properties on the website including all types of SDA, non-SDA supported accommodation, private rental and properties for sale. The organisation has grown to offer a wide range of services including:

Services to support people with disability to achieve their home and living goals

A team of housing experts support people with disability to achieve their home and living goals. The Housing Hub also offers a free service for people under 65 living in aged care to explore moving out.

Free NDIS housing advice

A free helpline guides people with disability and their supporters to understand their housing and support options. The Housing Advice Line is available on 1300 61 64 63 and operates Monday - Friday from 10:00am - 3:00pm (AEST). The Housing Hub also runs free events and online learning sessions about NDIS housing options for people with disability. These events are co-facilitated by people with lived experience.

Expert consultancy to support housing providers to offer high-quality services

Specialised consultancy and training is offered for housing providers to enhance their ability to offer high-quality services to the people they support.

Insightful market data to inform housing providers about where and what to build

The Housing Hub captures market data on housing preferences for any given location within Australia to help housing providers decide where to build based on consumer behaviour and preferences via search behaviour.

To find out more: **housinghub.org.au**





UpSkill offers professional development to support coordinators and NDIS allied health professionals. Workshops cover a range of topics relevant to support coordinators and NDIS allied health professionals in their integral role of supporting people with complex needs to achieve good outcomes and live well in the community.

To find out more:

summerfoundation.org.au/upskill



RAC engagement

The RAC engagement team provide guidance and support to aged care providers and their staff to assist residents who are NDIS participants who are under 65 and want to explore more suitable housing options outside of aged care.

Contact our team on **1300 508 945** or email: racengagement@summerfoundation.org.au



Contact us:

Housing Advice Line: 1300 61 64 63 housing options@housinghub.org.au

Summer Foundation Information Service: 1300 626 560

info@summerfoundation.org.au

Hospital to Home Service: 1300 817 794

RAC Engagement Line: 1300 508 945

UpSkill: 1300 319 014



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