Voices of Care Leavers:

Ageing with Dignity after Childhood Institutionalisation

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To those who grew up in institutions and foster homes

The research team wishes to sincerely acknowledge all those who contributed to this study - particularly older Care Leavers, Care Leaver advocates and key advocacy groups. We are especially grateful to those who generously shared their stories, offering deep insights into the enduring impact of childhood institutionalisation across their life course. We acknowledge the profound trauma experienced by so many and recognise the lifelong consequences that continue to shape the lives of survivors today.

This report highlights the lived experiences of participants, some of which may be confronting for readers. In recounting their histories, participants engaged in a process that, for many, involved revisiting deeply traumatic events - sometimes for the first time. Their willingness to share reflects considerable strength and we acknowledge their contribution with respect and gratitude.

By illuminating the voices of those too often forgotten, we seek to foster understanding and empathy for those who were harmed by a system that should have acted to protect them. It also calls for systemic reform to address historical injustices and to ensure that, in later life, these individuals have access to the supports and services necessary to age in place with dignity and security.

Care Leavers Australasia Network

We acknowledge the vital role of the Care Leavers Australasia Network (CLAN), the national peak body representing people who grew up in Australia's and New Zealand's orphanages, children's Homes, missions, and foster care. Since its establishment in 2000, CLAN has been a tireless advocate for Care Leavers, ensuring their experiences are recognised and their voices heard in public, political, and service settings. CLAN provides counselling, advocacy, and practical support while working to secure justice and redress for past harms.

This study was co-designed in partnership with CLAN, whose knowledge, guidance, and connection to the Care Leaver community were fundamental. We acknowledge CLAN's decades of advocacy that laid the groundwork for this research and recognise their continuing leadership in advancing the rights, dignity, and wellbeing of Care Leavers.

Funding Body

We gratefully acknowledge the support of the National Centre for Healthy Ageing (NCHA), whose funding made this study possible. The NCHA is a partnership between Monash University and Peninsula Health, dedicated to improving the health, wellbeing, and care of older Australians through research, innovation, and system reform. By investing in projects such as this, the NCHA demonstrates its commitment to ensuring that the voices of marginalised groups are heard and that evidence informs the design of inclusive, person-centred models of care.

Language & Terminology

Participants in this study used a range of self-descriptors reflecting diverse histories and identities. Around 60% identified as “Forgotten Australians,” a term linked to the Australian Government’s national apology and public recognition of those who experienced institutional or Out-of-Home Care (OOHC) in the 20th century. Although the term originated in the 2004 Senate Community Affairs References Committee report, it remains relatively unfamiliar to the broader community and, in particular, to the aged care sector. Many Older Care Leavers contested the suggestion that the term enjoys widespread “public recognition,” while others preferred Care Leaver—a broader, contemporary term that foregrounds lived experience and survivor identity.

First Nations participants who were forcibly removed from family identified as members of the “Stolen Generations”, situating their experiences within the context of colonisation and intergenerational trauma. A smaller group identified as “Former Child Migrants”, reflecting histories of migration, family separation, and cultural dislocation. Given the emotional and political weight of these terms, this study uses “Care Leaver” as an inclusive umbrella term while respecting participants’ individual preferences.

The “Care-experienced” member of our research team (Sarah Morris) would like to highlight, that while “Care Leaver” and “Care experienced” are the broader contemporary terms used within popular discourse, “Care” is often something that was never received within these settings. Consequently, the researcher does not personally identify with these labels and recognises the significant debate within lived-experience and survivor-led communities regarding their appropriateness and the power dynamics embedded in such terminology.

Children’s institutions are a historical form of OOHC. In the language of policy and bureaucracy, the term “care” has been used to legitimise state intervention and the removal of children from their families. For many who lived in these institutions (and other forms of OOHC), however, “care” is an empty word—describing something that was promised, but never experienced.

Children’s Institutional settings include:

- orphanages and children's “homes” (which included dormitories and laundries)
- missions
- group cottage houses
- hospitals or mental health facilities
- youth detention centres
- places for people with disabilities
- schools that were part of a “care” facility
- foster “care”
- kinship “care”

Part 1: Research Team & Partnerships

Embedding Lived Experience – how lived experience was incorporated throughout the project

In partnership with CLAN this study adopted a co-design approach to identify the key needs and concerns of Care Leavers in relation to aged care services. This process enabled direct engagement with the older Care Leaver demographic ensuring their voices shaped both the research methods applied, the data collection process and trajectory, and the refining recommendations informed by the key findings of this study.

Sarah Morris, a care-experienced researcher with both social work training and first-hand experience of OOHC, was embedded within the project to bridge the divide between "researcher" and "researched." This positioning enhanced engagement with what is often described as a "hard-to-reach" cohort, facilitating trust and openness (Liamputtong, 2007). Participants shared a wealth of knowledge and deeply personal accounts of their time in institutions.

The methodology was grounded in lived-experience research principles, recognising the value of personal narratives and subjective experiences in understanding complex social phenomena (Atkinson, 2007). Semi-structured interviews, conducted within a reflexive and person-centred framework, allowed participants to control both the content and duration of their narratives. This approach aligns with participatory research principles, ensuring that the voices of those with lived experience are prioritised, respected, and authentically represented (Beresford, 2019).

The flexible interview format enabled participants to explore topics most salient to them while still addressing key research questions - acknowledging the diverse contexts and emotional landscapes each brought to the conversation (Smith & Osborn, 2008). With participants' consent, interviews were audio-recorded, transcribed, and thematically analysed to illuminate the challenges faced by older Care Leavers and inform future service provision.

Partnership with the Care Leavers Australasia Network (CLAN)

CLAN formally endorsed the Living Labs project and welcomed the opportunity to collaborate as a co-designed research partner with Monash University. In their letter of support, CLAN Chief Executive Officer Leonie Sheedy OAM JP and Life Member Dr Frank Golding OAM highlighted the significance of the study for advancing the aged care needs and priorities of Care Leavers. They noted its potential to document Care Leavers' key concerns, provide a forum for communicating those concerns to policymakers and services, and contribute to the development of a best practice model to support healthy ageing. CLAN also recognised the distrust that many Care Leavers hold towards external authorities and emphasised its role as a trusted organisation in facilitating engagement with the project.

In practice, CLAN contributed actively to the governance and co-design of the study. This included assisting with participant recruitment through its established networks, providing feedback on data collection instruments, and reviewing draft materials. These contributions, guided by the leadership of Sheedy and Golding, ensured that the research was both methodologically robust and firmly grounded in the lived experiences and priorities of Care Leavers.

Research Team

This project was undertaken by a group of researchers within the Department of Social Work at Monash University. Our team brings expertise in ageing, trauma, care systems, and lived experience research, with a shared commitment to advancing social justice and improving the lives of Care Leavers. Guided by principles of co-design, collaboration, and ethical research practice, we worked in close partnership with CLAN to ensure the study was grounded in the voices and priorities of Care Leavers themselves.

Professor Philip Mendes teaches social policy and the welfare state and community practice, and is the Director of the Social Inclusion and Social Policy Research Unit (SISPRU) in the Department of Social Work at Monash University. His research areas include the life experiences of young and older adults who grew up in forms of out-of-home care, welfare conditionality, Medically supervised injecting facilities, and social workers and policy practice. He is the author or co-author of 14 books including *Young people transitioning from out-of-home care: International research, policy and practice* (Palgrave, 2016), the third edition of *Australia's Welfare Wars* (UNSW Press, 2017), and *Empowerment and control in the Australian welfare state: A critical analysis of Australian social policy since 1972* (Routledge, 2019). His newest book, *From Resistance to Reform: Case Studies of Long-Term Social Justice Advocacy in Australia*, has just been published by Emerald.

Susan Baidawi is an Associate Professor in the Department of Social Work at Monash University, where she is the Director of Higher Degrees by Research and co-director of the Criminal Justice Research Consortium. She has over 15 years of qualitative, quantitative and mixed-methods research experience in the fields of child and family welfare and criminal justice and has authored more than 80 peer-reviewed journal articles, book chapters and reports to government in these areas. Her key field of research specialisation are young people with complex support needs, and she is the co-author of *'Crossover' Children in the Youth Justice and Child Protection Systems*, published by Routledge (2020).

Sarah Morris is a Research Fellow and Sessional Academic in the Department of Social Work at Monash University. A qualified social worker, her professional background spans child protection, mental health, and forensic practice. She has contributed to nationally funded projects on care transitions, youth housing, and ageing for care leavers. Informed by lived experience in out-of-home care, her research aims to advance trauma-informed and co-designed approaches to improve outcomes for care-experienced populations and drive systems reform.

Lena Turnbull is a Research Assistant and Teaching Associate in the Department of Social Work at Monash University. She is a qualified social worker and counsellor with professional experience across the disability, justice, and aged care sectors. Her research contributions span a range of social work issues, including Indigenous young people transitioning from out-of-home care, the criminalisation of children with disabilities in care, and social work education with a focus on student and staff experiences of assessment and feedback.

Part 2: Executive Summary

This study is the most comprehensive national investigation to date into the ageing experiences of people who spent their childhoods in institutional or OOHC. Co-designed with CLAN, it draws on a mixed-methods design: a national survey of 105 Care Leavers aged 50+, together with 24 in-depth interviews with Care Leavers, and three focus groups with aged-care professionals.

Key Findings

- **Formative harm in childhood:** Participants reported extensive abuse, neglect, loss of education, and dehumanisation in children's institutions, leaving long-term scars across health, housing, relationships, and trust in systems.

- **A life course of disadvantage:** Institutional harm cascaded into adulthood, producing high rates of chronic illness, disability, mental health conditions, housing insecurity, family violence, coupled with limitations in engagement in education and employment, and for some, involvement in the criminal justice system.

- **Guarded engagement with aged care:** Residential aged care was overwhelmingly rejected by older Care Leavers. Many participants explicitly stated a preference for death over entering a residential facility, reflecting deep fears of re-institutionalisation and re-traumatisation. Home care was more acceptable, but only when it safeguarded autonomy, dignity, and consistency.

- **Conditions for safer aged care:** Care Leavers and professionals identified what makes aged care acceptable - small consistent teams, trauma-informed practice, sensitive identification, advocacy through Care Finders, relational transitions, environments free from institutional cues, and respect for autonomy and dignity.

Recommendations

1. **Trauma-Informed Aged Care as the Foundation**

- Embed trauma-informed principles into all aspects of aged care.
- Make training mandatory, ongoing, and co-designed with Care Leavers and representative organisations to ensure workforce have a working understanding of care leaver history.
- Ensure these principles underpin workforce standards, qualifications, accreditation, care navigation, information delivery, and service design.

2. **Priority Access & Identification ("Gold Card")**

- Introduce an opt-in priority access card for Care Leavers covering aged care, health, housing, and mental health services.
- Establish sensitive identification processes to ensure Care Leavers are recognised without re-traumatisation.

3. **Expand Care Finder Program**

- Resource dedicated Care Finders and peer navigators with lived experience.
- Ensure long-term, trusting relationships to help Care Leavers navigate aged care systems and services.

4. **Home-First & Flexible Services**

- Prioritise support that enables Care Leavers to remain at home as they age.
- Provide flexible, personalised funding packages that safeguard autonomy, continuity of care, and dignity.
- Avoid institutional models that replicate past harms.

5. **Safe & Inclusive Residential Options**

- For those who do enter residential aged care, create environments that are small-scale, homelike, and free of institutional triggers.
- Train staff to recognise and respond to trauma histories, and involve Care Leaver agencies in transitions.

6. **Workforce Development & Training**

- Co-design and deliver training with Care Leaver organisations.
- Build skills across all roles (assessors, frontline staff, management).
- Focus on relational safety, cultural awareness, and trauma-informed practice.

7. **Role of Specialist Agencies**

- Provide ongoing funding for Care Leaver agencies to deliver counselling, advocacy, outreach, and specialist support.
- Strengthen collaboration between agencies and mainstream aged care providers.

8. **First Nations Response**

- Develop a dedicated approach for Stolen Generations survivors.
- Ensure Aboriginal and Torres Strait Islander organisations lead this response.
- Recognise distinct experiences and needs within aged care reform.

Conclusion

Care Leavers approach aged care with deep mistrust rooted in their experiences of childhood institutionalisation. Government institutions have a duty of care to older Care Leavers given the widespread neglect and abuse administered within childhood institutions and OOHC. Current systems risk replicating past harms. By embedding trauma-informed, relational, and flexible approaches across policy and practice, aged care can move from being a site of fear to one of safety, dignity, and respect. Reform is urgent: without change, many Care Leavers will disengage - or avoid aged care altogether - placing them at risk of neglect, isolation, and even suicide.

Part 3: Introduction & Background

Introduction

Known colloquially as Forgotten Australians, older (aged 50+ years) Care Leavers are the approximately 500,000 people who spent their childhoods in institutional OOHC - including orphanages, children's homes and foster care - from the 1920s to the late 1980s (Commonwealth of Australia, 2004; National Aged Care Alliance, 2017). Children were frequently placed in "care" due to poverty and hardship of the time rather than parental maltreatment, yet many experienced abuse and neglect within the OOHC system itself, in large institutional environments (Royal Commission into Institutional Responses to Child Sexual Abuse, 2017). Many in this cohort carry the lifelong impacts of maltreatment and neglect within institutional settings and have experienced significant disadvantage across adulthood (Golding, 2022). Some Care Leavers show signs of premature ageing and are now contemplating or entering residential aged care and community-based supports (Fernandez et al., 2016).

Existing literature on the long-term outcomes of Care Leavers shows that this group often experiences greater challenges across many socio-economic and health domains - greater contact with the criminal justice system, housing instability, and significant mental and physical health challenges - linked to maltreatment before and during care and to inadequate support across the life course (Sacker et al., 2021; Stein & Ward, 2021). As they age, Care Leavers experience higher prevalence of chronic disease and mental health conditions than the general population (Airagnes et al., 2016; England-Mason et al., 2018).

Accurately estimating how many older Care Leavers will require aged care is difficult: there are no reliable national data outlining their support needs. Nonetheless, the estimated size of the cohort points to a substantial potential demand and underscores the urgency of designing trauma-informed models tailored to their histories.

Policy attention is beginning to recognise these distinct needs: the Commonwealth Government identified Care Leavers as a key subgroup in the Aged Care Diversity Framework (Australian Government Department of Health, 2017b). Yet there has been only limited exploration of Care Leavers' specific needs and concerns regarding entry into aged care, and no representative data appear to be available (Commonwealth of Australia, 2021). While specific action plans have been developed (or are in development) for several key subgroups under the Aged Care Diversity Framework, there is not yet a dedicated action plan for Care Leavers (Department of Health and Aged Care, 2022).

In summary, many in this cohort were abused and neglected in children's institutions and fear being harmed again in aged care environments, including through erosion of power, agency and safety that can exist across institutional settings (Coram et al., 2021). Compared to the general population, Care Leavers often lack equivalent support from family and others to help them navigate and access services that best meet their needs. As the National Aged Care Alliance (2017, p. 2) notes, *"The ultimate measure of the effectiveness of aged care reform is how it impacts on the most vulnerable.*"

Accordingly, this study aimed to: (1) partner with CLAN through a co-design process to identify the key aged care needs, concerns and priorities of Care Leavers; (2) document and assess targeted actions taken by aged care providers to recognise and address these needs; (3) strengthen the limited evidence base on Care Leavers' experiences of, and requirements from, the aged care system; (4) inform the development of a dedicated National Aged Care Action Plan for Care Leavers; and (5) articulate features of a best-practice aged care model that supports safe, dignified and healthy ageing.

This study responds to existing knowledge gaps by foregrounding older Care Leavers' perspectives on aged care. A national survey was conducted, complemented by qualitative engagement (interviews and focus groups with older Care Leavers), to explore: (1) childhood care settings and duration; (2) adult experiences around health, education, employment and relationships; (3) experiences with residential and community-based aged care; and (4) preferences for future care. Building on earlier work, we also tested the perceived importance of service features frequently recommended for this population - choice, flexibility, independent advocacy and trauma-informed practice - by asking respondents to assess their relevance.

Background

A literature review was conducted to establish the existing knowledge on this topic (Turnbull et al, 2024). Given the dearth of literature focused specifically on older Care Leavers in Australia and their views and experiences of aged care, we broadened eligibility for inclusion. The following criteria were used: (1) Participants were either Care Leavers aged 50+ or professionals working with them; OR (2) The study reported findings or recommendations relevant to Care Leavers and aged care service provision, policy, or practice.

Seventeen publications met the criteria: one international study, six Australian scholarly publications (three stemming from one large-scale study), and ten Australian publications classified as 'grey literature'. The findings were thematically organised into (1) preferences and experiences of Care Leavers and (2) recommendations for practice and policy. The resulting literature review was published in the Journal of Gerontological Social Work in 2024 (Turnbull et al, 2024) and outlined existing knowledge concerning older Care Leavers' experiences, and preferences regarding aged care. A summary of these findings follows here.

Preferences and experiences of Care Leavers

Strong preference to remain at home

While preferences like staying at home and retaining control are common among older adults, Care Leavers face additional considerations. For many, the prospect of institutional aged care is trauma-linked to earlier experiences in orphanages and residential care; one study which reported on interviews with 16 Care Leavers found a strong preference for support at home to avoid re-institutionalisation (Browne-Yung et al., 2021).

Evidence outside aged-care-specific studies points the same way. A national longitudinal study of life outcomes (surveys n=669; interviews n=92; focus groups n=77) found that older Care Leavers frequently feared re-institutionalisation and re-traumatisation in aged care (Fernandez et al., 2016; 2017). Practitioners report similar concerns (Browne-Yung et al., 2022; Coram et al., 2021), echoed in grey literature and palliative-care guidance (AFA, 2019; CLAN, 2022; Australian Government Department of Health, 2019a).

Problematic features of aged care services

Evidence from both Care Leavers (Browne-Yung et al., 2021; Fernandez et al., 2016) and key stakeholders (Coram et al., 2021; Browne-Yung et al, 2022) - including practitioners, community providers, advocates, and Care Leaver support organisations - highlights persistent problems with the design and delivery of aged care services to Care Leavers. Reported concerns span rigid, one-size-fits-all models; curtailed choice in daily matters such as medicines and routines; and entrenched power differentials. The institutional character of many settings - limited privacy, shared living, and sensory or architectural cues (e.g., extended corridors, layout, odours, institutional labels) - can be re-traumatising (AFA, 2019; Australian Government Department of Health, 2019a; CLAN, 2022; Tuart Place, 2019). Other commonly cited triggers include; the re-use of names of former orphanages as the name of the contemporary aged care facility, incontinence, certain holidays or foods, religious iconography, and media coverage of the Royal Commission into Institutional Responses to Child Sexual Abuse (AFA, 2019; CLAN, 2022; CLAN, n.d.).

Workforce constraints limit trauma-informed care

High staff turnover, variable skills, cultural and linguistic differences, and constrained resources impede the delivery of trauma-informed, care-leaver-sensitive care (Browne-Yung et al., 2022; Australian Government Department of Health, 2019a).

Additional barriers to access and navigation

Limited family support can make navigating complex aged care pathways harder (Australian Government Department of Health, 2019a; Smith et al., 2022; Tuart Place, 2019). Other barriers include cost, service availability, lack of information, and transport (Australian Government Department of Health, 2019a).

Service features preferred when accessing aged care

Where support is sought, Care Leavers prefer services that prioritise autonomy and consistency, which avoid requiring repeated disclosure of personal - and often traumatic - histories (Browne-Yung et al., 2022; Browne-Yung et al., 2021; Coram et al., 2021).

Recommendations for policy and practice

Embed trauma- and care-leaver-informed, person-centred care

Converging evidence supports aged-care models that are trauma-informed, attuned to the specific histories of Care Leavers, and grounded in person-centred practice. This view emerges from research with Care Leavers (Browne-Yung et al., 2021) and work in related care contexts (Australian Government Department of Health, 2019a; Fernandez et al., 2016), from stakeholder perspectives on aged care (Browne-Yung et al., 2022) and comparable services (Coram et al., 2021; Frederico, 2020), and from guidance issued by peak organisations and support agencies (AFA, 2019; CLAN, 2018; CLAN, n.d.; Tuart Place, 2019).

Provide additional supports

Recommended measures include flexible funding to sustain living at home, ongoing access to counselling, and advocacy/navigation support (Alliance for Forgotten Australians, 2019; Australian Government Department of Health, 2019a; Browne-Yung et al., 2022; Browne-Yung et al., 2021; CLAN, 2018; CLAN, nd; Coram et al., 2021; Fernandez et al., 2016; National Confidential Forum, 2021).

Strengthen quality assurance

Services should implement systematic review and continuous quality improvement processes to ensure safe, high-quality, tailored care (National Confidential Forum, 2021; Tuart Place, 2019).

Develop specialised options

Some authors call for specialised support and residential services designed around the distinct needs of older Care Leavers (Coram et al., 2021; Fernandez et al., 2016).

Implementation gap

Resources and training exist - for example, from Helping Hand, Relationships Australia and Flinders University (2021 & nd), and the Department of Health and Aged Care (2021) - but it is unclear how widely staff are aware of, using, or embedding these tools, and their effectiveness for improving outcomes for Care Leavers remains under-evaluated.

Summary

Although the evidence base is limited, converging themes signal an urgent need for the aged care sector to respond more precisely to the distinct needs of older Care Leavers. A strong preference to avoid residential care - and to receive support at home - raises questions about how well current models deliver safe, appropriate, trauma-informed, person-centred care for this cohort. Workforce instability and skill variability undermine implementation and likely contribute to disengagement by Care Leavers.

Continuous quality improvement is essential given evolving needs and persistent risks of harm recurrence. While attention to post-care support has grown, comparable focus within aged care has lagged despite the continuing marginalisation, service barriers and poorer health experienced by many Care Leavers across the life course (Sacker et al., 2021). Services must both recognise and adapt to these distinct needs.

Part 4: Methods

Methodology

Our study used a multi-phase, mixed-methods design co-designed with the Care Leavers Australasia Network (CLAN) and service partners, and grounded in trauma-informed, participatory, lived-experience principles. Three complementary components were conducted: (1) a national survey of Care Leavers aged 50+, (2) semi-structured in-depth interviews with care-experienced adults, and (3) focus groups with aged-care stakeholders. Recruitment was purposive via care-leaver organisations, and data collection modes were tailored for accessibility (online, telephone, and in-person options with an optional support person). Quantitative survey data were analysed using descriptive statistics, while qualitative data (open-ended survey items, interviews, and focus groups) underwent thematic and narrative analysis. Findings were integrated across strands to triangulate evidence and generate practice and policy recommendations specific to older Care Leavers.

Ethical Considerations

This study was approved by the Monash University Human Research Ethics Committee. All participants provided informed consent prior to participation, with clear explanations of the study's aims, their right to withdraw at any time, and the measures taken to ensure confidentiality and data security. Participants were offered a $25, $50, and $40 supermarket voucher to acknowledge and reimburse their time for the survey, interview and focus group participation (respectively).

Acknowledging that participants may have a history of trauma and ongoing mental health challenges, the research team implemented measures to ensure an ethically sound approach that minimised the potential for re-traumatisation. At all data collection points, there was deliberate avoidance of questions about participants' experiences of abuse and neglect in childhood institutions. While some questions in the survey addressed potentially negative adult experiences, such as family violence, mental illness, and relationship breakdowns, these were structured as forced-choice or yes/no questions, avoiding the need for detailed responses. Each section was also introduced with a summary of its content, allowing participants to decide whether to proceed or skip that section, thus giving them control over the questions they were asked and chose to answer.

The researcher-assisted surveys, as well as the interview phase, used a lived-experience methodology that centres personal narratives to understand complex social phenomena (Atkinson, 2007). Author Sarah Morris, who has first-hand experience of OOHC, conducted the in-person surveys. Additionally, she conducted all but one of the interviews which were conducted in a way that grounded shared experience to foster trust and openness and elicit rich qualitative data (Liamputtong, 2007). Interviews were reflexive and person-centred: participants controlled the content and duration of their narratives, consistent with participatory principles that prioritise and respect lived experience (Beresford, 2019). With consent, interviews were audio-recorded and transcribed for analysis.

National Survey of Care Leavers

The survey comprised a combination of closed-ended, Likert scale, and open-ended questions. It was designed in collaboration with Care Leaver support organisations and piloted with a small group of Care Leavers for clarity and accessibility. Survey data collection took place between October 2023 and July 2024.

The survey collected information across four main domains:

1. Demographics and life history, including childhood care settings, housing and income history, education, employment, and adult relationships.
2. Health and support needs, such as mental health, physical health, disability, experiences with services, and social support networks.
3. Aged care access and preferences, including current use of services, anticipated future needs, and preferred models of support.
4. Prioritisation of service features, where participants rated the importance of various aspects of aged care (e.g. consistent workers, choice, trauma-informed staff, pet-friendly services).

These items were drawn from prior recommendations in grey literature and qualitative research, allowing the study to test their broader applicability and support. Feedback from the piloting stage resulted in refinement of questions and a shortening of the survey length. The survey was created and hosted on the Qualtrics Insight Platform. Participants were required to provide consent before beginning the survey, and no identifiable information was collected. The survey took approximately 15 minutes to complete. The full survey instrument is provided as Appendix A.

Participants and recruitment

Participants were adults aged 50 years and older who had spent part of their childhood in institutions, foster homes, orphanages, or group homes. Typically, aged care services are offered to non-Indigenous individuals aged 65 and older, and to Aboriginal and Torres Strait Islander people aged 50 and above. To account for this age disparity, as well as premature ageing among Aboriginal and Torres Strait Islander peoples owing to the impacts of colonisation and accompanying systemic disadvantage, we included any Care Leavers aged 50 and over in our study (Australian Institute of Health and Welfare [AIHW], 2024).

Given the hidden and hard-to-reach nature of older Care Leavers, we employed a purposive non-random approach. Recruitment occurred in partnership with Care Leaver support agencies, who disseminated the survey through newsletters and direct outreach.

To support accessibility and inclusion - particularly for participants with cognitive impairment, low literacy, or digital barriers - the survey could be completed online, by phone, or in person. Our researcher with lived experience of OOHC conducted 33 surveys in these assisted formats, reading the questions aloud and recording responses. Participants could also choose to have a support person present. These strategies enabled participation from individuals who might otherwise have been excluded, including those with mild cognitive impairment or difficulty navigating traditional research tools.

Industry partners from Queensland and South Australia invited this team member to attend their service and access potential participants. This recruitment method was highly successful, overcoming access and trust issues. For in-person completions, no identifying information was collected, and responses were entered directly into the online Qualtrics survey by the researcher. Surveys were conducted in a private setting, with only the participant and, where applicable, a consented support person present. These measures were taken to ensure participant privacy and data confidentiality.

Data analysis

The quantitative data, derived from structured survey questions, were analysed using simple descriptive statistics. This involved reviewing percentages, means and frequencies to summarise the responses (Flynn & McDermott, 2025). The analysis aimed to provide an overview of the trends and patterns in the participants' perceptions of aspects of aged care.

The qualitative data, obtained from open-ended survey responses, were analysed thematically to identify and interpret recurring themes and patterns in participants' experiences and perceptions of aged care. Thematic analysis followed a systematic process of familiarisation with the data, generating initial codes, searching for themes, reviewing and naming themes (Braun & Clarke, 2021).

The integration of quantitative and qualitative analyses allowed for a robust interpretation of the data, combining quantitative trends with deeper insights into individual experiences and perceptions.

In-depth Interviews with older Care Leavers

Participant recruitment and sampling

Participants were recruited via purposive and snowball sampling through established relationships with state-based support agencies for care leavers, identified and engaged through the National Aged and Community Care Roundtable for Forgotten Australians. Agencies shared study information through newsletters, direct outreach and word of mouth. Interested individuals contacted the research team directly or with agency support.

Eligibility required participants to be aged 50+ and to self-identify as having spent time in institutions or OOHC as children. No exclusion criteria related to cognitive capacity were applied; anyone able to provide informed consent was eligible. To reduce barriers, support persons could attend interviews, and locations were flexible and participant-led.

Data collection

Twenty-four interviews were conducted between November 2023 and April 2024. Most were in person, with our lived-experience researcher travelling across several states. Participants chose the location - either at a partnering agency or in their home - aligning with trauma-informed principles of autonomy, choice and emotional safety.

Consistent with the study's qualitative, narrative focus, demographic variables (e.g., age, marital status, socio-economic indicators) were not systematically collected; this approach strengthened the depth of storytelling, but limits interpretation of the findings against background characteristics.

The interview schedule invited open-ended accounts of ageing and engagement with aged care services, including fears, preferences and recommendations. Twenty-three of the 24 interviews were conducted by the lived-experience researcher by design, supporting ethical aims of trust, understanding and safety given the sensitivity of topics (trauma, systemic failures, personal hardship). Throughout, the interviewer's shared background supported sensitive navigation of trauma-related content and upheld trauma-informed priorities of autonomy, emotional safety and respect. Interviews ranged from six minutes to one hour and 25 minutes, allowing participants to determine depth and scope.

Data analysis

Early familiarisation indicated that participants routinely situated aged-care perceptions within broader life histories - childhood and time in OOHC through to adult life. In response, a thematic analysis approach was employed to examine the interview data. This method was chosen due to its capacity to illuminate how participants construct meaning from their past and present experiences, allowing for a holistic understanding of their life trajectories (Flynn & McDermott, 2025). A narrative, life-course lens informed interpretation and the organisation of themes (childhood → adulthood → ageing/aged care) to examine how participants construct meaning across their life course, illuminating links between early institutionalisation, adult challenges and current interactions with aged care.

Analysis proceeded through:

- Transcription and familiarisation: all interviews were transcribed and reviewed by at least two members of the research team.
- Initial coding: two researchers independently coded the same two transcripts, then reconciled differences to agree on an initial code list ensuring conceptual clarity and coverage.
- Iterative coding: researchers then coded separate transcripts, meeting regularly to review progress, refine codes and incorporate emergent themes, maintaining rigour and consistency.
- Narrative structuring: data were organised around key life-course stages—childhood experiences, adult life, current aged-care needs and future concerns.
- Interpretation and synthesis: attention focused on how participants connected early experiences to present realities, including recurring themes, contradictions, and the influence of structural and systemic factors (Flynn & McDermott, 2025). Pseudonyms were used for deidentification purposes.

Focus groups with stakeholders

Participant recruitment and sampling

For this part of the study, the focus was on hearing the voices of key stakeholders with in-depth knowledge of the experiences and needs of Care Leavers considering aged care.

Recruitment was conducted through multiple avenues, including direct outreach to known organisations with requests to circulate study information to their staff, publication in the National Centre for Healthy Ageing newsletter, and posts in aged care-related Facebook community groups. While efforts were made to recruit a broad range of practitioners, recruitment proved challenging. As a result, those who participated may reflect a sub-group of professionals who are particularly motivated or invested in improving outcomes for this population. Participants were drawn from various states and territories across Australia; however, information on their qualifications was not collected.

Data Collection

Data were collected through three online focus groups conducted between October 2024 and February 2025. A total of fifteen professionals working in or alongside the aged care sector participated in the research. Participants held diverse roles, including community services educators, aged care advocates, lived experience advocates, care finders, and service managers, offering a broad perspective on current service delivery and system-level challenges.

A semi-structured format was used to guide the discussions, allowing for both consistency across sessions and flexibility to explore emerging themes in depth. Each focus group centred on participants’ perspectives regarding the capacity of aged care services to respond to the unique needs of older Care Leavers. Key discussion areas included systemic and practice-level barriers, examples of effective and ineffective approaches, and the application of principles such as choice, control, and flexibility in service delivery. Participants were also invited to reflect on opportunities for improving policy and program responses to better support ageing Care Leavers. All sessions were audio-recorded and transcribed with participants’ consent.

Data analysis

Thematic analysis was undertaken to identify recurring patterns and key insights relevant to aged care policy and practice (Braun & Clarke, 2021). Following transcription, data were read multiple times to support immersion and familiarity with the content. An inductive approach was adopted, allowing themes to emerge directly from the data rather than being pre-determined by existing frameworks. This approach was chosen to ensure that the analysis remained grounded in participants' lived professional insights and reflective of the complex realities they described.

Initial coding was conducted by two researchers, who identified meaningful segments of text and assigned descriptive labels. These initial codes were then reviewed, refined, and grouped into broader categories to capture higher-level themes. Throughout the process, the researchers remained attentive to both convergences and divergences in participants’ perspectives, with particular attention paid to issues that cut across roles and organisational contexts. To support rigour and trustworthiness, preliminary themes were discussed between the two researchers and refined to ensure the analysis was contextually grounded and responsive to the aims of the study.

Part 5: Findings

This chapter integrates data from the survey, interviews, and focus groups into four themes that trace the pathway from childhood OOHC experiences to ageing: (1) formative harm in childhood; (2) tracing the impacts of childhood harms into adulthood; (3) guarded engagement with support and aged care; and (4) suggestions for safe, acceptable aged care. Data were woven theme-by-theme: the survey findings provide breadth (percentages reported as x/n (y%), while interviews and focus groups add depth through standalone, verbatim quotations.

Participant Accounts of Institutional Harm: Use of First Hand Narratives

Experiences within children's institutions were characterised by significant adversity, marked by systemic abuse, neglect, and dehumanising practices that profoundly shaped the lives of those who endured them. Participants in this study recounted deeply traumatic incidents, revealing the oppressive environments within these institutions and the enduring impacts on their physical and mental health across the life course. These narratives point to a broader pattern of systemic failure in which children were subjected to harsh punishments, exploitative labour, physical and sexual abuse, and the complete absence of genuine care.

At the same time, it is important to acknowledge that not all Older Care Leavers wish to disclose their childhood backgrounds, and that choice must be respected. The cohort is diverse: while some participants identified as survivors, others described themselves as thrivers. Many expressed a desire simply to be treated with respect and dignity, without continual reference to their past trauma. Recognising this diversity of experience and identity is crucial to avoiding stereotyping or deficit-based labelling.

In the sections that follow, we include participants' own words—even when distressing—to represent their experiences honestly and respectfully. The realities they endured deserve space and recognition: to be heard, remembered, and no longer swept under the rug. The following themes capture the shared experiences of participants, shedding light on both the challenges they faced and the lasting legacies of childhoods stolen by these institutions.

Theme One: Formative harm in OOHC

For older Care Leavers, their journeys started pre-removal, within the family home, however it was frequently removal into and time in OOHC that set the foundation for their future life experiences. Across data sources, participants experienced sudden and poorly explained removals, spent long periods in care - most commonly in large, regimented institutions - and were exposed to sexual and physical abuse, dehumanising practices, neglect, poor living conditions, and disrupted schooling. These childhood conditions set the baseline for how safety, trust, and authority were understood later in life (developed further in Themes 2–3).

Experiences of removal and separation from family

Early experiences of family instability and neglect were common, including the loss of parents, abusive caregivers, separation from siblings, and being passed between relatives or institutions.

> *"Well, I was born a drover's daughter, Mum, Dad and eight kids. Lost Mum in 1959, and then I ended up with an abusive grandmother who, after my grandfather passed away, allowed for me to be raped for money because the people were boarding with her. So I copped the brunt of that. I used to get belted. I told my cousins and my youngest brother that he was my brother, and got a belting for that." - Evelyn*

Participants stated that removal was often a shock, accompanied by confusion and a lack of explanation. Trust in authorities was undermined when removal occurred suddenly, leaving children bewildered and betrayed.

> *"So they took me away and they took me to [interim child accommodation and remand centre] at that stage, and I couldn't understand why." - Malcolm*

Some participants internalised blame or reflected on their own behaviours to make sense of removal. Others spoke of perceived unfairness - such as siblings being allowed to remain in the home - creating lasting feelings of injustice.

> *"I was the only one because my brother, he's four years younger than me, and I was the only one removed because when they came in - because mum used to keep me home to look after the other kids because she was very sick….. Can you believe that? I cannot believe it, I still can't get over it." - Ruth*

These recollections reveal the emotional turbulence of removal and its enduring impact, which was evident in the participants even when recalling events from early childhood.

Time in OOHC; types of placements

A small number of participants across the survey and interviews identified as former child migrants. While their institutional experiences in Australia mirrored the experiences of children, they faced the added trauma of forced migration from their home countries. These participants described being sent to Australia as children without their knowledge or consent, often misled about the nature of the move. Guardians or authorities made life-altering decisions on their behalf, with no parental involvement.

> *"I came out as a child migrant in 1947. I lived in an orphanage in England, and I was seven and people came to the orphanage and said, 'Hands up all the kids who want to go to Australia'. I just presumed Australia was outside the door, so I put my hand up with all the other kids, and they put us on a boat for six weeks and sent us to Australia. And we went to an orphanage in Western Australia, but there was about six different boatloads of children that came. I came in the November, the 7th, of '47, but the kids had come before that and kids came after me. I think 130 British children were exported from England, not to Australia - Canada and South Africa - without their parents' permission. A priest*

> *signed all our documents as our guardians and we came, put in an orphanage. It was pretty tough." - Louise*

Regarding all participants, time spent in OOHC care ranged from six weeks to 21 years; the mean was ~9 years, indicating many spent a substantial portion of childhood in care. Survey participants could select multiple settings to reflect movement across placements. Out of a total of 169 responses, the most common settings they had experienced in childhood were orphanages (n=45, 27%), children's institutions (n=30, 18%), boys'/girls' homes (n=34, 20%), and group homes (n=13, 8%), with smaller proportions reporting time spent in foster care, youth detention, and mental health/disability institutions or adoption. These distributions indicate that most participants experienced the large, regimented institutional environments described by the Royal Commission into Institutional Responses to Child Sexual Abuse (2017), which highlighted widespread abuse, neglect, maltreatment, lack of oversight, inadequate care, multiple placements leading to displacement and instability, and significant isolation and stigma.

Abuse in care

Once in OOHC, participants described experiences of sexual and physical abuse, dehumanising practices, neglect and poor living conditions. Participants recounted being stripped of their identity, reduced to numbers, and addressed derogatorily. Some did not know their real names until leaving care.

> *"Do you know we had no names? Yeah, we were just a number. Fact. I never knew my name until they kicked me out at age 14. How dehumanising." - William*

Accounts of physical abuse included severe punishments, public floggings, and humiliations such as wearing wet sheets for bed-wetting. Fear of harsh penalties for minor infractions was constant.

> *"We had one little eight year old girl, and this just drives me insane every time I think about it. There was one person in the gulag in New South Wales, had her hair all chopped off, and what do we do? We all grow our hair. We don't have to do a thing to it, it just grows. Every time her hair grew she had it chopped off again, and then she'd get a flogging in front of all of us. She was in the nude, they took all of her clothes off, and they just flogged her and flogged her and flogged her. Where was society when that was going on?" - William*
>
> *"I wet the bed till I was 13… we used to have to put the wet sheet over our head and go into the dining room, stand there in front of everybody and try and eat your breakfast under the wet sheet." - Malcolm*

Sexual abuse was widespread, often starting at a young age and continuing for years.

> *"I was in there from the age of three until I was nine and a half. Every day, I was abused. Physically. I'd wake up in the middle of the night and somebody was all over me like a rash. I was sexually assaulted from the front and the back. When*

> *I'd wake up in the morning, I was covered in blood. I'd complain about it and I'd just get a whack." - Margaret*

Participants reported insufficient food, poor hygiene, and lack of medical care. They described only having one pair of underwear, infrequent baths, and inadequate dental hygiene.

> *"You see that's why our health is no good. I've lost all my teeth… we used to have to line up, wet our finger with - they used to make their own kerosene soap, big baths, and you wet your finger and that's how you cleaned your teeth. And the kerosene burnt and got me pyorrhea. I had pyorrhea of my gums, really red, sore, and bleeding, and I lost all my teeth." - Malcolm*

Disrupted schooling / lack of education

The schooling experiences of Older Care Leavers were often disrupted or prematurely terminated, with many experiencing frequent placement changes that, in turn, led to repeated disruptions in their education. Of the 88 participants who responded to this question, 13% (n=11) left in primary school, 46% (n=40) left secondary school without a certificate and 6% (n=5) completed secondary school with a certificate. This was further supported by interview data with many recalling being denied basic schooling while institutionalised and leaving OOHC unprepared for work.

> *"If I had the proper education, I could've been anything. But it didn't happen that way." - Walter*
>
> *"I was mad over education because of how difficult it was for us to make our way in life. When we left the home, we were only taught to clean. I stayed there till I was nearly 16 and a half, I went there when I was nine months old." - Louise*

Others described education replaced by abuse and religious indoctrination.

> *"Why are you abusing us?' I said, 'We are human beings, we did not ask to be born. We were stolen. We were denied an education. All we got rammed down our throats was religion, religion, religion." - William*

Conclusion

Participants' accounts describe a continuum of harm that, for some, included experiences such as poverty, family instability, abuse, neglect, and displacement (including child migration) prior to removal, and was then compounded by institutionalisation. The regimented and isolating nature of institutional settings - where physical and sexual abuse were common - produced lasting physical, emotional, and psychological impacts. This theme documents the formative harms associated with out-of-home care; the enduring consequences across adulthood and into ageing are examined in the next theme.

Theme Two: The long trail into adulthood

The impacts of childhood institutionalisation did not end when participants left care; rather, they cascaded into adulthood, shaping life opportunities, health, relationships, and trust in systems across the life course. Many described a long trail of disadvantage that began in childhood and carried through to their adult years, marked by disrupted education, insecure housing, poor health, and fractured family ties. The legacy of trauma continued to reverberate in multiple domains of life, creating both practical and psychological barriers to stability and wellbeing.

The sub-themes that follow trace these interconnected impacts. They illustrate how early harm led to systemic mistrust, compounded disadvantage, and vulnerability in health, housing, work, and relationships. These experiences also shaped older Care Leavers' interactions with criminal justice, welfare, and community services throughout adulthood. Exploring the compounded disadvantages across the life course reveals how these enduring impacts have shaped participants' ageing experiences and created distinct support needs in later life.

Health burden

When asked whether they experienced major health issues throughout their life, 79% (64/89) of survey respondents indicated that they had, reflecting the literature that suggests that Care Leavers experience a higher prevalence of health challenges (Sacker et al 2021). For many participants, the legacy of institutionalisation was carried most heavily in their bodies and minds. The absence of care in childhood, coupled with exposure to abuse, neglect, and chronic stress, left enduring imprints on physical and mental health. Accounts revealed lives marked by premature ageing, persistent trauma symptoms, chronic illness, and poor access to timely or appropriate treatment. These burdens were not experienced in isolation, but interacted with disadvantage in housing, work, and relationships, compounding vulnerability over the life course.

Physical health challenges

The survey did not specifically ask about physical health challenges, however, participants in the interviews shared a range of health problems which they linked to the harsh conditions and practices of institutional life. Tasks such as forced child labour and corporal punishment were remembered not only as traumatic at the time, but also as the origin of chronic pain, joint damage, and long-term disability.

> *"The nuns would hit you on the knuckles… Now I've got arthritis badly."* - Louise

> *"Yep, very poor medical health, bones. We've all got knee problems, I reckon that's from scrubbing the cover way that they used to do. We would scrub, scrub, scrub, scrub, scrub, honestly, and all of us have got bad knees."* - Ruth

> *"We had to scrub concrete, long, long patches of concrete with a toothbrush… That's what we used to have to do. Scrub long, long patches of cement, and I*

> *mean long, on your head to knees in the middle of winter with no cardigan, freezing cold with a toothbrush.” - Carol*

As they aged, participants described facing compounding health decline - heart disease, arthritis, respiratory conditions such as COPD, and recovery from major medical events including aneurysms and cancers.

> *“But I know my body’s breaking down slowly. I’m getting to 70 now. My body’s starting to break down.” - Walter*
>
> *“I’ve had an aneurysm, right? I’ll show you the scar from my aneurysm. But I’ve had two lots of cancer over the last – the aneurism I had probably eight–10 years ago, the cancer in the last five years, two lots. I had throat cancer and I had the lung cancer as well.” - Richard*

Several reported being dismissed by health professionals, which reinforced reluctance to seek medical support. Despite these barriers, many emphasised their own determination in managing conditions and working towards recovery, underscoring both resilience and unmet needs in healthcare. These accumulated health burdens have shaped ageing by accelerating physical decline and limiting independence in later life.

Mental health challenges

Mental illness was a pervasive feature of participants’ lives. Survey responses showed that 65% had been formally diagnosed with a mental illness, a rate considerably higher than the general Australian population, where 42.9% report a lifetime mental disorder (ABS 2023). A further 35% suspected they experienced undiagnosed conditions, most commonly complex post-traumatic stress disorder (C-PTSD), anxiety, and attention deficit hyperactivity disorder (ADHD). This suggests that the actual prevalence of mental health difficulties in this cohort is even higher than reported.

A significant proportion (38% 57/88) of survey respondents also disclosed spending time in a mental health facility, highlighting the seriousness of the challenges they faced. These figures reflect both the enduring impact of early trauma and the ongoing vulnerability of Care Leavers to psychological distress throughout their lives.

The high prevalence and severity of mental health issues have profound implications for ageing. They not only increase the likelihood of complex support needs in later life but also amplify mistrust of systems and services.

Trauma sequelae

Participants described a lifetime of psychological impacts traceable to early institutional harm. In adulthood, these manifested as diagnosable conditions discussed above, as well as episodes of acute distress and suicidality, and day-to-day patterns of avoidance and hyper-vigilance. Many spoke of the ongoing labour of managing symptoms while trying to keep life moving, linking these struggles to childhood abuse, entrenched self-blame, and the absence of validating support. Several also described periods of acute despair, hopelessness, and anger.

> *"For us, I think a lot of it is PTSD. I suppose you've got a few other symptoms there amongst it all but most of it is that I think and sexual abuse and then maybe from addictions over years, other things might've happened to add to it because that's been a coping mechanism, so whether it's drink or having a joint or whatever, relaxes the nervous system and helps you eat." - Margaret*

> *"It's terrible. They took away our childhood, and then here we are in old age all alone again, and nobody gives a shit, that's how it feels. If I wasn't mentally capable I think I would have gone, in the circumstances. You've got nothing to live for when it comes to things like that. What have you got to look forward to?" - Louise*

> *"I chose to go and play sport to be a mug, you know what I mean? To be a gangster or be this and hang at Kings Cross and do that, be in the surf club. That was my break away from my mental agony I was going through from what happened to me when I was six. I still always had it there because I always had a bad temper." - Walter*

Alongside mental health conditions, participants carried layers of grief - family separations, deaths of loved ones, and the loss of relationships that never fully formed after removal. Some described becoming desensitised to death over time, shaped by cascading experiences of loss throughout their lives.

> *"I had a friend die last week - my son's godmother. She was 89. She was just about to have a birthday in February. I don't cry so much now, when I hear death, as I used to. I think I grew up fast in the home. You had to. You'd know that. And you had to be an adult before you were an adult, you know?" - June*

Persistent loneliness in older age was also a dominant theme. People described being physically close to family or community but feeling profoundly apart, echoing the dislocation established in childhood. Protective strategies such as withdrawal, vigilance, and tight boundary control were common and understandable, yet they often reinforced isolation.

> *"The old age is the loneliness, it's horrendous. When you haven't a family, or you had a family - it's like as I said to my son, I had a family but it's like my family died in a car accident and I'm mourning the loss of every one of them. But the fact is that I know they're here, just up the road, and that's my biggest heartache." - Louise*

> *"We're very cruel you could say, cruel to ourselves… we're scared for them to see that - find where we're vulnerable… I've had that happen to me over the years by people." - Rose*

> *"A lot of us don't like socialising with others much in the community, we're a bit more sheltered, don't fit in and then we're scared for them to find where we're vulnerable, that's what we're scared of because they know then when to target you and I've had that happen to me over the years by people. They find your weakest link and they know they can get in and they'll target it. So, that's another thing that comes back to trust and everything too." - William*

Together, these accounts show how trauma, grief, and loneliness interact over time: symptoms make connection harder; losses accumulate without space to mourn; and protective withdrawal, while adaptive, can deepen isolation. The persistence of these sequelae into older age compounds vulnerability and shapes older Care Leavers' aged care needs in distinct ways.

Housing instability

Survey findings highlighted stark disparities in housing security for older Care Leavers. While 36% (32/88) of respondents owned their homes, this was less than half the rate of the general Australian population aged over 65 (82%) (AIHW, 2024). Forty percent (n=35) resided in government housing, a further 8% (n=7) in social or disability housing, and 14% (n=12) in private rentals. Two percent were homeless or in temporary accommodation at the time of the survey. Across the survey cohort, 61% (54/89) reported having experienced homelessness or unstable housing at some point in their lives, reflecting broader evidence that Care Leavers are disproportionately vulnerable to housing insecurity.

Interview accounts gave depth to these statistics, revealing Care Leavers' persistent anxiety about losing housing, precarious tenure, and unsafe or unsuitable environments. Others described the long-term precarity of housing shaped by poverty, relationship breakdowns, and limited options.

> "But my point is as a child, I had nothing practically and only got money to myself when I was 15 when I started work…So I've just gradually got – this is my third house. So I always sort of look at it, I don't want it to go to waste. I want it to be sold and the money go to my children, which they haven't had a lot." – *Elizabeth*

For those reliant on government housing, ongoing instability was compounded by unsafe conditions, delays in transfers, and fears of theft, vandalism, and violence in their neighbourhoods.

> "Only upstairs I feel safe. I don't go much out after 5 in the afternoon because I see a lot of fights, a lot of arguments. I've had my windscreen and my window smashed in the car. My car won't stay here. I'll leave it over at my mate's place. I won't leave it here to get smashed up again." – *Ray*

Together, the data show that secure and suitable housing is far from guaranteed for older Care Leavers. Past experiences of displacement and institutionalisation make housing security especially critical, yet many continue to live with uncertainty, fear of eviction, or unsafe surroundings.

Education, work and income

Educational disadvantage was one of the most consistent legacies of institutionalisation. Later-life qualifications were uncommon: 20% (n=18) finished TAFE; 16% (n=14) completed university; including 2% (n=2) a master's degree; 2% (n=2) a PhD. These achievements were hard-won given many left "care" with severe gaps in literacy and schooling, creating barriers that followed them throughout life.

> *“Because of the age I was when I got out, it put me back with my schooling it stuffed me right up. I never sort of could get far with my schooling and then when I got to high school it was even worse.” - Margaret*

Older Care Leavers’ frustration at being denied early opportunities was palpable. Several described ongoing grief about what they had missed, and how the struggle to “catch up” often felt overwhelming.

> *“It’s frustrating because we so much want to better ourselves and live a bit more comfortable and learn. We’re always willing to learn because we weren’t given that opportunity as children. So, I find that hurts. I’ll go down into tears and depression over that. That’s how much that’ll drop me down. Go, ‘Mate, come on. Why can’t I do this? Why can’t I do that bit? What’s wrong with me?’ and then I get angry at them and I get in this angry, attack mode and it’s not good.” - Rose*

For some, the absence of education translated into lifelong illiteracy or limited employment options.

> *“Well, I can’t read and write or anything like that, so I find it very hard to get on with my life. But I’ve learnt to live with it. You know, like I’ve tried to learn to read and write, but just couldn’t pick it up.” - Arthur*
>
> *“I worked cleaning people’s floors because I didn’t have any education much, you know. In the school, if that’s what you’d call it - there was no order of anything.” - Carol*

These educational gaps often confined participants to insecure, physically demanding, or poorly paid work. Survey data showed that while 91% (81/88) had engaged in paid employment at some point, financial insecurity was a dominant theme: 40% reported “almost always” (36/89) struggling, 21% (19/89) “often,” and 28% (25/89) “sometimes,” with very few experiencing sustained stability.

Despite these constraints, participants’ working lives reflected remarkable adaptability and resilience in the face of adversity. They reported employment across a wide range of occupations, including teaching, nursing, labouring, cooking, disability support, sewing, factory work, librarianship, gardening, academia, and psychology. Many described piecing together varied forms of work over their lifetimes, drawing on practical strengths, resourcefulness, and self-directed learning. Survey responses further highlighted the pursuit of additional skills training—from sign-writing and cooking to information technology, counselling, human rights, and aged care—demonstrating a sustained commitment to self-improvement and lifelong learning. Recognising this diversity of experience and identity remains essential to avoiding stereotyping or deficit-based labelling.

Some moved from service jobs into professions such as nursing, while others built small businesses from hands-on skills or stitched together multiple roles to stay afloat. These stories reflect determination to survive and succeed despite systemic barriers, even if stability was elusive.

The combined weight of disrupted education, insecure employment, and persistent financial struggle shaped ageing in significant ways. Many entered later life without assets, superannuation, or the financial security typical of the broader population, leaving them more reliant on government support and vulnerable to poverty in old age.

Relationships: Partners, parenting & intergenerational effects

Across the cohort, intimate and family relationships were both central and fraught. Although 86% (77/88) of survey respondents had married or lived de facto at some point, only 20% (17/88) were currently partnered. This is significantly lower than the general population of Australians 65+ where 56% are currently partnered (ABS 2022). Most survey participants (87% 77/89) had children, yet 27% (21/89) said their children were raised outside their home; of these, 38% (8/21) involved state removal and 62% (13/21) relied on kin or friends.

A massive 74% (65/88) indicated they had experienced family violence in their lifetime, highlighting the high vulnerability of Care Leavers to such experiences. The survey did not specify whether respondents were victim-survivors, perpetrators, or both at different points, leaving open the possibility of complex roles shaped by trauma and relational disruption.

Interviews reflected these realities. Some described lifetimes of partner violence and instability that spilled into parenting and care arrangements:

> *"I ended up with another abusive bloke that broke nearly every bone in my body, ripped my hair out, and I walked out and left him. Took my kids and run….I knew the Welfare was on my tail … so I just kept on going." - Evelyn*

Grandparent caregiving and disrupted kinship ties were common, often shaped by substance use and criminal justice involvement in the next generation:

> *I cared for [my granddaughter] - I think she was nine or 10. It wasn't long. It wasn't long before she ran away… They were both on drugs. It was drugs… I tried everything to fix my son up… he ended up in jail… When my son died my other daughter said, 'Well, at least he hasn't got his demons anymore.'" - June*

Participants also traced explicit intergenerational connections with child protection:

> *"My daughter, my Aboriginal daughter's children, the whole lot, mate; stolen generation, the whole lot I've been through, darling, and it's shocking what they did." - Katrina*

> *"Yeah, my 18 year old granddaughter was taken from my daughter when she was a week old." - Helen*

Alongside rupture were strong protective impulses and boundary-setting in parenting and grandparenting, shaped by institutional trauma and fear of harm:

> "I am so strict with my grandchildren… 'Your friends can come here, but you are not allowed there to sleep, that's it.'" - *Ruth*

Some spoke of profound bereavement - child deaths, suicidality, separations - and the long shadows these losses cast over later relationships:

> *“I lost my daughter in ’69… I lost another one through cot death in 1970.” - Alice*

> *“On 15 December 1995 my boy decided that he’d jump out of a tree with a rope tied to his neck. I felt him die.” - Helen*

The combination of high rates of relationship breakdown, pervasive family violence, intergenerational child protection involvement, bereavement, and protective hyper-vigilance leaves many Care Leavers entering older age with fragile or fractured support networks. While some sustain bonds with children or grandchildren, these are often complicated by histories of trauma, loss, and mistrust. Others face later life with few, if any, dependable family ties. Together, these patterns reflect a lifelong struggle to build and maintain safe, stable relationships, with enduring consequences for connection, belonging, and support in older age.

Contact with forensic mental health and criminal justice systems

A significant proportion of participants reported involvement with the criminal justice system across their life course. Twenty-one percent had spent time in a prison or forensic correctional facility, either as children or adults. This pattern reflects a broader reality: that for many Care Leavers, the state’s response to childhood neglect and institutionalisation was not protection but punishment.

The Royal Commission into Institutional Responses to Child Sexual Abuse (2017) noted that throughout much of the 20th century, state legislation blurred the lines between welfare and justice. Children who were neglected, destitute, or deemed “uncontrollable” could be sent to reformatories, training schools, or even prisons, despite not having committed crimes. In effect, neglect itself was criminalised, and many Care Leavers were institutionalised or incarcerated for the circumstances of their abandonment and poverty rather than any offending behaviour (Royal Commission into Institutional Responses to Child Sexual Abuse, Final Report, 2017). These trajectories have been noted to persist in contemporary child protection systems, including in Australia (Baidawi & Sheehan, 2019).

Interview accounts revealed how justice system involvement intersected with loss, family breakdown, and ongoing disadvantage. For some, prison was a turning point that coincided with relationship collapse and deeper marginalisation:

> *“When I got older, I went to prison and my wife left me” - Charles*

Others described the long shadow of correctional orders shaping daily life even in later years:

> *“Because I’m on this order, correctional - I’ve only got another four years to go and I get off it. But they’ve got to approve [housing]– if they don’t approve it and their attitude is, he’s got a place. We’re just going to leave him there.” - Arthur*

The mistrust of police and justice systems ran deep, particularly for Aboriginal participants, who emphasised how racial bias and system responses compounded trauma rather than provided protection:

> *"Yeah, but don't go to the police for help. Don't use the system for help. And if you're white, hold onto that because if they find out you're fucking black mate, you're in trouble… They take your spirit. That's what they do, they take your spirit, but they haven't got mine yet." – Helen*

These accounts reveal how contact with the criminal justice system was rarely isolated to an event or period - it was entangled with childhood neglect, institutionalisation, racism, family violence, and ongoing disadvantage. These experiences leave lasting marks, with justice system involvement shaping identity, relationships, and trust in authority well into later life. For many Care Leavers, contact with police, courts, and corrections reinforced feelings of stigma and exclusion, deepening the challenges of building safe and stable lives.

Non-aged support needs and experiences of support

Across domains, participants reported substantial support needs (aside from those related to ageing) that were met unevenly and often in ways that reinforced mistrust. Survey data show cumulative demand: 53% (46/87) reported a disability requiring support yet only 29% (10/45) of those received NDIS assistance (with the age cut-off shifting many to other systems later in life); and 56% (50/89) had experienced alcohol or drug issues. Despite this, people drew on multiple supports: 55% (48/88) received regular support from family, 63% (55/88) from friends or community, and 83% (74/89) from professionals and organisations - most commonly GPs, care-leaver services, psychologists, and support workers.

High level of engagement with services did not necessarily mean high levels of support. Many reported that encounters with services felt punitive, invalidating, or re-traumatising; participants described systems that did not understand trauma, triggers, or withdrawal:

> "They don't understand triggers… When we start to isolate, we'll withdraw… it's triggering." - *Rose*

Redress and justice processes were common and frequently experienced as reopening wounds with little accountability or follow-through:

> *"Forty years later… they rang me up, rattled my cage, unlocked it, let me out and wonder why they couldn't control me." - George*
>
> *"I started drinking again too much, I started gambling… because I realised… I'm drinking blood money." - George*
>
> *"It made you feel $20,000, is that all you're worth?" - Mary*
>
> *"They just didn't really want to pay out anything… they just turned a blind eye… because I had a criminal history." - Ray*

> *“Mine’s just laying in a bank. I’ve never touched it. I don’t want it.” - Carol*

> *“Money doesn’t heal… I gave most of it away to be honest with you.” - Ruth*

When participants reported positive experiences with services, these were grounded in a sense of respect for privacy, continuity, and choice. Trust was built through stable, well-boundaried relationships and through participants’ control over the sharing of their personal information.

> “I’ve got one worker… she’s the main one that I trust… I only trust that one worker to know all my business.” - *Rose*

Costs, logistics, and bureaucratic load contributed to negative experiences with services. Access was constrained by out-of-pocket costs, reimbursement delays, and fragmented pathways.

> “You’ve got to pay for everything… If you see two doctors a week, there’s your money gone.” - *Ruth*

Participants also indicated that mistrust of institutions and authority (including faith-based services) emanating from their experience of early harms in institutional and religious settings shaped lifelong scepticism toward authority.

> *“Well, that’s the thing is from this environment that we come from, kids like us that have been institutionalised and that, I get so angry because society - I don’t know, well, the Catholic Church in itself is an absolute joke as an institution. The bigger the institutions the worse they are.” - Richard*

> *“The abuse of children is the number one rule of society, you abuse children, you get the book thrown at you. Because a child, that’s where they’re innocent! You’re abusing a child, you’re abusing their innocence, and that’s just disgusting, it’s disgusting. Well that’s why they shifted them [priests] around - they shifted them from one place to another. But to take away the innocence of a child - and also too it’s a bloody sense of mistrust between us and the institution as well.” - Richard*

Taken together, these experiences show that older Care Leavers approach later-life support with deep awareness of what helps and what harms: respect, stability, and genuine understanding foster engagement, while histories of coercion, bureaucracy, and broken trust fuel apprehension that new systems will repeat old patterns.

Conclusion

Across health, housing, education and work, relationships, justice contact, and service use, a consistent pattern emerges: early institutional harm set in motion cascading disadvantage that accumulated across the life course for older Care Leavers. Disrupted schooling narrowed pathways into decent work; financial precarity and poor health compounded housing instability; grief, loneliness, and trauma symptoms strained intimate and family relationships; and contact with justice and welfare systems often reflected punishment or proceduralism rather than care. These domains did not operate in isolation - they interacted and amplified one another, producing a long trail of risk and insecurity into later life.

Running through the accounts of older Care Leavers is a deep mistrust of systems, learned from histories in which help arrived as control, disclosure was met with disbelief, and redress or clinical responses reopened wounds without accountability or continuity. Where support was stable, boundaried, and trauma-literate, participants engaged; where it was coercive, extractive, or chaotic, they withdrew. Taken together, the evidence shows how compounded disadvantages across the life course have shaped participants' ageing - leaving many with fragile or fractured networks, constrained resources, and a clear, hard-won sense of what safety, respect, and real support must look like.

Theme Three: Guarded engagement with aged care: present-day perceptions, barriers and behaviours

When speaking about aged care, participants conveyed a mix of apprehension, pragmatism, and guardedness. Their accounts reflected a cautious weighing-up of options and a deep scepticism about whether services could ever truly meet their needs. Survey and interview data revealed both current and expected use of aged care supports, ranging from limited home care packages to anticipated future reliance. Participants spoke candidly about their views of residential care, often in stark terms that included an explicit *“preference for death”* over entering an institution. In contrast, home care was seen as preferable - but only under specific conditions that preserved independence, dignity, and a sense of safety.

What was most striking, however, was that when asked about aged care, participants almost always responded by reaching back into their childhoods. The anticipation of aged care was closely tied to memories of institutional life - orphanages, homes, foster care - where “care” was experienced as control, harm, or abandonment. These enduring associations meant that aged care was rarely imagined as a fresh start, but rather as a possible return to the very environments they had spent a lifetime trying to leave behind.

Underlying these perspectives were powerful drivers: fear of re-institutionalisation, risk of re-traumatisation, loss of autonomy, concerns about dignity, and anxiety about neglect, loneliness, or poor treatment. Together, these shaped a cautious and conditional approach to aged care, where engagement was possible but rarely without reservation.

Current and anticipated aged care use

At the time of the survey, none of the participants were currently living in residential aged care facilities and only 6% (5/89) anticipated needing residential care within the next five years. Some (35%, 31/89) were already receiving aged care support at home or in the community and almost half (47%, 26/57) expected to need, or continue needing, home-based support in the next five years. This pattern underscores a clear preference for ageing in place, where support is provided on their own terms.

Support included help with transport, cleaning, gardening, meal preparation, personal care, and medical needs. For many, this assistance was essential to manage physical decline while still holding onto independence. Yet reliance on external help also stirred discomfort, with several linking it to fears of intrusion or loss of privacy.

> *“And of course then - and now I’m here, I can’t get anyone - I try to do everything I can for myself, but I know I have to get aged care because I’m having trouble cleaning with my back and all that sort of stuff. But I’m worried, I’m thinking it’s like an invasion of my privacy again. You know what I mean?” - Louise*

Stated preferences for various aspects of care

Participants were asked to rate the importance of various aspects of care when considering aged care support at home, in the community, or in a residential setting. Table 2 compiles their responses when asked about the important aspects of both **community and**

residential aged care. The responses show that participants placed the highest importance on consistent, trauma-informed, and affordable support that respects their autonomy and personal boundaries. Nearly all valued choice, control, and staff who understand the impacts of childhood institutionalisation, while priorities such as religious support, cultural responsiveness, and specialised care were less universally rated but still significant for many.

Table 2. Importance of aspects of aged care (community and residential) (n=69)

Statement	Extremely or moderately important	Somewhat or slightly important	Not at all important
Having consistent workers who understand my needs	100%	0%	0%
Being able to make my own choices	99%	1%	0%
Having choice and control over how much personal information I share with staff	96%	4%	0%
Support staff who understand the impact of childhood institutionalisation	96%	3%	1%
Support is free/affordable	96%	3%	1%
Having flexibility in my support	95%	2%	3%
Support staff who understand trauma and its impact	93%	6%	1%
Access to an advocate to help navigate the aged care system	91%	7%	2%
Access to counselling or psychological support	90%	9%	1%

Services are animal friendly so I can have my pet with me	78%	7%	15%
Access to specialised support ONLY for people who have spent time in childhood institutions, group homes or foster care	75%	14%	11%
Staff that are responsive to my cultural background and needs	71%	25%	4%
Staff that are supportive of my religious beliefs and practices	54%	30%	16%

Perceptions of aged care

When participants spoke about aged care, their responses rarely focused only on services in the present. Instead, perceptions were shaped by a powerful interplay of memory and anticipation. The idea of entering aged care—particularly residential care—was often inseparable from earlier experiences of institutionalisation, with childhood trauma resurfacing in how they imagined later-life support. Even when services were acknowledged as necessary, they were rarely described with ease or neutrality.

Concerns about the workforce were central to these guarded views, cutting across both residential and home-based support. Participants stressed that the quality of aged care ultimately depended on the people providing it, and many described workforce conditions as undermining safety, dignity, and trust. Instability was one of the strongest concerns:

“The turnover of staff and staff knowing that you’re a Care Leaver, but you don’t know anything about the person who’s providing the care for you” (keystakeholder).

Others emphasised cultural mismatches and poor training, observing that: *“These people are brought in from overseas…. And they don’t understand our way” (Carol)*, and calling for *“better trained [staff], with more understanding about what all of us want in life, not just the old people and not just because we’re old” (Dorothy)*. Experiences of disrespect were also described as endemic: *“If they change their policy in the aged care facilities, there’s lots of things they’ve got to change in those places. One, respect. There’s none” (Margaret)*. Finally, the risks of chronic understaffing were raised in stark terms: *“Overworked, underpaid and putting all these peoples lives at stake with one person manning that whole area. Disgusting. That’s neglect” (Rose).*

Within this context, two distinct sets of views emerged. Residential aged care was overwhelmingly associated with fear, control, and the erosion of dignity—with some participants stating they would rather die than enter a facility. By contrast, home care was seen as a preferable, though not uncomplicated, alternative: valued for allowing independence and connection to community, yet shadowed by concerns about privacy, quality, and continuity of support.

The following sections explore these perceptions of aged care in detail, drawing on both survey data and interview accounts.

Residential aged care

Survey findings revealed a striking consensus among older Care Leavers: residential aged care was overwhelmingly the least-preferred option. When asked about where they would want to live if they could no longer care for themselves at home, 84% (63/75) said they wished to remain in their own homes. Of these, 70% (44/75) preferred professional support funded by a government package, while 30% (19/75) preferred help from friends or family. A smaller group (15%, 11/75) indicated they would consider a retirement village if adequately supported, and only one participant nominated a residential aged care facility as their preferred arrangement.

When asked about their *least* preferred living arrangement, 84% (63/75) of survey respondents selected a residential aged care facility, followed by smaller proportions who were averse to living at home supported by family/friends (7%, 5/75), retirement villages (5%, 4/75), or professional in-home support (4%, 3/75). In open-ended responses explaining this aversion, six participants explicitly said they would rather die than enter a nursing home.

These survey findings, reinforced by interview accounts, demonstrate that residential aged care is not perceived as a neutral or acceptable option. Instead, it is strongly linked with past institutional trauma, loss of autonomy, and fears of neglect - to the extent that some Care Leavers articulated death as preferable.

Preference for death over nursing homes

The most striking finding was that six survey respondents explicitly said they would rather die than live in a nursing home, stating things like *“I'd rather be taken out the back and shot,” “I would rather step out in front of a train,”* and *“I'd knock myself off rather than live in a nursing home.”*

Interview data echoed this intensity:

> *“No way. I’ll top myself before I go into one of those places.” - Margaret*
>
> *“I’d sooner put an ounce of lead in my head because they really don’t give a rats.” - William*

Key stakeholders in the focus groups also echoed these sentiments:

> *“I’ve got about eight clients who’ve said to me that they will suicide before they go into residential. That’s how strongly they feel.”*
>
> *“Total and utter fear of returning to the system. Total and utter to the point that she would suicide over it. That’s how severe it is.”*

Fear of institutionalisation

For many, residential care was seen as simply another institution - evoking the same conditions that had caused harm in childhood. This was supported by short answer responses in the survey, and by interview data.

> *"It's just another institution." (survey)*
>
> *"It will be like being back in the detention centre." (survey)*
>
> *"It would remind me too much of my childhood." (survey)*
>
> *"I don't want to be in a home, because I've been shut away… to be locked behind closed doors again - no, not for me." (June, interview)*
>
> *"I don't think I can go to a nursing home… I'd feel like I'm on death row because that's what it would be. You'd never get out." (Carol, interview)*

This was reinforced by key stakeholders that work directly with Care Leavers.

> *"I think the most enormous block, for a Care Leaver - if you've at any point been in institutional care, and it's been a negative experience, which invariably, the majority of times it has been, the thought of moving into aged care is horrific. Because most are yet another institution."*

Trauma and re-traumatisation

Participants feared that entering a nursing home would retraumatise them, reopening wounds from institutional childhoods.

> *"My younger years were stolen from me by an institution." (survey)*
>
> *"Trigger for past childhood trauma." (survey)*
>
> *"I struggle in institutional settings." (survey)*
>
> *"It's affected me by being shut away… so many people that have been in the homes when they were younger don't want to be locked away again." (June, interview)*

Loss of independence and autonomy

Participants feared the loss of control inherent in residential care. Independence and choice were described as non-negotiable.

> *"It would deprive me of independence." (survey)*
>
> *"No choice or control." (survey)*
>
> *"I don't trust that I would have the freedom to be myself." (survey)*
>
> *"I would lose some of my independence." (survey)*

> *“Why should they be told by anybody what they got to do?… When you get to my age you don't want somebody telling you what to do.” (Margaret, interview)*

Concerns about treatment and abuse

Experiences and perceptions of neglect and mistreatment in aged care reinforced rejection of residential facilities.

> *“Worried about treatment from staff.” (survey)*
>
> *“Due to the well-known abuse within aged care facilities.” (survey)*
>
> *“The way they treat people is not ok.” (survey)*
>
> *“I have seen theft, I have seen abuse.” (survey)*
>
> *“They don't get looked after properly. They don't get fed properly. They're told when they're going to do what they’ve got to do.” (Margaret, interview)*
>
> *“I don’t like the way once they get to a point where they can’t look after themselves they are treated like shit. I’ve seen them try force-feeding and forcing tablets down their throats… they’ve left them laying in their own faeces all day. That’s not right. You treat people with dignity and if you can’t, you don’t belong in that line of work.” - Alice*

Desire for dignity and privacy

Dignity and privacy were seen as incompatible with residential aged care.

> *“Loss of dignity and privacy.” (survey)*
>
> *“No privacy or independence in a nursing home.” (survey)*

Feelings of loneliness and isolation

Participants associated nursing homes with abandonment and social death.

> *“I would feel alone and isolated.” (survey)*
>
> *“They’re there waiting to die.” (survey)*
>
> *“LONELINESS.” (survey)*
>
> *“It would feel like being abandoned and completely depressing.” (survey)*
>
> *“Aged care’s a really big problem for me…. Fear of being locked in somewhere… it’d just be too scary for me.” - Irene*

Survey respondents were asked to rate the importance of various aspects of care when considering aged care support at home, specifically in a residential setting. Their views about the important aspects of residential aged care are compiled in Table 3. Participants placed the highest importance on residential aged care facilities that respect autonomy, safety, and organisational accountability. Nearly all valued how owners treat staff, the reputation and history of the organisation, the ability to leave freely, and having control over privacy and daily routines. Choice over staff rostering, and the gender or age of carers, as well as flexibility around meal times, were also significant for many. By contrast, sharing cultural or religious backgrounds with staff was seen as less important overall.

Table 3. Importance of aspects of residential aged care

Statement	Extremely or moderately important	Somewhat or slightly important	Not at all important
How the owners of the facility treat their staff	98%	2%	0%
About the organisation that runs the facility	96%	2%	2%
If I can leave the facility freely to visit people or places	95%	3%	2%
Whether the organisation that runs the facility was involved in childhood institutions	92%	3%	5%
If I can lock my door when I want to	91%	8%	1%
If I can choose what I do each day	90%	10%	0%
How the support staff are rostered	88%	8%	4%
If I have a choice over the gender or age of the staff that dress or care for me	80%	15%	5%
If I can choose what time I eat meals	80%	12%	8%

If the staff share similar cultural background to me	43%	28%	29%
If the staff share similar religious beliefs to me	26%	22%	52%

Survey and interview findings revealed that residential aged care was overwhelmingly rejected by older Care Leavers, with many describing death as preferable. This rejection was rooted in strong associations with past institutional trauma, fears of re-institutionalisation, loss of autonomy, mistreatment, and isolation. Participants emphasised the non-negotiable importance of independence, dignity, and choice, and described nursing homes as retraumatising, undignified, and unsafe.

When asked what mattered most if residential care were unavoidable, participants prioritised organisational accountability, autonomy, and safety: how owners treat staff, the reputation and history of the organisation, freedom to leave, privacy, and daily choice were rated as extremely important by nearly all. While preferences around staff rostering, carer gender/age, and meal flexibility were also significant, cultural or religious alignment with staff was generally considered less important.

Home care

Compared with residential care, participants generally preferred home care because it allows them to preserve autonomy, routines, and identity within familiar surroundings. This preference, however, was conditional: support had to be respectful, flexible, predictable, and delivered by known people. Help was welcomed when it augmented capacity (doing with, not to), aligned with personal priorities, and did not replicate institutional control.

When home care was available to participants, confidence was undermined by waitlists, funding gaps, rigid task rules, and workforce churn. Participants described packages that would not stretch to what mattered most, providers prioritising set menus of “allowable” tasks, and frequent changes of workers that eroded trust and safety. Training and communication gaps showed up in poor bedside manner, language barriers, and carers steering time toward activities the person did not want.

> *“They didn’t treat you in a particularly friendly or helpful manner. It was like it’s all too much for them almost. I just thought, hmm, I don’t like that. I don’t like that.” - Irene*

> *“I would like to see all of them better trained, with more understanding about what all of us want in life, not just the old people, and not just because we're old. But we all want to be respected, and cared for, and handled gently,” - Dorothy*

> *“I don’t want to do a social, I want to mop my bloody floor.” - Helen*

Concerns about control and safety also surfaced when unknown workers entered the home, especially without proper introductions or where there was little say over who held keys, what information was shared, and how honesty or reliability could be assured.

> *"Lack of flexibility, and lack of control really, of that person, and lack of knowing about them. You could do a police check on people and find that they didn't have a criminal record, but you don't know how honest they are, do you?" - Irene*

Participants wanted clear roles, shared decision-making, and carers who recognise them as experts in their own lives. That included agreeing the task list at the start of a visit, respecting preferred order and pace, accommodating cultural and gender preferences, and allowing refusals or rescheduling without penalty. People also emphasised continuity (the same few workers), plain-language communication, and minimal gatekeeping - *one* accountable coordinator rather than being bounced between departments.

> *"I would like to make the choices without having to go through seven or eight different people... I'm still here because I've figured out what's good for me." - Helen*

Stakeholder critiques: why mainstream aged care feels unsafe and is often avoided

The guarded engagement described by Care Leavers was strongly echoed by key stakeholders, who were frank about mainstream aged care's current limitations in meeting this group's needs. They confirmed that mistrust of institutions, lack of trauma-informed practice, and inflexible service models are not only participant perceptions but systemic realities. Across focus groups, stakeholders described three system-level problems that map directly onto Care Leavers' guarded engagement: mistrust and fear of institutional care, invisibility and weak trauma literacy, and resistance to mainstream service models.

Mistrust and fear of institutional care.
Stakeholders reported that institutional settings routinely trigger memories of control, abuse, and powerlessness, making residential aged care feel like a threat rather than support:

> *"My relative is a Forgotten Australian… going into aged care and she's going in with absolute fear because it's a system… they inflict on you, they force you."*
>
> *"They remember being dragged out of bed. Told when to eat. Told when to go to bed. For some, aged care is not just scary - it's a threat."*

These fears are compounded by harmful encounters across health, justice, and welfare, which prime avoidance of any new "system."

> *"There's that historical fear which is - why wouldn't you be terrified of institutions run by church and government where you were abused so badly as kids?"*

This mistrust of institutions extended to institution names and the buildings themselves being traumatic triggers for older Care Leavers.

> *“The other thing for Care Leavers that can be really triggering is if the facility itself has a religious name. Can be a great comfort to some, and it can be incredibly triggering to others. And we’ve got lots in WA where they’ve been refurbished. They’re the same institutions that they were abused in, have been refurbished.”*

Invisibility and lack of trauma-informed practice.
Stakeholders were unequivocal that the workforce often lacks awareness of Care Leavers and the impacts of childhood institutionalisation - despite formal recognition under the Aged Care Act:

> *“The aged care system is absolutely not set up for Forgotten Australians… Most of the time, they haven’t heard of them at all.”*
>
> *“With Forgotten Australians, they’re going to be 0.2% of the people in the aged care so people won’t be used to it, they won’t be informed, they won’t be accommodating.”*

Routine practices (rushed handling, rigid schedules) are commonly retraumatising:

> *“They’re pushy and they’re grabbing arms… ‘Come on… breakfast.’ I would imagine that their whole day would be full of trauma.”*

Language and cultural gaps can deepen disconnection:

> *“Most people that work there… not speaking English… For some of our clients, it feels like no one hears them. It reinforces that belief that they don’t matter.”*

Resistance to mainstream service models.
Stakeholders observe active avoidance - even when support could improve safety - because services are perceived as inflexible, impersonal, and controlling:

> *“They don’t want these services… we’re trying to convince them… but they don’t want them.”*

This extends to home care: strangers entering the home can feel like a loss of control or the start of unwanted escalation: *“If someone gets a toe in the door, they’ll lose control.”*

Cost emerged as a major barrier to accessing aged care and related services, particularly given participants’ histories of state and church neglect. Many Older Care Leavers expressed a deep sense that, after the harms and abandonment they experienced, governments and churches bore an enduring moral responsibility for their care in later life. As one participant explained:

> *“They feel like the government and churches owe them. They don’t want to pay money to a system that never did the right thing by them.”*

In addition to this sense of injustice, many Older Care Leavers described profound insecurity and anxiety about costs. They often found it difficult to obtain clear, plain-English information about fees and entitlements, which compounded their fear of financial exploitation or exclusion. Together, these concerns highlight how economic barriers are entwined with histories of institutional betrayal and ongoing distrust of formal systems.

Conclusion

Taken together, the findings show that Care Leavers approach aged care with deep ambivalence and caution. Residential care was overwhelmingly rejected, often described as worse than death, because it evoked memories of childhood institutions—control, abuse, and confinement. Home care was more acceptable, but only when it safeguarded autonomy, dignity, privacy, and continuity of relationships. Even then, engagement was conditional, with fears of intrusion, workforce churn, and rigid systems undermining trust.

Stakeholders reinforced these concerns, highlighting systemic barriers that mirrored Care Leavers' fears: risk-averse institutional practices, a workforce with little awareness of Care Leavers or their trauma histories, and rigid, transactional service models that feel impersonal and controlling. They noted that many clients actively avoid aged care, perceiving it as unsafe, unaffordable, or re-traumatising, with even home support viewed as a potential loss of control. For some, facilities with religious branding or regimented routines were described as emotionally threatening in themselves.

These parallel accounts - older Care Leavers' lived experiences and stakeholders' systemic critiques - converge on the same conclusion: mainstream aged care, as currently designed, is not neutral terrain for this group. Instead, it too often replicates the very conditions they most fear. Understanding these dynamics is critical, because it highlights not only why Care Leavers engage with aged care guardedly, but also what must change if services are to become safe and acceptable. The next theme sets out those conditions and pathways forward.

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Theme Four: What safe, acceptable aged care looks like (conditions & solutions)

Theme Four brings together what older Care Leavers and key stakeholders told us about what safe, acceptable aged care looks like - both the conditions that must be present and the practical solutions that make them possible. Their accounts move beyond critique to describe a positive standard: care that restores autonomy, honours dignity and respect, builds trust through consistent follow-through, and recognises the dignity of risk as part of adult life.

Accordingly, this theme is organised in three parts. We begin with the principles that participants said must anchor any acceptable service. We then show strategies that work in the current system, and conclude with participant-driven recommendations that translate these insights into action.

Principles

The accounts of Care Leavers and key stakeholders reveal a set of core principles that must underpin aged care if it is to be acceptable and safe for those with experiences of childhood institutionalisation. These principles are not abstract ideals but are grounded in lived realities: they reflect what was systematically denied to Care Leavers in childhood and what is now essential for ageing with dignity. Across interviews and focus groups, participants consistently pointed to the centrality of autonomy, trust, dignity, and respect - alongside the recognition that risk is part of a meaningful life.

While stakeholders often framed these principles through policy, training, or practice reforms, Care Leavers spoke from lived experience, describing what it feels like to lose control or be disrespected, and what it means when services instead offer choice, recognition, and follow-through. Taken together, these perspectives highlight that the foundation of good aged care for Care Leavers lies less in new structures and more in how people are treated day to day: whether their voices are heard, their choices upheld, and their humanity acknowledged.

The following sections outline these principles in detail, using the words of Care Leavers and key stakeholders to illustrate what they mean in practice.

Autonomy, choice and control

For older Care Leavers, autonomy, choice, and control are inseparable: the right to make decisions, the ability to act on them, and the assurance that those decisions will be respected. These principles were described as non-negotiable, reflecting both what was denied in childhood institutions and what is essential to feeling safe in later life.

> *“You have to look at things that really suits you as a human being, and with your spiritual and your emotional and your personal self. I don’t think having anyone take over aspects of my life would have been very good for me at all.” - Irene*
>
> *“I would like to have choices about what I do. Yeah, I don’t want to be told that you’ve got to be in your flat by some time in the night time. I don’t want to be told anything about how I live, I want to just make the rules up to suit me. I do that, and I’m fine with that.” - Ruth*

This was supported by key stakeholders in focus groups, who reflected on their understanding of what is important to Care Leavers, particularly in residential care environments.

> *“It’s really important to our clients that they don’t feel trapped, and we have very open facilities where people can leave easily and then return when they’re ready to. Our residents don’t respond well to rules, just generally speaking, so keeping rules to an absolute minimum, and allowing people to live their lives in whichever way they choose, as long as it’s not having a negative impact on other people is something that works well with this background.”*

> *“Nothing is more triggering I think for Forgotten Australians than that feeling out of control and everything about the way aged care runs currently promotes that in them.”*

Trust and safety

While trust and safety were emphasised strongly by key stakeholders, older Care Leavers themselves rarely spoke about *safety* in direct terms. Instead, their accounts placed weight on autonomy, dignity, and control - conditions that inherently generate a sense of safety without naming it explicitly. For many who grew up in unsafe institutions, “safety” may feel too abstract or even hollow unless demonstrated through consistent action and respect. As one stakeholder explained, *“When you say you’re going to do something, you need to do it. And if you can’t, you go back and say so. That breaks down walls.”*

Stakeholders also highlighted the importance of shared responsibility for safety, where both staff and Care Leavers feel secure, respected, and part of the organisation:

> *“We want to make sure that they feel valued, that they feel part of the organisation as well… let’s just talk about it and come up with a plan so that you’re safe, staff feel safe as well, and let’s just work on this together.”*

Taken together, these perspectives suggest that for older Care Leavers, safety is less about formal safeguards and more about positive lived experience: being listened to, having genuine input, and knowing that promises will be kept. In this way, trust becomes the vehicle through which safety is felt.

Dignity and respect

For Care Leavers, dignity and respect were described as fundamental to safe and acceptable care. After childhoods marked by control and dehumanisation, participants emphasised that ageing does not lessen the right to be recognised as a full human being. As Alice explained, *“It doesn’t matter where you are, you have to treat people with respect and dignity. It’s what we deserve. It doesn’t matter how old we are. The key is respect and dignity of who we are.”*

Respect, however, was not seen as abstract courtesy but as something enacted in everyday interactions and systems. It meant being listened to, recognised as the expert in one’s own life, and not forced to navigate unnecessary bureaucracy to have simple choices honoured. As Helen put it, *“I would like to make the choices without having to go through seven or eight different people... I’m still here because I’ve figured out what’s good for me.”*

Dignity of risk

For key stakeholders, dignity was not only about courtesy or recognition but also about the dignity of risk - the right for people to make choices about their lives even when those choices carry some danger. This principle was seen as essential to treating people as adults with agency, rather than as passive recipients of care. As one stakeholder explained, *“We’ve always been accepting of people’s lifestyles, even if there is some risks associated with that. It’s great to hear a lot more talk about dignity of risk these days, but this is something we’ve* *focused on very heavily for many years, and not being judgemental of those choices that people are making."*

Stakeholders emphasised that enabling dignity of risk required both organisational tolerance and careful processes. It meant starting early conversations about capacity, recognising when people could make their own decisions and when others might need to step in: *"The key thing for us… is beginning to think about their capacity to make their own decisions. We have a wonderful group of clinical nurses… and working relationships with neuro-psychs… different pathways if a resident has capacity to make decisions that put themselves at risk versus an individual who doesn't."*

This approach was also embedded in policy, where resident choice was intentionally echoed throughout procedures, even in risk management:

"If you were to look through ours, you would see us trying to mitigate that risk, but at the same time the dignity of resident choice will be mimicked through nearly every policy. We are very risk tolerant, obviously, but if we weren't, we wouldn't be able to work with the consumer group that we were with."

Finally, stakeholders highlighted the importance of clarifying responsibility—distinguishing between risks that the organisation must manage, and those that belong to the resident, provided they have capacity to choose:

> *"We spend a bit of time thinking and talking about who is responsible for the risk as well… there are situations where it's the resident's risk and they're competent to make that decision and take the risks that they want to and enjoy the consequences."*

Together, these perspectives show that dignity of risk is not about disregarding safety, but about respecting people's right to live on their own terms. For older Care Leavers, who were denied such agency in childhood, this principle has particular significance in shaping what safe and acceptable aged care looks like.

Strategies in the current system that work

Stakeholders highlighted that while the aged care system remains fraught with challenges, certain strategies have proven effective in supporting older Care Leavers. A recurring theme was that awareness-building only works when it is ongoing and reinforced. One practitioner, who delivers information sessions about Forgotten Australians to aged care managers and staff, explained that while participants are often curious and even *"dumbfounded"* when they first hear about older Care Leavers, this interest *"doesn't equate to referrals"* unless workers are reminded through repeated follow-ups in team meetings. One-off training was seen as insufficient; embedding knowledge required persistence and reinforcement within everyday practice.

Trauma-aware and flexible approaches were also viewed as essential. Workers described the importance of recognising traumatic triggers - such as loud noises, being spoken to in a directive way, or being placed in closed rooms - that could echo survivors' earlier experiences of institutionalisation. Training encouraged staff to adapt the environment and style of engagement so that people felt a sense of choice and control, without requiring them to disclose their entire story. As one facilitator put it, staff do not *"need to get their full story"* to understand what issues might arise; instead, they can *"accommodate what they as an individual prefer to do with your service."*

Examples from residential aged care providers illustrated how flexibility could transform outcomes. One service described deliberately slowing down the admission process for a man with a history of failed placements, inviting him to first join for lunch, then spend occasional days, and eventually transition into staying overnight. Over time, the facility became his home - on his terms. In another instance, a resident requested to be left alone at meal times as a test of staff behaviour. Workers complied, only for him to later criticise them for being "so bloody rude." The manager gently reminded him that this was what he had asked for, prompting him to laugh and begin to engage. Both examples underscored that allowing people to set the pace, and respecting their boundaries, could help overcome deep-seated mistrust.

The most consistent message, however, was also the simplest: ask. Stakeholders stressed that genuine progress often came from asking individuals directly how they identified, what their experience had been, and what they needed. This approach acknowledged that not everyone was comfortable with the labels "Forgotten Australian" or "Care Leaver," but that services could still offer dignity and choice by tailoring support to individual preferences.

Another effective strategy was embedding lived experience into advocacy and service design. Participants noted that systems risk minimising or overlooking the needs of older Care Leavers unless those with direct experience are present to articulate them. As one stakeholder explained, without lived experience voices, *"other people are going to go, 'oh, what the hell?' and give up."*

The Role of Care Finders

Several stakeholders pointed to the Care Finder program as a particularly promising development. The Care Finder program is a free, face-to-face service established to assist older Australians who do not have a trusted support person and who face difficulty navigating the aged care system. Delivered through Primary Health Networks, Care Finders provide intensive, personalised support with understanding and accessing aged care services, completing My Aged Care processes, and linking individuals with broader community supports. The program was introduced following recommendations from the Royal Commission into Aged Care Quality and Safety and is designed to complement existing My Aged Care channels by ensuring that the most vulnerable older people can access the services they need (Department of Health and Aged Care, 2025).

Participants explained that the program was created to address the fact that aged care is *"really hard to access,"* particularly for people without family support or who had historically fallen through service gaps. Care Finders were described as advocates who take the time to build trust, support people through assessments, and stay involved during transitions into home or residential care.

One provider explained that Care Finders often act as the consistent presence during difficult or repeated attempts at entry to residential aged care, "*ringing the aged care facility* *and saying, ‘This is what this client needs to make this transition successful.’”* Participants praised the program for attracting experienced staff and for offering individualised, trauma-aware support. Stakeholders also valued the fact that Care Finders can remain involved even after someone has entered care, ensuring continuity in what is otherwise a highly fragmented system.

At the same time, stakeholders acknowledged that the program is not uniformly effective. Because it is delivered through Primary Health Networks, each region has *“a different flavour*” depending on who holds the funding. While some Care Finders have deep expertise in working with vulnerable populations, others are more oriented to older people in general and may lack the skills to engage with those who do not readily trust services. As one participant noted, the role works best when underpinned by trauma-specialisation, yet this was not always guaranteed.

Overall, however, the Care Finder program was described by participants as *“such an amazing program”* precisely because it gives vulnerable older people someone *“specialised”* to help them navigate an otherwise *“incredibly complicated”* system. In this sense, it reflects the kind of funded advocacy and relational support that Care Leavers had long called for, even as stakeholders stressed the importance of ensuring that delivery is consistent across the country.

> *“Care Finders really take that extra time and effort to build relationships, get to know people and then work alongside them to get into the system, get through the assessments and then help them select either the right home care provider or the right residential aged care provider. There's no limit of time, so they can stay involved after someone's moved in.”*

Finally, providers described ways of negotiating the tension between regulation and resident dignity. At one service, staff worked with the regulator to relax strict sign-in requirements for a man who resisted reporting his movements, eventually agreeing that he only needed to check in by 9am the next day. *“Ninety-nine out of 100 times, he was back in bed by 9am, very safe*,” staff recalled, while also noting that this compromise allowed him the freedom he valued. Similarly, some organisations created new roles focused specifically on social and emotional support, recognising that residents often prioritised connection, advocacy, and practical help over constant medical oversight. As one provider reflected, *“what we really desperately need… is that social support.”*

Together, these strategies demonstrate that even within a constrained system, trust can be built when services prioritise persistence, flexibility, dignity, advocacy, and lived experience.

Aged Care Recommendations from Care Leavers and key stakeholders

The study asked both Care Leavers and key stakeholders what changes would be needed to make aged care more responsive, safe, and supportive for people with histories of institutionalisation. Their recommendations reflected a shared concern with the shortcomings of the current system, but also a strong belief that meaningful improvements are possible. What follows are the recommendations that emerged directly from participants. They highlight areas for change across training, identification, advocacy, home and residential care models, physical environments, and workforce practices. These insights are presented as distinct from the researcher-driven recommendations that follow later in this report.

Embedding trauma-informed care across the system

Care Leavers and stakeholders consistently called for trauma-informed care to become the foundation of aged care practice. Training should not be occasional or optional, but built into induction, reinforced through ongoing professional development, and supported by policies and standards. Participants noted that trauma-informed practice benefits everyone in aged care, while being critical for those with deep histories of harm.

> *“All staff need to have training and they need to have ongoing training… This needs to start at the top and come down so they need to be trained first. There needs to be policies and procedures that reflect that practice.” (Stakeholder)*
>
> *“If you did that on trauma informed care as a very basis… it’s a very good start… and the principles around consistency of staff…” (Stakeholder)*
>
> *“They should be aware of what we’ve been through, the traumas in our lives. If they’re taking care of us in our own homes, what we have is precious because we’ve had to fight for it.” (Alice, Care Leaver)*
>
> *“They need to know that some of them have been sexually abused… Don’t come up in our face… I will have a traumatic stress problem.” (Edith, Care Leaver)*

Identifying Care Leavers sensitively and respecting choice

Both groups emphasised the importance of recognising when someone has a care background, without making disclosure compulsory. Some recommended that aged care intake should include a standard but optional prompt about past care, ensuring that support can be tailored without requiring people to self-label in ways that feel stigmatising.

> *“A Care Leaver’s definition could be similar [to homeless designation]… they don’t have to opt in, but they are identified in the system… At some stage there’ll be someone they might open up to.” (Stakeholder)*
>
> *“There’s probably nothing wrong with directly asking… and then just absolutely respect someone’s right to say, ‘I don’t want to discuss that’… or, ‘these are the things I need you to do to keep me safe.’” (Stakeholder)*
>
> *“I would be happy with it, personally… I want people to know that there’s something behind it.” (James, Care Leaver)*

Strengthening advocacy and navigation through Care Finders

The Care Finder program was singled out as one of the most promising developments in aged care. Care Finders were seen as trusted advocates who could stay alongside a person during the daunting process of entering home or residential care, pushing systems to adapt to individual needs. Stakeholders praised the program for attracting experienced staff and for giving people without family a reliable support. At the same time, they cautioned that delivery varies across Primary Health Networks, with some Care Finders lacking trauma expertise.

> *"The care finder program is such an amazing program… we've been able to really successfully advocate for people." (Stakeholder)*
>
> *"That sort of advocate type role which is funded could suit that individualised nature… And that's to a large extent, the role of the Care Finder." (Stakeholder)*

Resourcing home-first care with flexibility and continuity

Both older Care Leavers and stakeholders emphasised that staying at home for as long as possible should be the default goal. To achieve this, they recommended higher funding levels for Care Leavers, more flexibility in how hours are used, and having support delivered by small, consistent teams. Flexibility was seen as crucial - for example, allowing workers to leave and return when someone is triggered, without losing hours.

> *"Higher levels of support… to enable them to stay at home longer… block funding works much better." (Stakeholder)*
>
> *"Block funding allows flexibility… whether they should do things with them, for them, just sit and be with them, or leave and come back another time… without them having lost their four hours of support." (Stakeholder)*
>
> *"We worked as a small team… so… if someone is sick, there's not a stranger going in." (Stakeholder)*

Specialised capability without geographic exclusion

Participants raised the possibility of specialist services or hubs for older Care Leavers, but warned that if such facilities only exist in major cities, people will be forced away from community and country. A preferred model was for specialist centres of expertise to support and train mainstream services while also providing dedicated care where possible.

> *"Having one or two places where you've got a large number… a specialised version of looking after older people with that background." (Stakeholder)*
>
> *"My concern is that if you're going to set up specialty facilities, you're only going to be able to do them in large cities… people are going to have to move very much out of their area." (Stakeholder)*
>
> *"They shouldn't even put them in nursing homes or anything.. they should have forgotten buildings for people that have gone through torture and traumatic stress, and they should build places for them. Not this bloody aged care stuff; put them somewhere else and build other places where we're going to feel safe, you know, and secure." - Edith*

Making transitions relational and at the person's pace

Care Leavers and stakeholders highlighted the need for gradual, relational approaches to transitions, particularly into residential aged care. Rather than abrupt moves, participants recommended staged visits, negotiated rules, and flexible regulatory interpretations that preserve dignity while still meeting safety obligations.

> *"You have to build some form of trust… 'why don't you come and have a look… Have a meal… If you don't like it, that's okay.'" (Stakeholder)*

Designing environments that support dignity and autonomy

Practical changes to the physical environment were repeatedly suggested to reduce the clinical feel of aged care and restore a sense of autonomy. Recommendations ranged from colour-coded wayfinding and improved hygiene to resident-controlled spaces for cooking and restaurant-style dining options.

> *"Colour coded… so easy to remember… follow that mauve line." (Stakeholder)*
>
> *"Make it not so clinical… carpet is not a good idea… all you could smell was the urine soaked in it." (Stakeholder)*
>
> *"A restaurant that's open from seven in the morning to seven at night, and you go and order your meal… becoming more and more achievable." (Stakeholder)*
>
> *"Definitely no keys and locks. I think you would have to be willing to stay there and if it was good enough, you would want to stay there. You don't have to have everything perfect, but clean and you can get up and make yourself, that's a big thing, to get up and be able to make yourself a cup of tea when you want." - Ruth*
>
> "*Well, I'd like to see them, as I said, made into - the nursing homes, not so institutionalised. And give people a say in what's going on. Maybe even have a group in the nursing home. Not everybody's nutty that goes into a nursing home." - Carol*

Workforce support, continuity and respect

Finally, both groups stressed that workforce conditions must change to enable continuity, respect, and responsiveness. Recommendations included small team structures, opportunities for staff to share the load on difficult days, and valuing lived experience in governance and practice.

> *"People are regularly triggered… some days you can manage… some days you just need to say, 'Can you please be with Bill today? I'll work inside.'" (Stakeholder)*
>
> *"Care leavers… should have a certain amount of money that we can use." (Stakeholder)*
>
> *"Lived experience is just essential." (Stakeholder)*

> *“Not everyone's got dementia or anything… have a little forum in there that can put ideas forward for what they'd like to see in this, in the particular nursing home that they're in.” (Carol, Care Leaver)*

Summary

Together, the recommendations of Care Leavers and stakeholders point to a system that must become more trauma-informed, flexible, and respectful. They call for stronger training, more consistent staff, funded advocacy roles, flexible home-based care, environments that feel less institutional, and genuine inclusion of lived experience in governance. These voices make clear that change is not only possible but urgently needed if aged care is to provide safety, dignity, and trust for people who have lived through childhood institutionalisation.

Conclusion

Across interviews and focus groups, older Care Leavers and stakeholders converged on a clear picture of “good care” in relation to aged care systems and services. At its core are everyday practices that return control to the person, uphold dignity and respect, and build trust through reliable, transparent action. The dignity of risk is integral rather than optional: people must be supported to make real choices, even when those choices carry managed risks.

Participants also articulated how these principles could be realised in contemporary systems and practice: embed trauma-informed practice through mandatory, ongoing training and aligned policies; identify Care Leavers sensitively without coercion; strengthen Care Finders to provide persistent, trauma-specialised advocacy; resource a home-first approach with flexible funding and small, consistent teams; make transitions relational and paced; redesign environments to feel less clinical and more navigable; and support the workforce to share the load while maintaining continuity.

Taken together, these voices outline a pragmatic blueprint for acceptable aged care for people with histories of childhood institutionalisation. They describe conditions and solutions that are achievable, scalable, and immediately useful - provided systems commit to consistency and follow-through. These participant-derived insights form the foundation upon which the report’s subsequent researcher recommendations are built.

Part 6: Discussion & Conclusion

Contributions to Knowledge

This study is the most comprehensive investigation to date into the ageing experiences of Care Leavers in Australia. Part of these findings have been published in the *Australian Journal of Social Issues* (Turnbull et al., 2024; Morris et al., 2025), reinforcing the national relevance and rigour of this research. While earlier studies and grey literature had begun to document their strong preference to remain at home and deep-seated fear of residential aged care - often linked to memories of institutional childhoods (Browne-Yung et al., 2021, 2022; Fernandez et al., 2016, 2017; CLAN, 2018, 2022) - our research both validates these patterns and builds upon them. By drawing on the largest national sample yet assembled, this study confirms what has long been voiced by advocates and survivors, but also adds new dimensions that sharpen, deepen and extend existing knowledge.

First, it demonstrates with greater clarity than previous studies the intensity of rejection of residential aged care, with participants articulating an explicit preference for death over institutionalisation. While earlier research referred to aversion, and CLAN's 2018 submission to the Aged Care Inquiry cited a member's statement that they would rather die than enter a facility, our findings show that this sentiment is deeply felt. The language equating residential care with re-traumatisation and loss of dignity underscores that fears of re-institutionalisation are not merely symbolic - they are existential. This finding heightens the urgency of reform: if residential aged care is experienced as worse than death, the risk is not just disengagement from services but suicide, making change a matter of immediate safety as well as dignity.

Second, the study details the specific workforce-related conditions that drive mistrust. The literature had flagged high staff turnover, cultural and linguistic differences, and limited trauma-awareness as barriers (Browne-Yung et al., 2022; Department of Health, 2019a). Our data confirm these concerns while adding nuance: finding specific factors that are deemed important to Care Leavers such as having consistency in staff, choice and control over decision-making and staff that understand the long-lasting impact of childhood institutionalisation. Additionally the findings show the information that older Care Leavers want to access about residential aged care: how the owners of the facility treat their staff, transparent information about the organisation that runs the facility, and the freedom to leave the facility freely. These insights extend earlier accounts of "workforce constraints" into a more vivid picture of how practice and workforce conditions shape the perceived safety of care.

Third, the findings deepen understanding of what "home-first" means in practice. The preference to remain at home is well established (Browne-Yung et al., 2021, 2022; Fernandez et al., 2016), but our participants described the conditions that make home care not just preferable but feasible for older Care Leavers: small, consistent teams; flexible funding that allows carers to adapt in the moment; and the ability to pause or rearrange visits without penalty. These concrete insights move beyond broad endorsements of "person-centred care" toward operational detail about what trauma-aware home care looks like.

Fourth, this study contributes new evidence of strategies that are already working. The literature has called for trauma-informed models and greater flexibility (Tuart Place, 2019; Coram et al., 2021), but has offered little empirical detail about practice on the ground. Our data provide examples of gradual, relational admissions to residential care, of staff explicitly testing and respecting boundaries, and of the transformative role of simply asking Care Leavers what they need. These vignettes demonstrate that trauma-aware approaches are not theoretical ideals but practical methods already being trialled in some services.

Fifth, the role of advocacy and navigation emerged as a critical solution, with the Care Finder program highlighted repeatedly. Grey literature has long called for funded advocacy (AFA, 2019; CLAN, 2018), but our study is among the first to capture how Care Finders are operating in practice: acting as trusted intermediaries, persisting through repeated admissions, and tailoring supports to individuals. At the same time, participants noted variation in delivery across Primary Health Networks and gaps in trauma specialisation, pointing to the need for evaluation and standardisation.

Taken together, these contributions extend the literature in three important ways. First, they move beyond describing problems - such as re-institutionalisation fears or staff turnover - to documenting the conditions and solutions that can make care acceptable. Second, they highlight the life-course continuity of trauma, showing that triggers in aged care are not incidental but directly linked to institutional features of childhood care (routines, locks, lack of privacy). Third, they bring into sharper focus the centrality of trust and relational continuity: the finding that what feels safe is not policy language or formal safeguards, but consistent, respectful interactions over time.

Despite these advances, important gaps remain. There is still no research highlighting perspectives from Care Leavers currently in residential aged care. Exploration and evaluation of trauma-informed training models tailored to this group are also needed. The relative merits of specialist facilities versus mainstream services with embedded trauma expertise are unresolved. Finally, little is known about how Care Leaver identity intersects with other forms of marginalisation - such as Aboriginal identity, disability, or homelessness - in shaping aged care experiences. Addressing these gaps will be crucial if the sector is to build sustainable, evidence-informed responses.

Implications for Policy

The findings align with broader reform momentum following the Royal Commission but highlight areas where policy must go further.

- **Trauma-informed care as standard:** Training must be mandatory, ongoing, and embedded in policy - not left to discretion. Like cultural safety, trauma-informed practice should be recognised as a baseline standard across aged care.

- **Recognition of Care Leavers:** Care Leavers should be explicitly recognised in aged care policy and reporting systems, with sensitive identification processes that respect choice. This would enable targeted supports without forcing disclosure.

- **Strengthen and standardise Care Finders:** The Care Finder program has shown promise but delivery is uneven. National consistency, adequate resourcing, and trauma-specialisation are needed to make Care Finders a reliable pathway for vulnerable older people.

- **Funding reform to support home-first care:** Current individualised packages are too rigid. Block funding or flexible loadings for Care Leavers would allow continuity, small team models, and the flexibility needed when trauma responses disrupt service delivery.

- **Balance specialisation with access:** Specialist hubs or facilities may help, but must not force relocation away from community. A hybrid model - mainstream services supported by specialist centres of expertise - would avoid geographic exclusion.

Implications for Practice

At the practice level, the research offers clear lessons for providers and workers.

- **Ask and adapt:** Workers should directly ask individuals what they need, how they identify, and what helps - without requiring disclosure of the full story. This simple step emerged as one of the most powerful strategies.

- **Prioritise continuity and small teams**: Care Leavers thrive when supported by a small, consistent group of workers who know them well. Team approaches also allow staff to share the load when someone is triggered.

- **Adopt flexible, trauma-aware approaches:** Slow transitions, relational trust-building, and respect for pace and boundaries make a tangible difference. Workers should be supported to adjust routines, environments, and interactions in trauma-sensitive ways.

- **Embed lived experience:** Including Care Leavers in advisory, training, and governance roles ensures services remain accountable and responsive.

- **Design home-like environments:** Simple changes - private spaces, colour-coded wayfinding, restaurant-style dining, and removal of institutional cues - help restore dignity and autonomy.

Strengths and Limitations

This project represents the most comprehensive investigation to date into the aged care needs, experiences, and preferences of older Care Leavers in Australia. Several strengths warrant emphasis.

First, the use of a mixed-methods design - including a national survey of 105 older Care Leavers, 24 in-depth interviews, and three focus groups with aged care professionals—

allowed for triangulation across multiple perspectives. This breadth ensured the findings were not limited to a single lens, but reflected both lived experience and practitioner insights.

Second, the project benefited from strong partnerships with Care Leaver advocacy organisations and the involvement of a lived-experience researcher in recruitment, design, and analysis. These elements enhanced trust, accessibility, and relevance, and enabled participation from individuals who may otherwise remain excluded due to literacy, technology, or mistrust of institutions.

Third, the project deliberately prioritised accessibility and inclusion. Survey participation could occur online, by phone, or face-to-face, and questions were designed to avoid re-traumatisation by not requiring detailed disclosure of childhood abuse. These approaches strengthened both the ethical foundation and the representativeness of the data.

Finally, by integrating perspectives from Care Leavers and professionals, the study was able to identify not only needs and preferences, but also the system-level barriers and enablers that shape service responses.

Nonetheless, several limitations must be acknowledged. While the survey recruited the largest sample of older Care Leavers to date, it was still relatively modest in size and not statistically representative of the estimated 500,000 Australians with care-leaving histories. Recruitment relied heavily on support organisations and networks, which may have resulted in a sample more connected to services, and potentially underrepresented those who are highly isolated, distrustful of systems, or disengaged from support. The focus groups with professionals, though diverse in role, drew from a small number of motivated participants and may not capture the full spectrum of views within the aged care workforce nationally.

Similarly, while Aboriginal and Torres Strait Islander Care Leavers were included at higher rates than their general population proportion, the study did not specifically tailor design or analysis to First Nations experiences, which remain an important area for further work.

Taken together, these strengths and limitations highlight both the value and the boundaries of the evidence presented. The study makes an important and novel contribution to understanding the intersection of childhood institutionalisation and later-life care, while also pointing to the need for further, more representative, and longitudinal research.

Part 7: Recommendations

The recommendations that follow arise directly from the voices of older Care Leavers, their advocates, and professionals who work alongside them. Across surveys, interviews, and focus groups, participants described aged care systems that are often ill-equipped to meet their needs, shaped by distrust of institutions, ongoing impacts of childhood trauma, and a strong preference for safety, autonomy, and dignity in later life.

The recommendations are grounded in the recognition that governments and institutions were responsible for systemic neglect, abuse, and disconnection experienced in childhood. That responsibility does not diminish with time. As this cohort enters later life, there is both a moral and practical obligation to ensure aged care supports are designed in partnership with Care Leavers, responsive to their histories, and distinct from the very institutional environments where harm occurred.

Eight interlinked recommendations are presented. They begin with a foundational commitment to trauma-informed aged care, which must underpin every reform. From this base flow proposals to expand priority access, improve navigation and information, embed de-institutionalisation, strengthen the role of Care Leaver agencies, secure lived experience in system reform, stabilise the workforce, and deliver a dedicated First Nations response.

Together, these reforms set out a pathway for aged care that does not replicate the harms of the past, but instead creates environments where older Care Leavers can age with safety, respect, and choice.

1. Trauma-Informed Aged Care as the Foundation

The term "trauma-informed care" *was regarded by Care Leavers as empty jargon, reflecting a perceived disconnect between rhetoric and practice. Many participants observed that services claiming to be "trauma-informed" often lacked awareness of Care Leaver histories and the systemic neglect and abuse experienced within historical Out-of-Home Care (OOHC) settings. Participants argued that genuine trauma-informed practice cannot occur without an informed understanding of the historical contexts and collective trauma of those who have lived within these settings.*

Trauma-informed aged care for older Care Leavers means recognising the lasting impacts of institutional childhood abuse and neglect, ensuring services are safe, relational, flexible, and respectful, and embedding practices that reduce re-traumatisation. It requires sensitive identification, meaningful choice, long-term trust with workers, and training co-designed with Care Leavers and Care Leaver agencies - so that care is not only delivered, but delivered in ways that uphold dignity, autonomy, and safety.

All reforms must be grounded in these trauma-informed principles.

- Mandatory, ongoing training for all aged care workers (from assessors to frontline staff), co-designed and co-delivered with Care Leaver organisations.

- Trauma-informed practice must be embedded into qualifications, workforce standards, and accreditation, not treated as optional.
- Trauma-informed practice underpins: care navigation, assessment, information delivery, workforce reform, and service design.

2. Priority Access & Identification (Gold Card)

Expand priority access to essential services that allow Care Leavers to age in place, including in-home aged care, medical and dental care, housing, and mental health supports.

- Establish an opt-in Priority Access (Gold) Card for older Care Leavers, including Forgotten Australians, Child Migrants, and Stolen Generations survivors.
- The card provides priority access and reduces re-traumatisation by enabling sensitive identification without repeated disclosure.

3. Expand the Care Finder Program

Ensure older Care Leavers can navigate systems and access information in ways that build trust and reduce overwhelm.

- Expand the Care Finder Program with dedicated roles based in or partnered with Care Leaver agencies. Care Leavers should have access to these services regardless of family involvement. They should be resourced to develop relationships over time and deliver information in a range of ways; in person, over the phone, or in small groups - not just digital or bureaucratic channels.
- All navigation and communication should be trauma-informed, relational, and culturally safe.

4. De-Institutionalise Aged Care & Develop Specialist Residential Alternatives

Reform should be guided by the principle of de-institutionalising aged care for Care Leavers: shifting resources away from large, institutional settings and towards home-based, community, and small-scale alternatives that uphold autonomy, dignity, and safety.

- Where residential care is unavoidable, develop specialist, non-institutional models co-designed and co-governed with Care Leaver agencies.
- Environments must feel fundamentally different to the institutions in which Care Leavers were harmed.

5. Strengthen the Role of Care Leaver Agencies

Provide stable, long-term funding to expand the role of Care Leaver support agencies in:

- Trauma-informed counselling and peer connection.
- Service navigation and advocacy.

- Outreach to isolated and regional Care Leavers, including transport and mobile supports.

6. Embed Lived Experience & Advocacy in System Reform

Ensure Care Leaver voices are central to aged care policy and service design.

- Fund national and state advocacy bodies to continue research, peer support, and system navigation.
- Establish formal advisory structures that embed lived experience into decision-making.
- Participation must be inclusive, compensated, and representative of diverse Care Leaver groups.

7. Strengthen and Stabilise the Workforce

Address workforce instability so services are safe, consistent, and relational.

- Improve wages, conditions, and career pathways.
- Recruit and retain trauma-informed staff, prioritising continuity.
- Update accreditation standards to measure relational safety and respect, not just compliance.

8. Standalone First Nations Response

Develop a First Nations–led response for Stolen Generations Care Leavers, recognising their distinct experiences shaped by colonisation and intergenerational trauma.

- Fund Aboriginal Community Controlled Organisations to design, govern, and deliver programs.
- Ensure Stolen Generations survivors and advocates lead the work.
- Invest in culturally safe aged care models, distinct from generic “diversity” initiatives.

Practice Example: Wintringham’s journey to Specialisation Verification Status

While these recommendations set the framework for reform, practice examples already show what is possible. The following case study highlights Wintringham’s journey to achieving Specialisation Verification Status for Care Leavers. It demonstrates how leadership, trauma-informed practice, and collaboration with government and advocacy groups can translate principles into practice.

Background

Wintringham, a Victorian-based social justice organisation without historical ties to institutions or religious affiliations implicated in the abuse of older care leavers or subject to Royal Commission investigations, has actively sought specialisation verification for Care Leavers (under section 1.6., Department of Health and Aged Care, 2022). This initiative was sparked by the CEO's participation in a forum for Forgotten Australians, which ignited a commitment to addressing the significant gap in verified services available to this demographic. Building on its foundation work in trauma-informed care and homelessness services, Wintringham is well-positioned to enhance support for older care leavers, ensuring they receive the specialised assistance they need.

Key Steps in the Process

Initiation and Motivation:
The decision to embark on the verification process was significantly influenced by the passionate advocacy of the CEO Jane Barnes, whose vision for excellence drove this initiative forward. This leadership made it clear that achieving verification was not just an administrative task but a vital step toward enhancing service quality and accountability. Wintringham, with its well-established trauma-informed care practices, provided a strong foundation for this effort, reflecting its unwavering commitment to social justice. This organisational ethos emphasised not only compassion in care, but also a genuine desire to improve outcomes for those they serve, making the pursuit of verification an incredibly meaningful endeavour.

Challenges and Negotiations:
Throughout the verification process, several challenges arose that required strategic negotiation and adaptability. For instance, feedback collection was mandated by the Department of Health, Disability and Aging [DHDA] from Care Leavers at each of Wintringham's 30+ outlets; however, rather than following a rigid approach, Wintringham successfully negotiated a representative group method that simplified and accelerated feedback acquisition while ensuring diverse voices were heard. Additionally, when tasked with training interviewers in trauma-informed practices as per departmental requests, Wintringham proposed innovative alternatives such as soliciting written feedback from Care Leavers—this adjustment aimed to prioritise comfort levels while still gathering invaluable insights into their experiences. Furthermore, time delays became apparent as developing and obtaining approval for a comprehensive set of questions specifically tailored for older

care leavers took over three months; this duration highlighted not only the complexities involved but also underscored the necessity of thoroughness to ensure sensitivity.

Implementation:
In executing their implementation plan towards specialisation verification, Wintringham undertook meticulous efforts to identify Care Leavers through an exhaustive review of client histories; this diligence ensured sensitivity during outreach to avoid re-traumatising individuals who had already faced significant challenges in their lives. The feedback received from Care Leavers proved varied; notably poignant was one negative response from an Indigenous resident which illuminated critical gaps in culturally appropriate staffing—this realisation reinforced Wintringham's commitment to ongoing improvement and inclusivity within its workforce. Between March and April 2025, all required documentation was diligently compiled and submitted; by July 2025, this rigorous effort culminated in successful verification for two programs: Eunice Seddon Home based in Dandenong and their Port Melbourne Hostel—a testament to both hard work and dedication.

Departmental Support:
Throughout this intricate journey toward verification, support from the DHDA played an instrumental role in navigating obstacles efficiently. The DHDA took proactive measures by streamlining certain verification criteria—for instance, eliminating stringent requirements regarding staff familiarity with every detail concerning care leavers—this thoughtful adjustment significantly reduced workload pressures on Wintringham staff while maintaining focus on essential quality standards. Furthermore, having a designated contact within the DOHAC provided continuous support throughout various stages of implementation; this relationship facilitated quick resolution of roadblocks encountered during what could have been an arduous process—a partnership that exemplifies collaborative effort toward common goals centred around improving services for vulnerable populations.

Key Success Factors

Existing Foundations:
Wintringham had already taken significant strides in integrating trauma-informed care and comprehensive training into its service offerings, establishing a robust foundation for delivering effective and empathetic support to those in need. This foundational work not only demonstrates Wintringham's commitment to understanding the complex emotional landscapes faced by individuals transitioning into aged care services but also ensures that staff are well-equipped with the skills necessary to provide informed assistance. Furthermore, the organisation has cultivated established relationships with influential Care Leaver advocacy groups, such as the Alliance for Forgotten Australians. These partnerships are invaluable, facilitating seamless collaboration and building a sense of trust that is essential for meaningful engagement.

Non-Institutional Design:
The thoughtful design of Wintringham's facilities intentionally avoids institutional aesthetics that can often evoke feelings of confinement or distress among residents. This approach has garnered high praise from older Care Leavers themselves, who have expressed appreciation for an environment that feels more like home rather than an institution. Features such as

individual front doors provide residents with a sense of ownership and autonomy, while inviting verandas and meandering garden paths contribute to an overall atmosphere of comfort and safety. Such design elements are not merely aesthetic; they play a crucial role in fostering a sense of independence among residents, enabling them to feel secure as they navigate their personal journeys toward healing. Wintringham adopted a collaborative approach by working closely with the relevant department to tailor processes to meet the specific needs of older Care Leavers.

Collaborative Approach:
Wintringham embraces a collaborative methodology by working closely alongside relevant government departments and stakeholders to tailor processes specifically designed to meet the unique needs of older care leavers. This proactive engagement reflects a deep commitment to understanding the challenges faced by this demographic and adapting services accordingly. The organisation exemplifies integrity by actively seeking out feedback from Care Leavers themselves—valuing their insights even when criticism may arise—thus demonstrating respect for their lived experiences and fostering an inclusive environment where every voice matters.

Social Justice Alignment:
The absence of historical ties to institutions known for causing harm to care leavers significantly enhances Wintringham's standing as a trusted provider within this sector. By aligning itself with principles of social justice, Wintringham not only bolsters its credibility but also reinforces its dedication toward supporting marginalised individuals who have often been overlooked or mistreated by previous systems. This alignment serves as both a guiding philosophy and operational framework, ensuring that programs are designed with empathy at their core while striving tirelessly toward equity for all participants involved in their services.

Recommendations for Improvement

1. Support for Advocacy Groups
    - Small grants could empower Care Leaver advocacy groups to partner with aged care providers, easing the verification process.
2. Simplified Processes
    - Streamlining feedback collection and reducing administrative burdens could make verification more accessible to other providers.
3. Cultural Competency
    - Employing Indigenous staff and enhancing cultural training could address gaps in service delivery for Indigenous Care Leavers.

Conclusion

Wintringham's journey to verification highlights the importance of trauma-informed care, collaborative problem-solving, and non-institutional service design. Their experience underscores the need for tailored support from the DHDA and advocacy groups to encourage more providers to pursue verification.

Part 8: Conclusion

This study is the largest and most comprehensive investigation into the ageing experiences of Care Leavers in Australia. It confirms what earlier research and advocacy have long signalled: the harms of institutional childhood “care” echo powerfully across the life course, shaping health, housing, relationships, and trust in systems well into later life. For many Care Leavers, aged care is not simply a service to navigate but a site of profound fear, bound up with memories of past institutionalisation. The overwhelming rejection of residential aged care - with some participants preferring death over entry into a nursing home - signals the urgency of reform.

The findings make clear that aged care in its current form is not fit for Care Leavers. But they also highlight pathways forward. Trauma-informed care, priority access, home-first approaches, and collaboration with specialist agencies can transform aged care into a domain of safety, dignity, and respect. Providers like Wintringham show that this is achievable when commitment, leadership, and partnership with advocacy groups are present.

As the sector continues to move through significant reform, there is a narrow window to embed the needs of Care Leavers into policy, workforce development, and service design. If ignored, the risk is re-traumatisation, disengagement, neglect, and preventable suffering. If acted upon, reform can deliver aged care that not only avoids past harms but actively restores trust, autonomy, and wellbeing.

The voices of Care Leavers in this study are clear: they want to age in place, to be recognised, and to be treated with dignity. Listening to these voices, and acting upon them, is both a matter of justice and a measure of our collective commitment to those who endured so much in childhood. The responsibility now rests with governments, providers, and the wider community to ensure Care Leavers are never again failed by the systems entrusted with their care.

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Appendix

Survey

EXPLANATORY STATEMENT

Project ID: 35962

Project title: Building a best practice model to advance healthy ageing for care leavers (ex-residents of institutional out-of-home-care) entering the aged care system

Chief Investigator:

Professor Philip Mendes
Department of Social Work
Philip.mendes@monash.edu
Ph: 03 9903 1132

Hello! We are a group of researchers, and we want to ask you if you'd like to be a part of our study. We think you have important knowledge and experience because you grew up in places like orphanages, institutions, children's homes, group homes, or foster care in Australia.

Please read the important information below to help you decide if you want to take part. If you have any questions or want to know more, you can talk to the research team by contacting Lena Turnbull on 0433 097 781 or lena.turnbull@monash.edu Feel free to ask anything you want!

What is this study about?

We want to learn more about Australians who were in orphanages, institutions, children's homes, group homes, or foster care between 1950 and the late 1980s. Some people call this group "Forgotten Australians." Many of these people went through tough times and were mistreated during their childhood and teenage years while they were in these places. These experiences have had a big impact on their lives, even as they grew up.

We want to understand their stories and experiences better. Our goal is to know what they need and worry about as they get older and consider getting help from aged care support. We want to gather their personal experiences to create a guide. This guide will help explain how to take care of them as they get older, based on their own perspectives. Our hope is that this guide will help aged care providers support this special group of people and their unique needs as they age.

What are we asking you to do?

We would like you to answer a survey, and it will only take about 15 minutes of your time. The survey will ask you questions about the kind of help you think you might need as you get older. You can do this survey online, over the phone, or on a paper form - whichever way is easier for you. After the survey, you can leave your contact details if you want to also talk to the research staff in an interview. We can do this in person (if you live nearby), over the phone, or using a video call service called Zoom.

During the interview, we want to understand more about what you personally need. We know you have experience living in places like orphanages, institutions, children's homes, group homes, or foster care in Australia. And we also want to know about your thoughts and experiences with aged care services. You don't have to do an interview if you don't want to.

Why are we asking you to be involved?

We want you to be part of this study because you have a special experience. You have lived in places like childhood institutions, children's homes, group homes, or foster care. And now, you might be thinking about getting help from aged care services as you get older. You have a unique way of looking at things and understanding what you need as you age. We really want to hear from people like you who have been through similar experiences. By listening to you, we can better understand what you need, and this will help us make important changes and improvements for others in the future. Your voice is essential, and we want to make sure it's heard.

Who is paying for this study?

The research is paid for by the Living Labs Program, which is part of Monash University's National Centre for Healthy Ageing.

Consent to take part in the study and ability to withdraw

If you complete the survey, you're agreeing to be part of the research. But if you change your mind before you finish the survey, you can stop and not be part of it anymore. Once you submit the survey, your information becomes anonymous, and we can't get it back even if you ask.

What will you get from this study?

We would like to offer you a $25 gift card in recognition of your time. There will be an opportunity at completion of the survey to provide your email address or postal address to receive this gift card. Your contact details will not be attached to your answers in the survey.

Everything in this survey is kept private and anonymous. We won't know who said what, so your information is safe. We follow rules to keep everything secure. Only the researchers working on this study will see the information, and any data we don't use will be deleted after five years. If you want to know what we find out or have questions, you can talk to the main researcher. Their contact information is at the beginning of this information.

Complaints

Should you have any concerns or complaints about this study, you are welcome to contact the Executive Officer, Monash University Human Research Ethics Committee (MUHREC):

Executive Officer
Monash University Human Research Ethics Committee (MUHREC)
Room 111, Chancellery Building D 26 Sports Walk,
Clayton Campus Research Office
Monash University VIC 3800
Tel: +61 3 9905 2052
Email: muhrec@monash.edu

Thank you,

Professor Philip Mendes
Department of Social Work, Monash University

Did you spend time in Australian childhood institutions, children's homes, foster care, girls/boys homes, group homes or other institutional settings as a child?
Yes
No

Are you currently aged 50 years or over?
Yes
No

Are you willing to complete this survey?
Yes
No

The following questions are for people aged 50 or older who, as children, spent time in orphanages, children's homes, foster care or other childhood institutions. We want to learn more about your life experiences and thoughts on aged care support.
When we talk about aged care support, we are talking about receiving support from paid carers in your home, or in the community, or residential aged care homes like nursing homes.
Age and Gender
First, we would like to gather some basic facts about you by asking you some questions about your age and gender.
I am willing to answer these questions
I would like to skip these questions

What is your gender?
What is your current age?
Where you were born and now live
Now we would like to ask you some background information questions about where you were born and where you live now.
I am willing to answer these questions
I would like to skip these questions
What country were you born in?

Do you identify as Aboriginal and/or Torres Strait Islander?

Yes

No

I'd prefer not to say

Where do you live now?

Income & Housing

Next we would like to ask one question about the source of your income and one question about your current housing situation.

I am willing to answer these questions

I would like to skip these questions

What is the main source of your income?
Paid employment
Superannuation
Government payments and pensions
Other (please describe)

What is your current housing situation?
Residential aged care (also known as nursing home)
Own home (or paying mortgage)
Private rental
Social housing
Government housing
Disability housing (i.e. Supported Residential Service or SRS)
Short-term or temporary housing such as boarding house, hostel or hotel
Homeless (sleeping rough, sleeping in vehicle, couch surfing between friends) surfing between friends)

Accessing aged care support

We would now like to ask you about whether you are accessing any kind of aged care support, either at home, in the community or residential aged care.

I am willing to answer these questions

I would like to skip these questions

Do you currently live in residential aged care (also known as a nursing home)?

Yes

No

Do you think you will need to enter residential aged care (nursing home) in the next 5 years?

Yes

No

Are you currently receiving aged care support in your home or community?

Yes

No

What kind of support are you receiving?

Meals on wheels or other food support

Help with dressing or showering

Assistance with medication or other medical needs

Cleaning

Gardening

Transport to appointments

Support to access the community (shopping, visiting friends, etc.)

Other

In the next 5 years, do you think you might need to access aged care support to remain in your home?

Yes

No

Where you lived as a child

We would now like to ask you some basic questions about the settings you lived in as a child.

- I am willing to answer these questions
- I would like to skip these questions

Were you in a childhood institutional setting, group home or foster care at the following ages? (select all that apply)

- 0-4
- 5-9
- 10-14
- 15-18

What is the total number of years you think you spent in institutional settings, foster care or group homes?

What settings did you experience as a child? You can select more than one

- Orphanage
- With a foster family (or multiple foster families)
- Adopted by a family
- Institution for children
- Boys home
- Girls Home
- Group home

Youth detention centre

Other type of institution (mental health or disability)

Other (please tell us more)

Which of these terms do you like to use? You can select more than one

Care Leaver

Forgotten Australian

Member of the Stolen Generation

Former Child Migrant

Other (please tell us more)

None of the above

Adult life experiences

Now we would like to ask you some questions about your life experiences as an adult. We are trying to understand the relationship between your childhood experiences in institutions, your adult life experiences, and your attitudes towards age care.

I am willing to answer these questions

I would like to skip these questions

What is the highest level of education you have completed?

Primary School

Secondary school without certificate

Secondary school with certificate

TAFE or equivalent

Bachelors Degree

Masters Degree

Phd

Have you had any additional skills training throughout your education and career?

Yes (please tell us more)

No

Have you had paid employment throughout your life?

Yes

No

What was the main job for which you were paid?

Throughout your life, have you struggled financially?

Almost always

Often

Sometimes

Rarely

Never

Have you spent time in the military?

Yes

No

Have you been married or lived in a defacto relationship?

Yes

No

Are you currently married or in a defacto relationship?

Yes

No

Have you had children?

Yes

No

Did those children remain in your care?

Yes

No

Were those children removed from your care by the state?

Yes

No

Do you have contact with your children now?

I have regular contact

I sometimes have contact

I rarely have contact

I never have contact

Have you spent time in prison or a forensic / correctional facility?

Yes

No

Do you have a diagnosed mental illness? For example, depression, anxiety, or Post traumatic stress disorder

Yes

No

Do you suspect you have any undiagnosed mental health issues?

Yes, please specify

No

Have you spent time in a mental health or psychiatric facility?

Yes

No

Have you spent periods of your life homeless or in unstable housing?

Yes

No

Do you have a disability for which you require support?

Yes

No

Do you have an NDIS package?

Yes

No

Have you experienced issues with drugs and/or alcohol throughout your life?

Yes

No

Have you experienced family violence?

Yes

No

Do you have any major health issues?

Yes

No

Do you have regular family support?

Yes

No

Do you have regular support from friends or a community?

Yes

No

Do you have regular support from paid professionals or organisations? (i.e. GP, local council services, counsellor, psychologist, case manager)

Yes, please specify who supports you

No

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Next we would like to ask you some questions about what would be important to you IF you were considering accessing aged care support (i.e. support in the home or community, residential aged care or respite care).

I am willing to answer these questions

I would like to skip these questions

If you were no longer able to care for yourself due becoming old and frail, where would you prefer to live?

In my normal home, receiving support from friends or family

In my normal home, receiving support from paid professionals paid for by the government Living independently or semi-independently in a retirement village

Living in a residential aged care facility or nursing home

If you were no longer able to care for yourself due to becoming old and frail, where would you least like to live?

In my normal home, receiving support from friends or family

In my normal home, receiving support from paid professionals paid for by the government Living independently or semi-independently in a retirement village

Living in a residential aged care facility or nursing home

Why is that the place you would least like to live?

When considering aged care support (in your home or residential aged care facility/nursing home), how important are the following?

Extremely important

Having consistent workers who understand my needs

Having flexibility in my support

Being able to make my own choices

Access to an advocate to help navigate the aged care system

Accessing to counselling or psychological support

Support staff who understand trauma and its impact

Support staff who understand the impact of childhood institutionalisation

Staff that are responsive to my cultural background and needs

Staff that are supportive of my religious beliefs and practices

Access to specialised support ONLY for people who have spent time in childhood institutions, group homes or foster care

Support is free/affordable

Services are animal friendly so I can have my pet with me

Having choice and control over how much personal

Not at all important

Slightly important

Somewhat important

Moderately important

Extremely
important

information I share
with staff

Not at all
important
Slightly important

Somewhat
important
Moderately

important

When considering accessing aged care support (in your home or residential aged care/nursing home), to how far do you agree with the following statements:

Strongly
Agree

I want to be treated
with respect

I want to be treated
as a unique individual

It's important that
people around me
know my personal
history

It's important for me
to have a support
person to help guide
me through the
process

Neither

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Strongly
disagree Disagree
agree or
disagree Agree

Next we would like to ask you about what is or would be important for you in a residential aged care setting or nursing home.

I am willing to answer these questions

I would like to skip these questions

If you were considering entering residential aged care or a nursing home, how important would it be to know the following?

Extremely
important

About the

organisation that
runs
the facility

Whether the
organisation that
runs

Not at all
important
Slightly important
Somewhat

important
Moderately
important

Extremely
important

the facility was
involved in
childhood
institutions

How the owners of
the facility treat
their
staff

How the support
staff
are rostered

If the staff share
similar religious
beliefs to me

If the staff share
similar cultural
background to me

If I have a choice
over
the gender or age
of
the staff that dress
or
care for me

If I can choose
what
time I eat meals

If I can choose
what I
do each day

If I can lock my
door
when I want to

If I can leave the
facility freely to
visit

people or places
Not at all
important
Slightly important
Somewhat
important
Moderately
important

How did you feel about entering your residential facility / nursing home? How

satisfied are you with the following?

Very
disatisfied

Food and meal quality

Food and meal timing

Staff attitudes and behaviour

Assistance with washing

and dressing

Social relationships

Very
satisfied
Somewhat

satisfied Neutral
Somewhat disatisfied

Very disatisfied

Medical and health care

Ease of family and friends visiting

Other (please specify) Very satisfied Somewhat

satisfied Neutral Somewhat disatisfied

agree Agree

The facility I live in provides good quality care

The staff that work in the facility are friendly and caring

The staff that work in the facility understand my needs

The staff that work in the facility listen to me

I have the ability to make my own decisions about my care

I have the ability to make my own decisions about how I spend my time

Other (please specify)

Neither agree or disagree Disagree

Strongly disagree

To what extent do you agree with the following?

Strongly

Is there anything that might improve your experience in your facility / nursing home?

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Thank you for completing this survey. Are you willing to be involved in an interview with us to tell us more about your experiences or wishes? This could be in person, over the phone or via video communication software Zoom.

Yes

No

Please provide your name and contact details (email or phone)

We would like to send you a $25 gift card as a thanks for completing the survey. If you would like one, please click this link. Please note your contact details will not be attached to your answers to this survey.