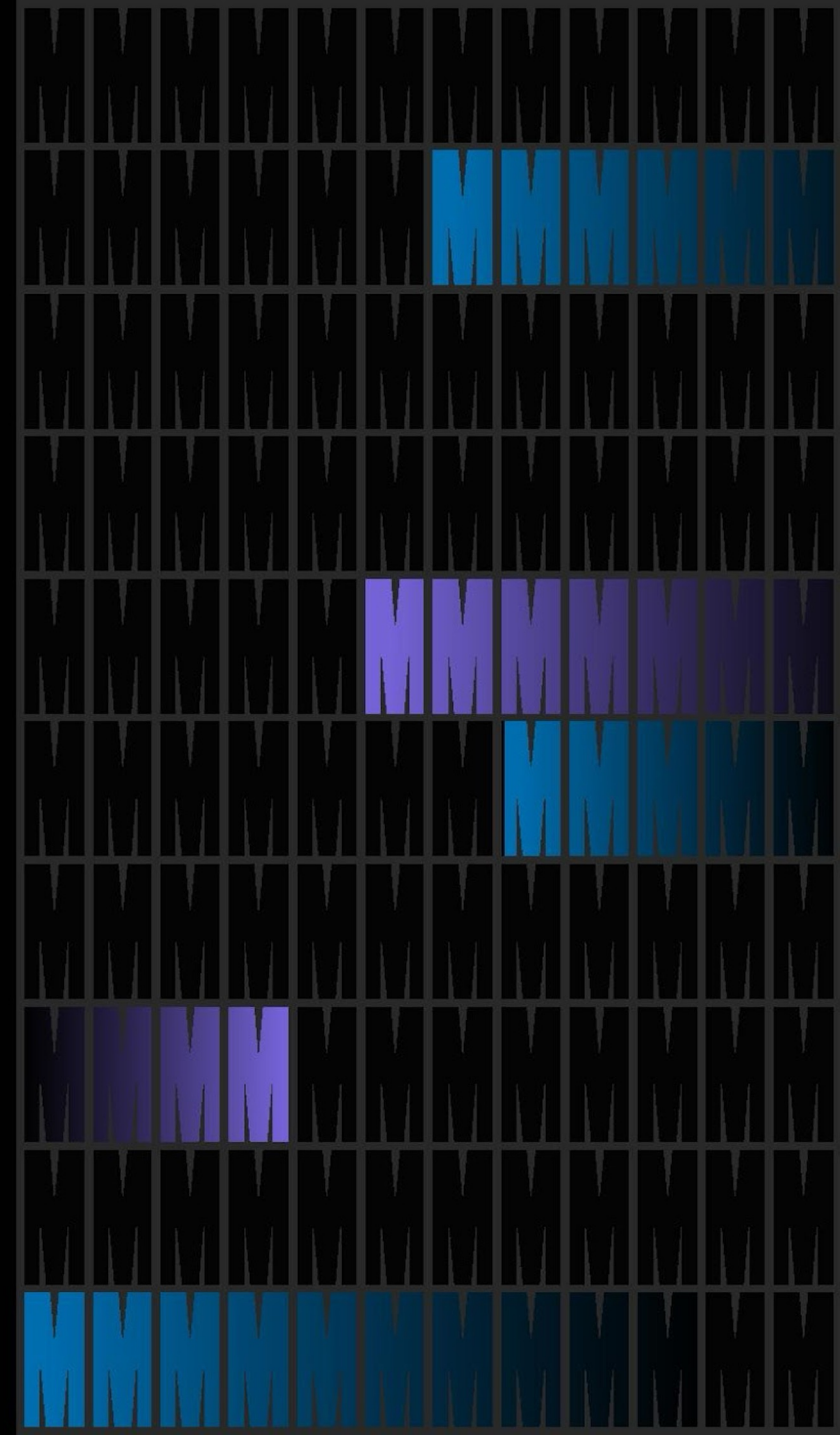
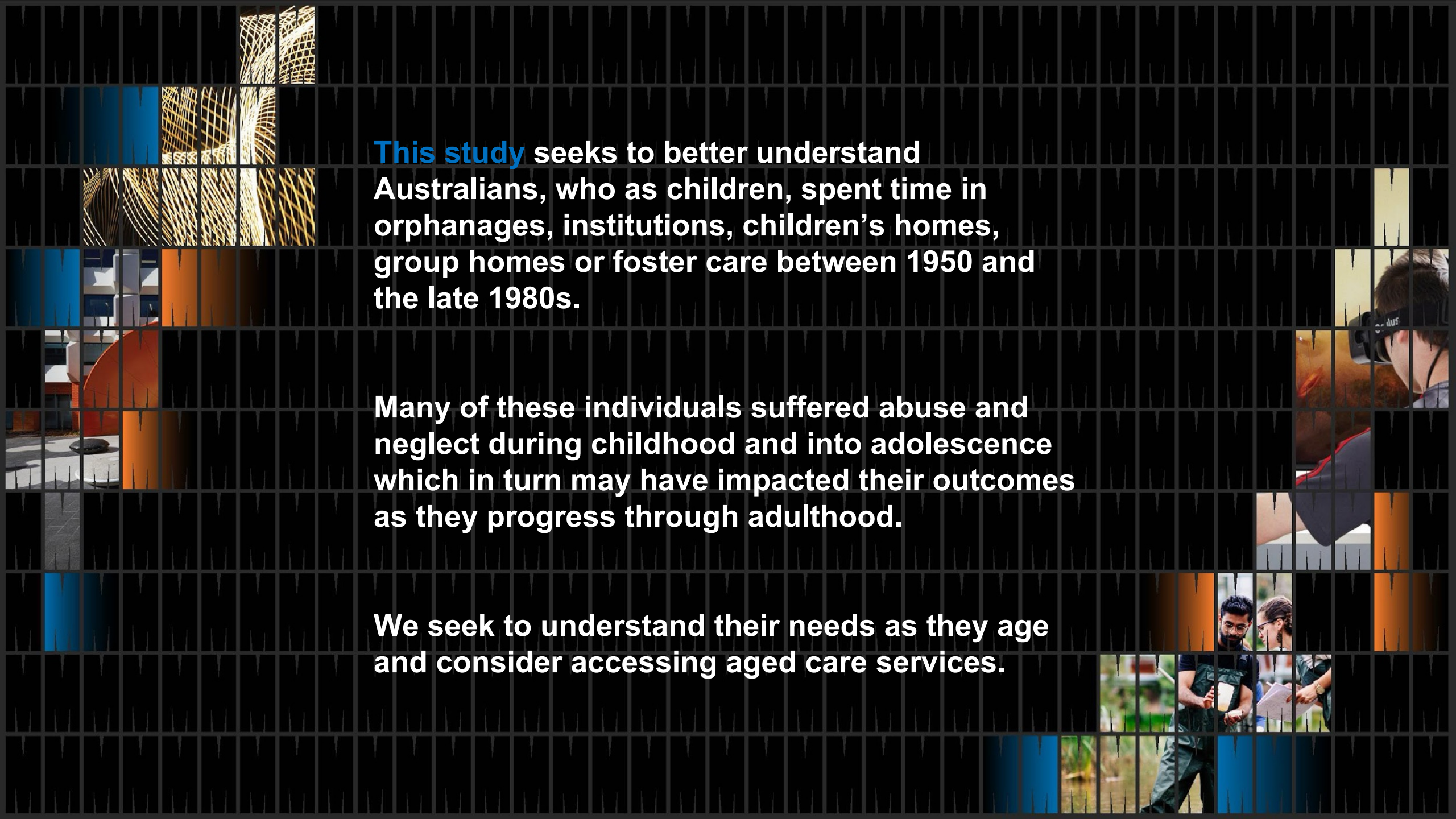


What the evidence is showing us about appropriate care and support for Forgotten Australians

Building a best practice model to advance healthy ageing for care leavers entering the aged care system

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This study seeks to better understand Australians, who as children, spent time in orphanages, institutions, children's homes, group homes or foster care between 1950 and the late 1980s.

Many of these individuals suffered abuse and neglect during childhood and into adolescence which in turn may have impacted their outcomes as they progress through adulthood.

We seek to understand their needs as they age and consider accessing aged care services.

THE RESEARCH TEAM

This project is affiliated with [The National Centre for Healthy Ageing in Melbourne, Australia](#) and receives funding from [The Commonwealth Government of Australia](#) through the [Community Health and Hospitals Grant Scheme](#).

- Professor Philip Mendes, internationally renowned expert on the experience and needs of care leavers.
- Associate Professor Susan Baidawi, who has over 10 years of research focused on young people in the child protection system, as well as the needs of older people in the criminal justice system.
- Lena Turnbull, research assistant
- Sarah Morris, “care” experienced researcher
- Care Leavers Australasia Network, key collaborators in co-designed process

CLAN offer support to people who have grown up in Orphanages, Children’s Homes, Missions, Foster Care and other Child Welfare institutions in Australia and New Zealand.

EMBEDDING LIVED EXPERIENCE INTO THE RESEARCH

This project is co-designed with the **Care Leavers Australasia Network**: a national, independent, peak membership body which represents, supports and advocates for care leavers. Their contribution to the project ensures that the voices of care leavers are embedded into every stage the research.

This team also has a key “care” experience researcher, Sarah Morris.



AIMS OF THE STUDY

- Partner with the **Care Leavers Australasia Network** (CLAN) via a co-design process to identify the key needs and concerns of care leavers regarding aged care services;
- Engage with **aged care providers** to advance awareness of the specific needs of care leavers;
- Examine what targeted actions have been taken to date by aged care providers to recognise and address these needs;
- Develop a **best practice aged care model** (and associated guide for service providers) that will advance the healthy ageing of care leavers.

HOW WILL THIS BE DONE?

1. **Scoping review** of key global literature to establish best practice in existing service provision
2. **Quantitative survey of care leavers** to establish key priorities for aged care services development
3. **Interviews and focus groups with care leavers, family and support people**, to advance deeper understanding of the lived experience of care leavers, and those aspects of their experiences that influence specific needs within aged care services and settings.
4. **Interviews and focus groups with key stakeholders** in policy, practice and service provision to deepen understanding of existing practice, what works, what doesn't, as well as ideal practice.
5. **Roundtable discussion with all key stakeholders**: care leavers as end users, policy makers, service providers, to establish an integrated community of practice that progresses best practices policies, programs and systems.

Collaboration and co-production principles are meaningfully embedded at every step of the research process

THE EXPECTED OUTCOMES

- **Adding to existing limited knowledge** regarding aged care system experiences and needs of care leavers
- **Advancing new and innovative strategies** to assist care leavers entering aged care
- **Supporting aged care providers** to develop policies to identify care leavers and develop required training to meet their specific needs
- Supporting the development of a specific **National Aged Care Action Plan for care leavers**
- **Developing a best practice model of care**, including specialist programs, to minimise re-traumatization of care leavers and support equity of access and outcomes in aged care for this group of older Australians.

The ultimate outcome is to **improve the quality of care** to this group of older Australians, in light of their childhood experiences

LITERATURE REVIEW: THE FINDINGS

According to the literature, care leavers:

- Have a very real fear of re-institutionalisation and re-traumatisation in aged care settings
- Want to remain in their home and receive in-home support
- Key components of aged care support are potentially triggering, including lack of flexibility, lack of autonomy, existing power imbalances between residents and staff, lack of privacy, enclosed spaces, communal living, receiving personal care and medical treatments, as well as physical features (corridors, disinfectant smell, dark panelling, names of institutions, etc.)
- May be exposed to other triggers such as certain holidays, particular foods, episodes of incontinence, visible religions symbols, etc.
- Workforce issues provide a challenge to implementing trauma-informed care, such as staff turnover, skill disparity, cultural/language barriers, difficulty meeting complex behaviour needs with limited resources.
- Lack of family support is an additional barrier to navigating aged care services, as well as prohibitive cost, lack of services or information about services, and lack of transport.
- Preference for care that prioritises autonomy and does not force them to divulge or repeat their story unnecessarily.

"I'd rather die in the middle of the street, get run over by a truck or a bus. I would not go into a nursing home"

Browne-Yung et al, 2020

INFORMING THE SURVEY: INCORPORATING FEEDBACK FROM CONSULTATIONS

When we examined the consultation data, the key feedback were in the following areas:

Language

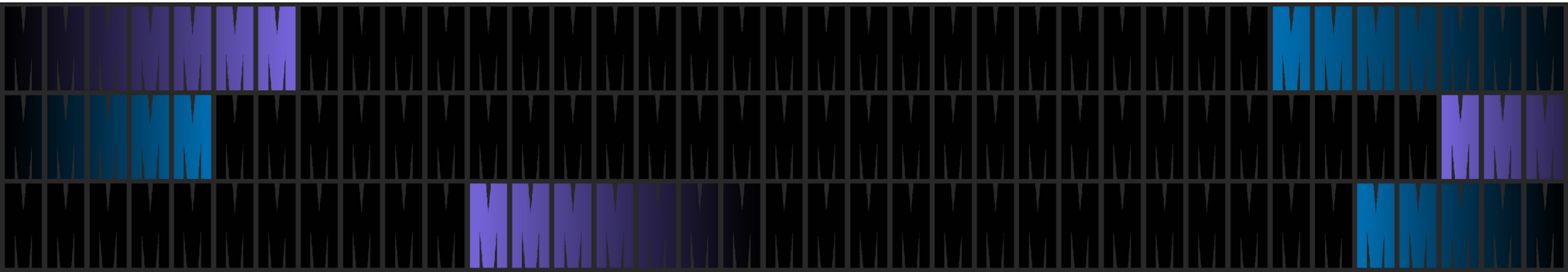
- Written communication should be warm and welcoming and in easy-to-understand language
- We rewrote the explanatory statement, and changed phrases within the survey, e.g. "if you were no longer able to look after yourself because of your support needs related to ageing" changed to "if you were no longer able to look after yourself because you were becoming old and frail".

Length

- Keep it short! We also decided to offer \$25 for survey completion, in recognition of participants' time.

Awareness around potentially sensitive issues

- Wherever possible, make it clear that sections can be skipped. We added invitations at the start of each section, noting what would be discussed and providing the option to skip the section.
- We removed some unnecessary and potentially sensitive questions, e.g. around ethnicity, income and reason for leaving care.



SURVEY FINDINGS

105 participants aged **50-87** who had spent time in institutions as children, with the average time spent in OOHC being 9 years.

Health and socio-economic disadvantage:

- 84% relied on government pension and 48% lived in government housing
- 86% had a defacto relationship or marriage but only 20% currently
- 59% left school without a certificate
- 91% worked in paid employment
- 61% indicated they had **always** (40%) or **often** (21%) struggled financially
- 87% had children, with 27% of these children living outside of their care
- 21% had spent time in a correctional facility
- 65% had a diagnosed mental illness and 38% had spent time in psychiatric institution
- 61% had experienced homelessness or unstable housing
- 53% had a disability requiring support
- 56% faced alcohol or drug issues
- 74% experienced family violence
- 79% had significant health issues
- 55% received regular support from family
- 63% received regular support from friends or the community
- 83% received regular support from professionals and organisations

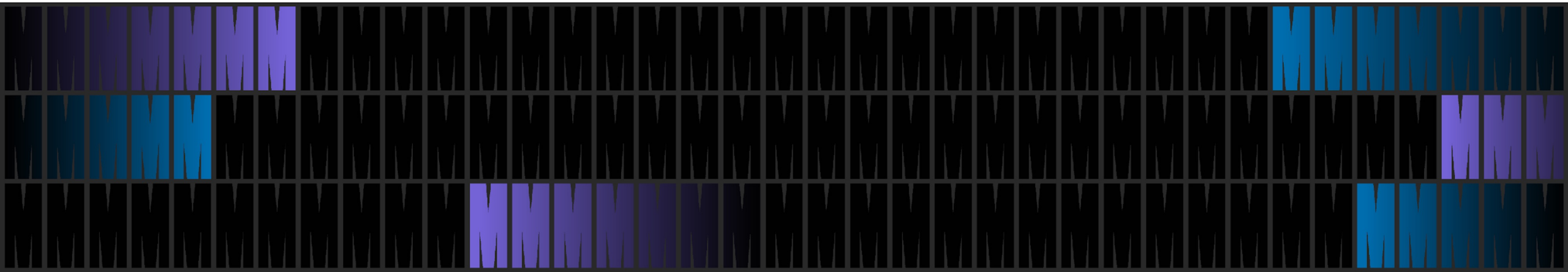
FINDINGS: PERCEPTIONS AND EXPERIENCES OF AGED CARE

No participants lived in residential aged care, 35% received support at home, 47% expected to need support within 5 years

When asked where they would prefer to live if no longer able to care for themselves, 84% preferred to remain in their homes with professional support (70%) or support from friends or family (30%). 15% preferred retirement village, only one participant chose a nursing home as their preferred option.

WHY?

- Preference for death – **“I’d rather be taken out the back and shot”, “I would rather step out in front of a train.”**
- Fear of institutionalization – **“I have lived in and been abused in too many institutions”**
- Trauma and re-traumatization – **“Trigger for past childhood trauma”, “my younger years were stolen from me by an institution”**
- Loss of independence and autonomy – **“It would deprive me of my independence”, “No choice or control”**
- Concerns about treatment and abuse – **“Worried about treatment from staff” “I’ve heard too many bad stories about nursing homes”**
- Desire for dignity and privacy – **“No privacy or independence in a nursing home”, “Loss of dignity and privacy”**
- Feelings of loneliness/isolation – **“I would feel alone and isolated.” “They’re there waiting to die.”**
- Distrust in the system – **“I have zero trust in it.” “It’s the system, just another part of the system that doesn’t work”**
- Negative perceptions of care quality – **“Some staff will never take the time to understand.”**



INTERVIEW FINDINGS

24 in-depth interviews with participants across Australia (none in NT or ACT)

Childhood Trauma: [Laying the foundation of their life story](#)

Physical, emotional and sexual abuse, institutionalisation and severe neglect in childhood left lasting imprints on every aspect of their life. Understanding the lasting impact of trauma is key to supporting care leavers in aged care.

Living the Legacy: [Lasting impact of childhood trauma](#)

The abuse and neglect led to limited educational and employment opportunities, health and mental health issues and psychosocial struggles. These had lifelong impact that continued to shape their life even in older age.

Present Lives: [Surviving systems, trauma and facing aging](#)

Many feel forgotten, struggling daily. Bureaucracy, past abuse and ineffective support foster deep mistrust of systems, which influences their perceptions of aged care.

INTERVIEW FINDINGS CONTINUED

Facing the Future: Perceptions and Experiences of Aged Care

Participants were reluctant to engage with aged care, because of mistrust, and fear of losing autonomy. Many rejected nursing homes, fearing confinement and re-traumatisation, and preferred home care. Workforce concerns abound with regards to staff shortages, cultural differences and perceived lack of quality care.

Recommendations for Reform

Systemic change towards trauma-informed, person-centred, empathetic care is needed. Staff training should develop interpersonal skills, respect of personal boundaries and compassionate care, as well as understanding the unique experiences and triggers of this group. Home-like environments that prioritise privacy and autonomy was preferred. Some recommended dedicated facilities for FA.



PUBLICATION DETAILS

Lena Turnbull, Sarah Morris, Philip Mendes and Susan Baidawi (2024)
“Older care leavers entering the aged care system: A scoping review”,
Journal of Gerontological Social Work,
<https://www.tandfonline.com/doi/full/10.1080/01634372.2024.2442509>



NEXT STEPS

- Data analysis of focus groups with providers and staff
- Final report to have clear recommendations for reform
- Share data with care leavers, families, supporters and staff

THANK YOU

We are very interested to connect with international researchers who are looking to advance this topic in their own countries.

Please get in touch!

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