A Rights-Based Exploration of ‘Safety’ in Home Aged Care for Older CALD Women with Disabilities

Project Executive Summary

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Australian Association of Gerontology (AAG) and National Ethnic Disability Alliance (NEDA)

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NDRP National Disability Research Partnership

Lead organisation: Australian Association of Gerontology (AAG)

Partner organisation: National Ethnic Disability Alliance

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Contributors and acknowledgements

We wish to thank living experience experts and participants from disability, aged care and CALD communities who made this project what it is. We would like to thank our governance group stakeholder organisations and representatives across aged care, disability, and advocacy sectors including the PICAC Alliance (Partners in Culturally Appropriate Care), the Older Person’s Advocacy Network (OPAN), People with Disabilities Australia (PwDA) and the Disability Advocacy Network Australia. We also wish to thank Mr Andrew Thiel for providing support to the rights and safeguard mapping in the literature review.

AAG
Australian Association of Gerontology

NEDA
National Ethnic Disability Alliance

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This project explored how older culturally and linguistically diverse (CALD) women with disabilities frame safety in home aged care, particularly in relation to their rights under the *Aged Care Act 2024*. It was co-designed by AAG, NEDA and co researchers with lived experience to ensure the project would address people's real-world needs and concerns.

The project used a multi-layered co-design model including:

- Governance group oversight with cross sector representatives
- Living experience expert reference group with diverse experiences
- Semi structured interviews with select representatives from the key group (older CALD women living with disability and accessing aged care)

Australia's aged care system relies on people understanding and using their rights. However, through our literature review we found very little peer reviewed research about how older CALD women with disability use and think about home care. This means there is limited evidence about older CALD women with disability to inform the aged care system and oversight bodies. This was an alarming initial finding that shaped our recommendations that more research and evidence is urgently needed.

Through our co-design work we noted that many older CALD women with disabilities face significant barriers that limit their ability to claim their rights in home based aged care. These include language, cultural expectations, low awareness, and limited trust in oversight systems. We also heard from older CALD women living with disability that many of their peers only access aged care during crisis situations which increases their vulnerability and reduces people's ability to make informed decisions. These insights changed the direction we took to develop our research proposal. Together, we decided to design a research project that would focus on raising aged care awareness and adapting rights advocacy tools through codesign.

Overall, through co-designing our research proposal we heard that:

- There is low awareness of aged care and rights, with participants and their networks of peers not knowing what services they can access or rights they hold. Participants found that information is often delivered too late or in inaccessible ways.
- Claiming rights can feel risky, as some participants felt that rights with legal processes, making them hesitant to speak up or make complaints.
- People have competing responsibilities which make self-advocacy more difficult. Participating women we worked with prioritised the care of others over their own needs, reducing their capacity and willingness to self-advocate.
- Engagement with services was more likely to happen after a crisis or as a reaction to a change, rather than on someone's proactive decision.
- The aged care system is complicated and for CALD women living with disability, navigating both the aged care and disability systems is very difficult and disempowering. This is especially true for people experiencing multiple social and cultural barriers.
- There are major evidence gaps and very limited research on the experiences of older CALD women with disabilities in aged care, which is concerning.

As a result of our literature review work, we identified a need for more research as there is little existing academic research published in this area. Our work with people in the community revealed a broader need for much more public awareness building around aged care and disability in a range of outlets and

formats. During the co-design process we came to see that improving safety requires more than having the policies, it requires ensuring people understand, trust, and can access the system. Our recommendations are framed around these insights, and our research proposal is informed by these initial learnings.

Priority areas brought to our attention through co-designing the research proposal (Appendix 1) include:

1. Building awareness early by providing clear and accessible information, not only about the aged care services available but the whole system including aged care rights. This needs to occur using culturally appropriate communication and trusted community channels as well as in a range of communication formats.
2. Making aged care rights practical and accessible, through simplifying rights information and complaints processes. It also means making rights discussions a normal part of aged care discussions and helping to reduce people’s fears around speaking up.
3. Improving inclusion and access to, not just aged care services, but to advocacy supports as well. This is complicated because it means being culturally responsive and disability-inclusive in the design of information campaigns, service delivery and in advocacy channels.
4. We also note that there needs to be much more coordination and connection across aged care, disability, and social care systems. We heard that familiarity with one system did not lead to confidence or familiarity with another. There needs to be accessible and reliable places that people can go to get information or raise concerns about their experiences in overlapping systems of support (e.g. disability and ageing).
5. There needs to be real work in research and data collection to understand and represent CALD and disability experiences in aged care. This research must start from an intersectional framing and embed the lived experience of a range of CALD and disability groups in policy design.

Conclusion

Through this process we have learned safety in aged care for older CALD women living with disability depends not only on services and regulation, but on whether people understand their rights, feel confident to use them, and can access support in ways that reflect their culture and lived experience. To improve outcomes, Australia’s aged care system must become more accessible, inclusive, and proactive about connecting with people from different backgrounds and with different disabilities. This starts by building a comprehensive evidence base about the lives of older CALD women with disability and their experiences of aged care. It includes policymakers working to build awareness earlier, simplifying the supports and systems people access, and ensuring that lived experience is central to service design and policy development. Without more evidence and these system changes, many older CALD women with disabilities will remain at risk of poor outcomes and exclusion from the care they need.

The issue we explored

Through co-designing our research proposal we explored the notion of 'safety' in aged care for older CALD women with disability. Our codesign process led us to examine how the Aged Care Statement of Rights could be a vehicle for safety in aged care for older CALD women with disability. We investigated what this notion of being an 'aged care rights holder' can mean for older women from CALD backgrounds living with lifelong (or most of life) disability while collating information on the institutional safeguards that are in place across aged care and disability support systems.

Why this issue matters

Both the aged care and disability support systems have undergone significant changes in recent years. This upheaval impacts older people living with disability, but specifically for older CALD women with disability, and this legislative flux can lead to unique risks compounded by system intersections and competing cultural norms.

Research about how older CALD women with disability experience, navigate and perceive their right to safety in aged care is lacking. Importantly, both the Royal Commission into Aged Care Quality and Safety and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability demonstrate that systems, attitudes and structures can make the world unsafe for people with disability and older people, especially where language and cultural barriers exist.

Thus, for those whose lived experience includes these intersections, there is a heightened risk of abuse, neglect and exclusion in care settings. We see the promise of aged care rights to safety as a potential avenue to prevent and address these heightened risks.

What was co-designed

We co-designed a research project concept and potential outcome intended to help older women from CALD communities living with disability experience safety and aged care through an aged care rights framework.

This research project was led by NEDA and AAG, in collaboration with older women living with disability, as well as representatives of disability, CALD and older people's rights and advocacy organisations. This was achieved through a 3-pronged structure which included a governance group of representatives from stakeholder organisations, a living experience expert reference group consisting of people with disability, knowledge of the aged care system and cultural and linguistic diversity as well as project partner organisations (NEDA and AAG).

We then utilised the networks from these groups to connect with older CALD women with disability who are utilising aged care services to create the research project proposal. While staff from the project partners (NEDA and AAG), drafted the proposal, the concepts and methods were developed under the leadership of people with lived experience of disability, aged care, and members of CALD communities.

What were our key lessons from the co-design process

Key lessons from the co-design in this project include but are not limited to:

- The importance of allowing time to form relationships across sectors and experiences
  - This includes developing a shared understanding of the systems, stakeholders and terminology that underpins the project, as well as the goals and objectives
- The need to work in a way that foregrounds people's individual skill sets
  - This means working with people in ways that plays to their strengths while also allowing all stakeholders to build capacity in less familiar areas through mentoring and two-way learning
- The need to be flexible and check-in with collaborators regularly
  - People's circumstances can change very rapidly and so finding alternative ways for individuals to stay involved in the project beyond the initially agreed upon terms of engagement is vital to maintain the collaboration.
- The overall project and proposal are stronger and more relevant to 'the real world' through the leadership of living experience coauthors and contributors.
  - While we brought our own organisational and living experiences lenses to the project, the shared knowledge across stakeholders led to a project that has genuine potential to improve the aged care journey for many people, not just our identified cohort.

What the future research could achieve

Future research in this area could contribute to the incredibly important goal of bringing greater aged care system awareness and transparency for older people with disability from a range of backgrounds. While we intended this project to identify ways to increase people's ability to advocate for their rights in aged care, during our codesigning work we learned that the aged care system for many remains incredibly unknown and opaque. Thus, while the project aimed to codesign a research proposal about aged care rights advocacy, lived experience insights led us to adapt our proposal further and include stages to create education components about aged care more broadly.

This means that regardless of the relatability of a rights tool or the adaption process, anyone involved in the delivery of this proposed project should come away better informed about what the aged care system entitles, how it can be accessed and where to find accurate and accessible information.

We believe a research project about adapting an aged care rights journey mapping tool (like the one shared with us from OPAN) could help promote awareness, encourage participation and connect eligible older adults with the aged care supports they are entitled to but often missing out on. Moreover, the process of adapting the tool through a codesign methodology could illuminate the ways disability is understood, experienced and supported in CALD communities who are ageing. Currently, there is a significant lack of policymaking specifically focused on this intersection, as highlighted in our literature review (Attachment 3). Future research as we have proposed could help:

- Increase awareness and understanding of the aged care system amongst multiple cohorts
  - Promote earlier intervention and proactive aged care journey planning

- Improve access to accurate, culturally appropriate and meaningful information about aged care and rights within aged care
  - Concomitantly exploring disability and ageing in CALD communities in a way that can inform policymaking
- Strengthen advocacy skills among older CALD women with disability in relation to aged care needs and entitlements
  - Adapt and validate tools that support aged care rights-based self-advocacy for multiple cohorts
- Connect under-served populations with appropriate aged care services as well as demystify aged care system architecture
  - Build awareness about the role of the Aged Care Quality and Safety Commission, the Aged Care Complaints Commissioner and accessing government funded Aged Care Advocacy Services
- Promote safer, higher-quality aged care through informed participation
- Build a preliminary understanding of the extent to which older people from CALD communities with disability access services and the barriers that prevent people accessing the services they are entitled to.

What people with disability, policymakers, advocates, services and others need to know about this project

Policymakers, services and advocates need to know how little information broad sections of the population have when it comes to aged care in general, let alone aged care rights. The living experience expert reference group highlighted for us the complexity of enacting one's aged care rights when there were additional barriers including (but not limited to) communication barriers born of ableist structures (such as the prevalence of non-access enabled website materials as primary means of information sharing), language barriers when English is not a preferred language, competing cultural lenses including religion, sexuality and within group conflicts/divisions, as well as socio-economic marginalisation.

Our engagement with older CALD women with disability suggests that they and their peers often prioritise the rights and needs of others around them, for example their older parents or adult children with disability who they viewed as more vulnerable, while deprioritising their own care needs and reducing their capacity to self-advocate. Concerningly, people we talked with highlighted that aged care support is more likely sought after crises or when significant changes force people to seek support while they also look after others. Our co-design process highlighted that people were particularly vulnerable at the point of first engaging with aged care because they were reacting to changes in circumstance while seeking to continue their support of others. This conflicts with the reablement ambitions of the new Aged Care Act, and it means people are entering aged care in times of crisis management. Policymakers need to understand this is the context people are self-managing in addition to the system barriers like waiting times and access.

We also learned that rights and claiming rights can be viewed as risky, since rights and advocacy were seen as parts of the legal system rather than an inherent part of everyday life and accessible within the aged care system architecture. This means that some of the positioning of the safeguards for aged care will seem not only out of reach but potentially burdensome as people feared they would incur legal costs or involvement with the court system if they were to claim these rights in the face of transgressions. We

cannot take for granted that people are familiar with the institutions of Australian governance since those who have grown up in different systems may distrust or fear engaging with government agencies. Therefore, it is not just the aged care system that policymakers, advocates and service providers need to make more familiar to people, but the rights-based redress mechanisms and complaints systems that have been built into the aged care system.

This co-design process highlighted areas for research and action. These include:

- Knowledge of aged care rights is low, particularly among CALD communities
- System navigation is complex, especially with intersecting barriers made more acute for people from CALD communities with disability
- Claiming rights can be perceived as risky or legalistic, which discourages the efficacy of the intended safeguards
- Older CALD women with disability told us they prioritise others’ care rights above their own
- Engagement with aged care frequently occurs only during crisis points, which increases people’s vulnerability and risk of rights violations

To address these issues, age care systems and advocacy support mechanisms must:

- Improve accessibility of content and services (language, formats, digital inclusion, outreach/promotion)
- Normalise rights as part of everyday aged care discussions to dispel fears of unintended consequences and reprisal
- Simplify and create inclusive complaints and advocacy pathways (including leveraging existing trusted sources of information in communities such as libraries, faith organisations, or hosting stalls and information sessions at existing public events)
- Provide CALD and disability-inclusive information and support pathways at all levels of the aged care system and complaints handling avenues
- Identify the extent to which older people from CALD communities with disability are accessing the supports they are entitled to and whether this is commensurate with per capita access rates in mainstream cohorts
  - This includes the rights and advocacy tools and systems available to older people seeking aged care.

Authorisation and endorsement

This Project Executive Summary has been reviewed and authorised by:

- Dr Amber Mills, Chief Investigator (AAG)
- Dr Ellen Finlay, Project Lead (AAG)
- Rebekah Dawson, Project Lead (NEDA)
- Vasiliki Kasidis, Co-researcher representative
- Dr Sandra South, Co-researcher representative
- Sara Jane Stanley, Co-researcher representative

NB: Ms Sadikshya Dulal, Partner Organisation Lead (NEDA) was unable to provide final authorisation and endorsement due to unexpected leave.

Disclaimer

This Project Executive Summary represents the views of the project team and does not necessarily reflect the views of the National Disability Research Partnership (NDRP) or the Australian Government.

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