

THE UNIVERSITY OF
SYDNEY
 —
 Sydney Policy
 Lab

Australia Cares

March 2024

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CARE IS COMPASSION, KINDNESS, PURPOSE, PATIENCE, DISCOVERY, PRIVILEGE, DIGNITY, DUTY, EXPECTATION AND HONOUR. LET I'M ON A STRING, WITHOUT INFORMAL CARERS, UNPAID AND UNTRAINED THE ONES IS ON YOU TO FILL THE GAPS. NEVER A TIME OF SUCH ABUNDANCE STAGE NOT SEXY, WHEN WILL YOU HEAR US? I'M TIRED OF PROTESTING, WE VALUE YOUTH, HEALTH, BURDENOME, YOU'RE NOT A SIGN, BURDEN THE WE DEEP IN EVERYONE'S PSYCHE, JUSTIFY LIFE-COMMON LANGUAGE OF STRENGTH REALITY HUMAN BEING DOING, FLIP THE NARRATIVE ON ITS HEAD, WHY ARE WE NUMB TO STRUCTURAL SYSTEMIC VIOLENCE?

GET OUT OF THE REEDS! STOP PROPPING UP A CARE EQUATION THAT DOESN'T ADD UP. MORE PEOPLE, MORE PRODUCTION, MORE CONSUMPTION, MORE CARE, MORE WORKFORCE, MORE MORE MORE. OUR PLANET DOESN'T HAVE MORE, PEOPLE DON'T HAVE MORE, WE NEED TO CREATE MORE THINGS THAT MATTER, WITH LESS, IT DOES NOT ADD UP. GETTING OLDER IS BECOMING CONSUMERIST - DO WE HAVE A USE BY DATE? - TO HELP THE MATHS RESOLVE CHALLENGES IN A BILLION WORLD, CAN WE CONNECT? EXPERIENCE SHARED HUMANITY? MORE CHANCES TO SHARE - IN LATERAL AND UNCONVENTIONAL WAYS, MORE COMMUNITY, MORE BELONGING, MORE WATCHING EACH OTHER'S BACKS, SLOW DOWN, TAKE TIME.

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Acknowledgment of Country

Ngyini ngalawangun mari budyari Gadinurada

We meet together on the very beautiful Gadi Country.

The Sydney Policy Lab acknowledges the generations upon generations of traditional custodians that have held responsibilities for Country, “custodian-ing” it from one generation to the next. We acknowledge the cultural protocols of protecting and holding knowledges that have sustained culture and Country for over 60,000 years.

Based in Sydney, we acknowledge the Gadigal Elders, past and present, and the beautiful Gadi Country where we work. We extend this acknowledgement to the Country, Elders and Ancestors of many other Aboriginal and Torres Strait Islander peoples across Australia. We honour and respect the sovereignty of the many Nations where we live and work.

We are committed to working respectfully and authentically with First Peoples across these beautiful lands, waters and skies.

Australia Cares

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Foreword

The COVID-19 pandemic highlighted the profound foundational role care and caring play in our society while exposing deep fissures in care policy that had developed over time.

Care services across all sectors experienced severe challenges to provide services that were person-centred. From early childhood education and care to disability care and aged care: the fact that most found ways to do so was remarkable, but there were often severe consequences for many involved. Alongside this, governments pulled policy levers that seemed unthinkable in the years prior.

With the acute phase of the pandemic behind us, we have the opportunity to learn from the way it tested Australian care policies and systems – in some cases breaking them, and in others showing new and better ways. We cannot miss the chance to embrace a holistic understanding of care and reimagine frameworks for how Australians wish to receive and provide care. This is the essential challenge taken on by the Sydney Policy Lab in the Australia Cares project.

Care is essential to much of our work at the University of Sydney. Students in our Faculty of Medicine and Health represent some 23 percent of the University's student population. They also account for one in five of the more than 66,000 students currently enrolled in 'Health' courses with NSW higher education providers – a generation who will provide care across the breadth of formal and informal settings. Our multidisciplinary research opens new possibilities for care in society. And when members of our academic community gather and connect with local communities across the state, they bring diverse strengths, needs, expertise and experiences in care.

What unites us is a desire to do work that has impact, creates social good and drives positive change. Convening with community in Broken Hill, Westmead and online, Australia Cares has brought together people with diverse expertise, including many of our scholars, colleagues at other universities and collaborators in civil society and government.

This is how striking breakthroughs come about – by gathering people with different disciplinary strengths, insights and research approaches to expand our ways of seeing, thinking and understanding. This is a vital contribution universities make to our country.

I commend all involved in this first phase of the Australia Cares project and welcome the publication of this compelling report. I look forward to the report having the policy influence the Australian people and the project's many and diverse collaborators deserve.



Professor Mark Scott AO
Vice-Chancellor and President
The University of Sydney

Australia Cares Advisory Group

Dr Sheelagh Daniels-Mayes, Lecturer in Indigenous Studies and Deputy Associate Dean, Diversity and Inclusion – Disability, University of Melbourne

Emma Dawson, CEO, Per Capita

Robert Fitzgerald AM, Commissioner, Ageing and Disability Commission NSW

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Professor Kathryn Refshauge, Emeritus Professor, University of Sydney

Andrew Vodic, CEO, Community Disability Alliance Hunter

We wish to acknowledge Professor Marc Stears and Martin Stewart-Weeks who instigated the Australia Cares project. Marc was also Chief Investigator for the project while Director of the Sydney Policy Lab and during a period of transition following his departure and appointment as Director of the University College London Policy Lab in March 2022.

With thanks to Dr Benedict Coleridge for research.

Authors' note

Our care systems are in crisis and have been for decades. Multiple royal commissions and the pandemic have exposed Australia's failure to provide the kind of care that people want for themselves and those they love. Tinkering around the edges of our existing systems will not be enough. We need to respond with new thinking about policies and systems, developed in partnership with those who know how to provide care and those who receive it.

Care is fundamental to a good life and a fair society. We can all be certain we will give and receive care in different contexts and at different times of our lives. For many people, being a caregiver is a significant part of life. So too is receiving care for many others who are dependent on formal and informal carers. Yet so often our society has put care on the bottom rung of importance.

People want to challenge the status quo. They want our society to value care and recognise its intrinsic value to our lives and the functioning of our society.

At its best, care is about our dignity, interconnectedness and agency. At its worst, care done poorly or for the wrong reasons can strip people of their agency and entrench disadvantage.

These are the key hopes and concerns we heard in a series of dialogues with public policy experts, care recipients and practitioners that led us to launch Australia Cares in 2022.

In this report you will find an unfolding story of care experiences, issues, challenges and pathways to finding policy solutions. The results highlight the significance of community voice in shaping the economy of any care system. The findings reported here suggest complementary stories of care from those givers and receivers of care. Taken as a collective story, they direct us toward policy imperatives.

We are grateful for the many people who have given much to this project including community members

and partners, university colleagues and the project's Advisory Group. Without the support of the Paul Ramsay Foundation for this exploratory phase of the project, such extensive community-led policy development would not have been possible.

Australians have stepped up to the challenge of thinking deeply about care and caring, with the intention that 'Australia Cares'. It's time to listen and act. Together, we can create new cultures, policies and systems of care.



Dr Kate Harrison Brennan
Director, Sydney Policy Lab
The University of Sydney



Professor Brendan McCormack
Academic Chair, Australia Cares
Head of School and Dean, The Susan Wakil
School of Nursing and Midwifery
The University of Sydney

1. Reimagining care

Another project on care

Haven't we been looking at this for decades? And haven't we already held royal commissions, developed new strategies and technologies, and restructured services with new quality standards?

Haven't we already watched workers strike, read the academic reports and done the economic modelling?

Why another project when there is already so much happening?

There's a lot happening because care really matters. It's deeply personal, even intimate. It's a feature of our closest relationships, where vulnerability and dependence play out. We give and receive care across the course of life, from birth to death. When care goes right, it builds agency, dignity and connection through the reciprocal relationships between those giving and receiving care. When it goes wrong, it's a deep breaking of trust. At its worst, care can be exploitative and abusive.

We're making a mess of it

Every week we see and hear reports of people deeply shocked at the care received by their aged parents; colleagues, friends and family members with disabilities; and children. It happens across all types of care, leading to repeated tragedies, injustices and public scandals, as inquiry after review after royal commission continues to expose. We witness the ongoing

social inequality experienced by First Nations people, often resulting directly from uncaring policies which shape the way care is provided at all levels across the country. We hear stories of exhaustion, understaffing and low morale told by nurses, early childhood educators, teachers, paramedics, aged care workers, disability carers and many others.

The many symptoms of our broken cultures, systems and practices of care are matched by a bewildering number of proposed remedies. It's as if a whole industry and infrastructure has grown up around plugging gaps and mending existing systems. Good people are doing good work and others are making a buck. But care in Australia remains deeply broken.

Why are we making such a mess? Why is too little changing for the better?

We're uncomfortable with care. Too often there's an undertone that characterises care as an unfortunate inconvenience, too private and too 'female' to be aired in public. Dependence and vulnerability are not words that come easy to us – we prefer to avoid thinking about them until we are forced to. 'God forbid it should be me. It's undignified.' We've painted those needing care as the unfortunate others, stripping them of their full personhood. So, we don't talk about it, even less celebrate it, and we've failed

to understand and share the rich stories of beautiful care, respectful care, dignified care and care that shows what it is like to really help someone to flourish as a person.

We've normalised a society of not caring. We know people are struggling. We know people are lonely. We know they're not getting the care they need on a day-to-day basis. We leave people feeling helpless or hitting bureaucratic brick walls when they reach out for support. We're almost numb to it and we never take on the kinds of transformational political, financing and resourcing decisions of the quality and scale that need to be taken if we're to really fix care systems.

"Why are we numb to structural systemic violence?"

Care Labs Inflammatory Essays

We've also accepted the shocking disconnect present when we expect wonderful care, whether from paid or unpaid family and friend carers, but we completely undervalue carers. We set up systems with individualised care, designed to enable people needing care to identify their goals and seek services, then we expect that to be supported by people who are invisible, disrespected, unsupported or paid very poorly. It is a gap we're somehow not seeing.

The language we use and stories we tell hide inequality. Care is deeply racialised and stigmatised. We hear narratives suggesting there are people who are 'deserving' and 'undeserving' of care. Often, those who are 'undeserving' are also those who aren't from racial or ethnic majorities. Those who are 'undeserving' are often those who need care the most. And, ironically, those who are 'undeserving' are often those who step into caring roles that others don't want to do, allowing our society and economy to keep ticking.

Stigma works both ways. On one hand, those who need care are stigmatised and shamed for their 'dependency' in a world where we are meant to be productive and self-sufficient. On the other, because we are uncomfortable with our own need for care now or in the future, we devalue and stigmatise those who step up to make us less vulnerable by providing care.

"Those who need care are subjected to shaming, ageism, ableism, and 'othering' in various guises. Those who give care absorb the compounding costs of loss of paid work, superannuation, access to paid parental leave, career progression and so on."

Care Labs collaborator

“Not caring results in human suffering, it results in real suffering. People who make the policies, who have the money to put a buffer between them, who were able to buy care and buy comfort – they will never understand that.”

Care Labs collaborator

Because we've failed to understand and value it, we've reduced care to a series of transactions, we deal with it in siloes and we think short term. Systematised policy responses to care have converted this deeply personal, unpredictable and relationship-based activity into units of labour and tools that can be standardised, measured and controlled. We look at it sector by sector, state by state, service by service, narrowing our field of vision and obscuring the interconnections between care as it plays out in different spheres.

In our current policymaking processes, we're advocating positions rather than opening hearts and minds. We're fighting it out within very tight parameters defined by current dysfunctional systems rather than demanding better from those who represent us.

At heart, what's broken is how we value care, the stories we tell ourselves about care, and the denial of our shared experience as people who give and receive care. And the ways we're trying to fix it aren't working.

So, in Australia Cares, we set out to do something different. We have set the bold ambition to reimagine care, and to do that drawing on sets of relationships and tools not usually deployed in policymaking.

Why Now?

During the height of the Covid pandemic we witnessed a wholesale shift in focus on care and the narrative of care. We saw care workers being clapped by politicians, decision-makers and the public. We witnessed the public call out failures in the care system that put those in need of care and care workers at risk. We experienced new charitable causes being established with the explicit focus of fundraising to support those in need of care but without the resources to acquire it.

This elevated focus on care and care work didn't last. Care became invisible again. Excitement that we had entered a new world of understanding of the importance of care disappeared as quickly as it arrived, and we returned to stories of broken systems, disrespected relationships and arguments about who should pay for care.

So, we want to write a new national story of care. A story that captures the value of care, its central place in communities and society, and is built on the rich mosaic of stories from those who give and receive care. We want to understand care deeply and make

it visible in all its messy glory. Only when we tackle the policy challenges of care in this context will we have any hope at all.

We're up for that challenge, because we absolutely need to do something differently if we want change.

We know there are the ingredients for new ways to transform care, and we're ready to put those together. We want to put the voices of different communities at the centre of this story – the voices of those grappling with care every day. We want to test the powers of community-led policy development, shaped by lived experience, informed by distinctive contributions from people with diverse perspectives and supported by academic and community expertise.

We know there's a genuine appetite from people at all points in our care system to take this on. There is courage and ambition. There's a thirst that the current opportunities for policy development is not satisfying, and a call for courage and leadership.

So, we set out on this project with curiosity and determination, asking:

- What if we posed bigger questions about the place of care in the community and our economy?
- What if we inverted the policymaking model, enabling communities to set the agenda and give policy guidance?
- What if we brought people with

diverse perspectives together to tackle those questions?

- What if we used the expertise and infrastructure of the University of Sydney to partner with communities?
- What if we stepped back from the short timeframes of political cycles?

In order to reimagine care, we have to reimagine policymaking. We asked: What if we dared to bring together the Sydney Policy Lab's core work of participatory policymaking with this most human and fraught issue of care? Could we co-create new policy insights that might just shift our cultures, systems and practices of care and develop new ways of making policy?

"It's a shame that we don't have leadership in this space. Politicians are not proactive: they're just always responding to crises. We don't have politicians with a vision generally valuing care, caring to see the importance, and so come to the public and say, look, this is so fundamental, and we need to fund it properly, and we need to bring about reforms."

Associate Professor Luara Ferracioli
The University of Sydney

What is 'care'?

The word care is generally thought to be a positive term, implying love and kindness. However, it is not always straightforward. The word care can be triggering and jarring for people who have had traumatic experiences of care systems or those whose caring labour is undervalued or unacknowledged. People with disability often prefer the terms support worker and family member to care worker or carer, seeing the word care as paternalistic and patronising. Many early childhood educators have also rejected the word care, preferring to emphasise the educational role they play in children's development.

Although its meaning and usage are contested, there are good reasons the Australia Cares project still uses the word. Care is finally getting the attention of governments and citizens. We believe that, rather than replacing the word care, it's time to re-imagine care. Australia Cares seeks to transform care so relationships, agency and dignity are at the heart of how care systems, cultures and practices are funded, designed and delivered.

A starting definition of care comes from feminist theorists, Berenice Fisher and Joan C. Tronto:

"Care is a species activity that includes everything that we do to maintain, continue and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web."¹

For Australia Cares, care is about 'healthfulness': cultivating 'environments of care that promote health', including 'healthful relationships' that support a person to flourish. Care is about person-centredness,



relationships, professional care, nursing care, care theories, care and support economies, and support services. It includes care for older people, children, people with disability, people from racial or ethnic minorities, people when they are sick and self-care. Care for Country is central to this approach to care as we recognise, value and centre our connection to land and each other in the life-sustaining web of relationships of which we are a part. Care in all its guises is a vehicle for creating flourishing persons, communities and populations. Flourishing happens when we are 'held' through various experiences as we move through life. We flourish when we experience beneficial, positive growth that pushes us to be the best versions of ourselves. When we are helped to make the most of our naturally occurring potential to care by channelling it for good, we don't just flourish as persons, whole communities have the potential to become more resilient.

Reimagining care encourages us to reflect critically on our language so that how we speak about care itself is caring. This means choosing language that helps people, including ourselves, to feel supported to live our best lives.

2. Reimagining policymaking

Our work in this project has explored community-led policymaking through two initiatives, each exploring particular methodologies: Care Labs and People’s Assemblies on Care.

We linked these initiatives with Stories of Care, lived experience research and an analysis of the care economy. These linked elements provide complementary perspectives to those obtained through the Care Labs and People’s Assemblies, and are summarised in the appendices to this report.

Our reimagining of policymaking across the different initiatives was built on some core elements.

We know people, relationships, Country and places matter a great deal, and we took time to build relationships with the communities we planned to work with, university colleagues and people with diverse perspectives on care systems.

We brought together distinctive academic approaches to the work, spanning person-centred and creative methods, ethnography, deliberative democratic processes and design thinking approaches.

Academics from 13 disciplines were involved across the project activities, anchored by Professor Brendan McCormack as Academic Chair.

We value different forms of knowledge and invited diverse expertise from people with knowledge from personal experience, community knowledge, knowledge as a practitioner, organisational knowledge and academic knowledge. We convened activities bringing together people of diverse age, gender, socio-economic background and life experience.

We created spaces that would maximise the opportunity for collaborators to have a positive experience of being and working together. From the design of activities and preparation of materials to the details of how spaces were set up, we created safe and inclusive spaces for knowledge co-production. In all of our activities, we invited people

to participate not only in their professional capacity, but by contributing their personal and lived experiences.

In this area of policy that is both highly intimate and social, we enabled opportunity for shared contemplation, attended to the inner worlds of collaborators and their social contexts, and enabled emotional engagement. We facilitated a dance between the use of creative individual and group methods – clay, poetry and metaphor, for example – matched with deep thinking, reflective discussions and systematic approaches through structured deliberative practices.

While we worked with structured plans, we were flexible with how these unfolded based on the flow of engagement with and between collaborators. We were able to stay focused on what was important in the moment and facilitate the emergence of new insights in a systematic and thoughtful way.

Care Labs

Online collaboration to discern care principles and apply these in thematic policy areas

Following many conversations in 2022, we identified the opportunity to explore community-led policymaking in two thematic areas where there seemed to be great interest from our community coupled with opportunity to have policy influence: aged care in the home and community and disability support in early childhood education and care.

Professor Brendan McCormack led this initiative. We convened a series of online workshops between March and September 2023 and invited a diverse mix of collaborators. Across four core workshops and four shorter sessions, 38 people from different geographical locations collaborated in this policymaking. Many of these people joined us for a final Care Lab in November at Australian Parliament House in Canberra with politicians and decision makers.

We adapted the methodology of Theory U to inform the Care Labs and the focus on ensuring meaningful engagement from all collaborators. Theory U is an awareness-based methodology for changing systems which challenges us to connect with our internal world – our beliefs, values, experiences and assumptions – to engage fully with the external world.

“What about if we tried to make this not about us? What about if we tried to make this about the people in the communities that we exist for? What about if we did that – we flip flop our mental maps around? What would our governance look like? What would our management structures look like? What if we actually lived up to the rhetoric?”

Lin Hatfield Dodds
CEO of The Benevolent Society

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Care Labs

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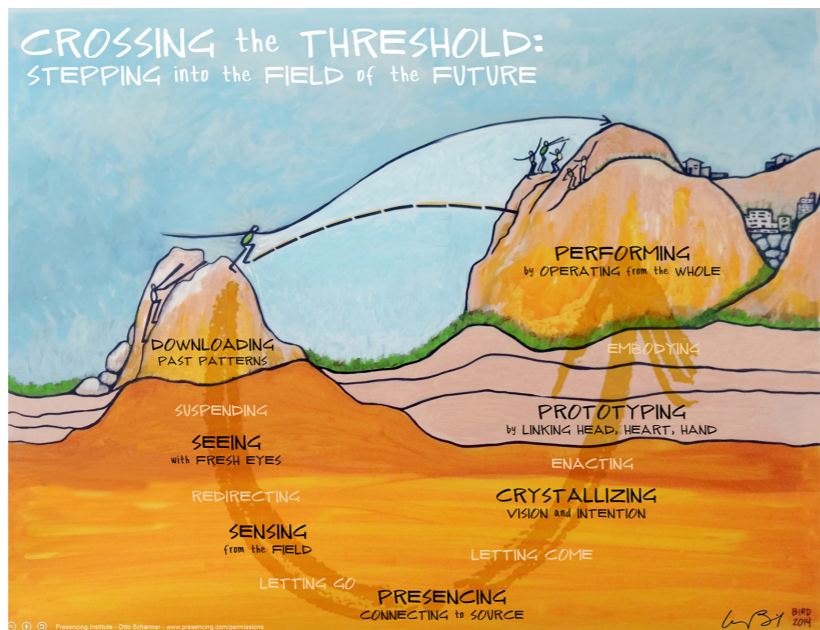
Care Lab collaborators

40+

People's Assembly on Care collaborators

20+

academic collaborators across 13 disciplines



In essence, Theory U combines principles derived from participatory action research, design thinking, mindfulness and civil society movements. These principles are consistent with the community and societal change underpinnings of Australia Cares and our collective intention of elevating care in society. We shaped the work of the Care Labs through the five collaborative commitments of Sharmer and colleagues, to provide us with a framework to guide our movement around 'the U'.² Importantly, our intention was to use the labs to get to the bottom of 'the U' – presencing – where we could all be content our collaborative explorations resulted in a shared understanding of care principles we could all 'settle with'.

As we invited our collaborators into this process, we clearly signalled we were seeking to enable a way of being and working together that was different from

the common experience of online workshops in which collaborators can be passive recipients of dense material presented by 'experts'. For example, we sent a Care Lab pack ahead of the sessions with a guide, creative materials and a snack. The initial signalling continued in the style of facilitation and theoretically-informed modes of interaction. We used personal artefacts, clay modelling and poetry as stories of care were shared. We developed poetry and collaborative 'inflammatory essays' to uncover care principles. Policy ideas were posited and tested using the Disney Creative Strategy method.



Top: Theory U illustration courtesy the Presencing Institute, licensed under Creative Commons BY-SA 3.0 Deed. Above: Care Labs pack. Below: Care Lab on Zoom; Canberra Care Lab in Australian Parliament House, November 2023.



Westmead and Broken Hill, where the University of Sydney has campuses



People's Assemblies on Care

Place-based, community-led policymaking

In 2023, we worked with two communities where the University of Sydney has a physical presence and campus: Westmead in western Sydney and Broken Hill in far-west New South Wales to hold People's Assemblies on Care.

These People's Assemblies were designed as a response to the weariness members of the Australian public felt at successive royal commissions doing post-mortems of policy failures in key policy areas related to care. Inspired by a wave of deliberative democratic exercises that have sprung up around the world, we selected a deliberative method to create a microcosm of a local community, a 'mini public'.

Dr Kate Harrison Brennan led this initiative, and Professor Brendan McCormack and Mariah Goldsworthy co-facilitated the People's Assembly on Care at Broken Hill. Professor Brendan McCormack, Professor Bandana Saini and Dr Kate Harrison Brennan co-facilitated the People's Assembly on Care at Westmead.

In prioritising the experience of community members, we chose a more informal approach rather than the rigorous deliberative methods that have been explored elsewhere. As in the Care Labs, we designed

activities that sought to enable a movement from precognitive to cognitive engagement with the topics and subject matter. We worked with world-leading design thinking agency Dust & Company to make use of design thinking methods, creating participatory and deliberative activities for the Assemblies.

For each Assembly, 20 community members were recruited. In Broken Hill, we worked with a broadly representative cross-section of the Broken Hill population, adjusted to ensure an equal representation of females and males as well as a higher proportion of Aboriginal and Torres Strait Island people than in the general Broken Hill community and people with experience of chronic illness. In Westmead, we focused selection on a cross-section of members of the community who have an Indian background. This was informed by insights from the first stages of the project in which those we spoke with in government and communities highlighted the need for policy development that reflected the values and

expectations of culturally and linguistically diverse communities. We specifically sought families living in multigenerational households.

The Assemblies were designed to run in two phases in each location. Phase one, a three-hour evening workshop, was an exercise in consultation and agenda setting which set-up for phase two, an all-day workshop on a weekend to deliberate on policy solutions. In 2023, we completed both phases in Westmead and phase one in Broken Hill.

Phase two of the Broken Hill People's Assembly on Care was scheduled for October. At the request of Aboriginal and Torres Strait Islander members of the community and the Aboriginal Community Working Party following the referendum on The Voice, we postponed the Assembly to allow them time to grieve the outcome. We will confirm plans for the next phase with the guidance of community representatives and local University of Sydney colleagues.



Broken Hill People's Assembly on Care phase one.

The relational economy

Aged care research and development

The services that make up the care sector play a pivotal role in our everyday lives, communities and economy. As the care sector becomes a larger part of our economy, innovation in the sector is becoming increasingly important.

However, the care sector's value is greater than what is measured through GDP alone with traditional measures of economic progress not capturing many of the benefits of care work.

There is a moral or even a relational economy at work based on reciprocity.³ The care sector extends the social ties and forms new relationships to provide care. Value, here, cannot simply be commodified and provided by the market and state.

In a stream of work on innovation in the aged care sector, we described the relational economy at work and analysed investment in the creation of new value in this economy through research & development (R&D).

We make the case for government intervention through public finance for R&D to support provision of aged care as a good and as an important part of the foundational economy – essential for wellbeing and human flourishing.

To achieve such ends, public finance cannot be for just big business and cities alone but should be invested across the whole economy. That is, across geographies, forms of infrastructure (physical, social and civic), organisational types, capabilities, jobs and skills. Without a holistic approach to investment in a relational economy, the current basis of value creation, including through the R&D that does take place, undermines what we value most as a society. At best, it provides benefit to only the top echelon, but without reciprocal relationships.

Improving the quality, effectiveness and efficiency of care services underpins human flourishing, improved wellbeing and better health outcomes in addition to higher economic growth. For example:

- Early childhood education and care workers influence long term health, educational and economic outcomes for children.
- Aged care workers improve life satisfaction, lower levels of loneliness and, through improving health outcomes, extend life and reduce health care use.
- Counsellors improve life satisfaction, economic participation and reduce health care use of their clients.
- Disability workers improve life satisfaction, increase economic participation and improve health outcomes of people with a disability.

Lived experience research

The lived experiences of people involved in care, from informal and formal care workers to the people they support, is foundational to the Australia Cares project. To learn from the ways people with lived experience are included in co-design and research, the Sydney Policy Lab initiated a reflective research program on lived experience methods. Through a series of interviews, dialogues and collaborative writing processes, we explored tensions between different approaches and core concepts underpinning lived experience methods, and shared examples of those methods in practice. Through our collaborative engagement, three core principles and values emerged as foundational to engaging people of diverse experiences.

1. **Critical reflection and ongoing learning:** Lived experience research requires researchers to question values and assumptions, be open to changing direction, and learn from the people and communities they work with.
2. **Meaningful inclusion:** We should consider how people with lived experience are being included throughout the design or research process. This means including people with lived experience as early as possible and being open to those people or communities changing the framing or research question. They are the closest to the topic of concern and their knowledge is to be privileged.
3. **Evolving cultures and institutions:** Including lived experience in research requires investing additional time and money in relationships with involved people and communities in authentic and reciprocal ways. Priority should go to ensuring people and communities benefit from their involvement in the research process and the outcomes.

Stories of care

What counts as care, and what agentive or dignified care means, differs for people across Australia based on a range of factors including their ethnicity, migration status, life experience, age, gender, sexuality and religion. In fact, for some communities and individuals, other values altogether might guide and structure care relations.

Through our Stories of Care, we have drawn on an anthropological approach and ethnographic methods. Anthropology has particular tools for understanding what care means within these different contexts, relations and lifeworlds because it is particularly sensitive to the relationships that build and sustain care. This element of the project is all about going to people in the everyday worlds they inhabit, following their care relationships and understanding their textured emotional experiences.

Through one-to-one ethnographic interviews with people who have collaborated in the Care Labs or People's Assemblies, we have yielded different kinds of insights, shedding light on the fundamental ethics of care they live, and the imaginations – utopian or otherwise – they have for how care should be organised in the future. This work compliments, but also questions, the other elements of the project, challenging researchers to reflect on whether the fundamental assumptions they have about the nature of care are universal.

3. Creating new knowledge

About care and caring

Across the project, people spoke about the gulf between their aspirations to live in a caring society and their lived experiences of care. Beyond the published reports on broken systems, which are numerous and compelling, we unearthed a sense of anger and frustration, and a deep sense of those being cared for and those doing the caring not being seen.

In sharing stories of care, we recognised that in caring and being cared for, we experience our shared personhood. Our collaborators shared rich personal experiences, beautiful stories of relationships and community shared between those being cared for and those caring. We were moved by stories of love, each intimate and individual but linking us with something shared and essentially human. We heard of the strong bonds within communities and families that enable care, and the personal and cultural significance of caring for family members. Care is central to identity and culture within many of the communities we worked with.

In contrast, stories were shared of the shocking lack of care and value given to those they love, whether it be as they age, seek disability support or come to Australia as migrants. We heard about a distressing level of 'othering' of people with disabilities, the invisibility of those outside of our major cities and the challenges of navigating more complex systems.

We heard that while caring is certainly difficult at times, it is not intrinsically burdensome. Our collaborators shared rich stories of the joys of caring – of enabling others to flourish. It is our cultures, systems and practices of care that impose a burden, placing pressure on the relationships between carers and those they care for. We heard stories of carers losing paid work to make phone calls and attend appointments, losing the capacity to build social connections; and facing poverty and lack of rest during retirement. We heard of the difficulties of navigating care in remote communities and the transcultural issues and challenges that get in the way of effective care and support for extended family systems in culturally diverse communities. There was a strong sense of these costs being invisible, to be covered privately and preferably quietly by individuals and households.

"I had to do a survey on wellbeing the other day and it wanted me to say I am happy a percentage of time and sad a percentage of time, and they had to add up to 100 percent. I'm like, emotions don't work like that. I can be 80 percent happy and 70 percent distressed."

Care Labs collaborator

We clearly heard the anger of carers. Anger at the load, invisibility and costs imposed by complex systems that are not working. Systems that don't make it easy for carers to access benefits and seem to serve the bureaucracy as an entity in itself rather than those who are navigating it. Family and friend carers shared stories of how they grieve the opportunities taken away by our systems, just as they celebrate the relationships and experiences gained through the human activity of caring.

"Who do they think is sitting around with all this free time to be everyone's power of attorney with the pain and the hardship of the hours on hold? I'm not even talking about providing the direct care – the indirect care carries an enormous cost where you have to take a day of unpaid leave to do your old mum's calls, but the rest of the economy doesn't respect that, and still, you have to work on their time. So, the gerontologist's office will not commit to calling you at a particular time. The hospital will not commit. Nobody will facilitate anyone else."

Care Labs collaborator

We heard the anger of those being cared for, of being 'othered' and made invisible. In our current systems and cultures, too often the rights of those caring are pitted against those they are caring for, as if we were playing a zero-sum game. Our collaborators have pushed back against that: rights to care and be cared for must be seen as complementary rather than being in opposition. My right to care with dignity and agency at its heart need not undermine your right to recognition and compensation. Your right to a voice and to build your skills as a carer must not be at the expense of my agency and dignity as I am cared for.

The failures of our care systems are experienced differently across communities. We heard stories of the failures in care provisioning and suitability for Aboriginal and Torres Strait Islander peoples, women, migrants and those living beyond metropolitan areas. We sensed a series of underlying questions: Are there those that deserve care and those that don't? Do those with money and assets after a lifetime of 'contributing' deserve more than those who have disability and will always require intensive support? Do we accept poorer quality care for some, just thankful that it's not us?

We heard the frustration and distress from underserved populations who are unable to access care for a range of reasons, from chronic shortages of care workers and care services to services that do not respond to

cultural needs or are inaccessible because of policy imperatives. We heard of the domino effect when workforce shortages in one industry or sector of care have impacts across whole communities of care. We heard of the importance of trust in relationships of care and the sometimes-devastating impacts

when this is absent. We discovered care cannot be considered without also taking account of housing, economic security, visa status and safety. In many of our conversations and in different contexts, the giving and receiving of care was linked to factors that might at first glance seem unrelated.

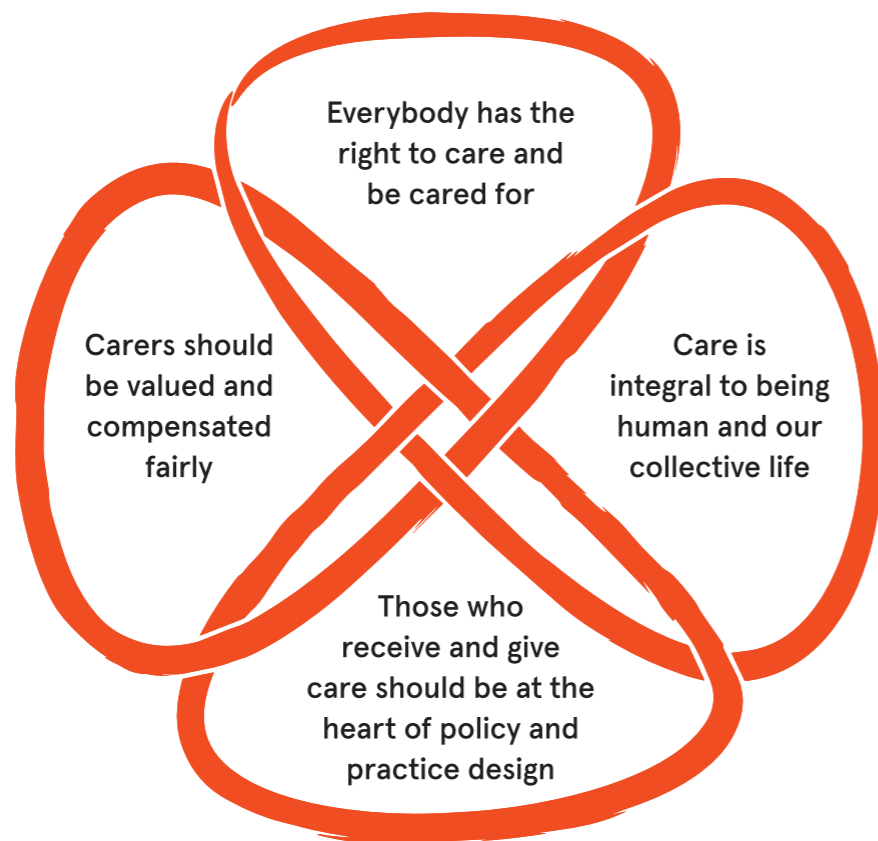
"The beauty of being a carer to someone we love, it's enormous ... And when my father for example, said to me, oh, living here with you every day, it's a Sunday. Because he felt my love and care that made me feel tall and strong, no matter how exhausted I was."

Care Labs collaborator

The reality for so many is that these are inextricably linked and any meaningful consideration of care requires that we enable these connections to be acknowledged, described and analysed.

These stories are consistent with what we know to be many of the problems and challenges in care systems. For example, there is consistent evidence over many years of international research that shows the impact on relationships, physical health, mental health and financial security of informal carer roles and family carer roles when they are not recognised, acknowledged and properly supported. The stories we heard bring this evidence into sharp focus and to life through lived experience.

The lived experiences of our collaborators also show how poorly equipped our care systems are to address geographic and cultural diversity among the Australian population. Arising from deeply listening to these stories are some fundamental questions we need to address as a society, including: How do we overturn histories of neglect, marginalisation and discrimination from care systems among some populations and communities? How do we rebuild trust in decision-makers at all levels to engage in active inclusion strategies? How do we suggest decision-makers need to understand the whole picture to develop collaborative and inclusive policies on care?



Policy solutions from Care Labs

Our collaborators were clear: we must do better with care policy. It should be underpinned by an interconnected set of principles and lead to a fundamental redesign of our systems. We worked with the Care Lab collaborators to systematically analyse the data collected during the Labs to generate the above four principles of care that transcend people, contexts and specialties.

These principles are 'action guides' for shaping ongoing developments in care and future work of the Sydney Policy Lab. The rationale behind each of these principles is described in the right hand table.

Further, collaborators called for key actions that would help these principles come to fruition:

- Resources to enable the development of a diversity of images and stories in which we

share the deeper experience of caring. It is time to get beyond soft focus, cleaned up images of caring that make invisible the gritty experiences such as those shared by our collaborators.

- The development of a rights-based framework for care policy. Our reimagination of care must place the rights to care and be cared for at the centre. Many of our collaborators were frustrated by their inability to make change at the level they desired without a rights-based framework on which to build.
- The development of quality standards and accountability at different levels, without the layers of bureaucracy and regulation that strip what is human out of caring. This should include deep consideration of how we can best measure the outcomes of quality care, of which the nature of the relationship between care

recipients and care providers is a fundamental element.

- A deep examination of complex and often bureaucratic systems to understand how and where they impose unnecessary burdens on those being cared for and those giving care.
- The development of methods to enumerate the invisible costs imposed on carers by our care systems and borne disproportionately by women.
- Funding initiatives that incentivise and support young people to engage in care. Such initiatives could build positive experiences of those giving and receiving care, contribute to telling a new 'story' about care and be part of the response to workforce shortages.
- Co-designing and funding local care hubs to support appropriate care, relationships and connection in communities.

“Those who need care are subjected to shaming, ageism, ableism and ‘othering’ in various guises. Those who give care absorb the compounding costs of loss of paid work, superannuation, access to paid parental leave, career progression etc.”

Care Labs collaborator

What we have	What we must build
A system which penalises and stigmatises those that are cared for and those that care	Care systems designed to support care and caring relationships
A system which makes invisible, and imposes a burden on, those who are cared for and those who care	Care systems that celebrate and value the place of care in all our lives
A system in which there are some who can access and afford quality care and some who can't	Care systems in which we have rights to be cared for and to care
A system built using a system-centred approach, with the perpetuation of the system at the centre	Care systems built using a person-centred approach with the perspectives of those with lived experience at the centre
A system in which the rights of those receiving care are pitted against the rights of those giving care	Care systems that recognise the complementary rights of those receiving care and those giving care

Policy solutions from People's Assemblies on Care

From the first phase of the People's Assemblies in Westmead and Broken Hill, driving questions for subsequent deliberation were developed. In Westmead, this focused on the care ecosystem and how transcultural issues and challenges get in the way of that ecosystem. While in Broken Hill, the driving question focused on

care navigation and the complexities associated with finding one's way in, around and through the care system. While we are still to conduct the second round of deliberation with the Broken Hill community, we gleaned sufficient detail from our initial engagement to highlight a clear focus for action. Those gathered in the People's Assemblies on Care, supported by University of Sydney academics and professional staff, offered eight solutions to the challenges they identified.



	Problem	Solution
1. Universal health care for all in Australia, regardless of visa	It's not guaranteed that if you're in Australia and in urgent need of health care you will receive that care. In emergency departments across the country, signs make clear that unless you have a Medicare card, you will have to pay for medical care received.	A humane approach to provision of medical assistance and care that provides a universal safety net for urgent and emergency care within Australia.
2. A new carer visa category	Parent Visas – contributory or non-contributory – are not meeting the needs of community members. The federal government 2023 Review of the Migration System highlighted that families are waiting for parent visas that never come. ⁴ A growing migrant population has driven demand beyond places available. While recognising that family structures and distributions of care across cultural groups differ, members of the migrant population experience acute and timebound needs for care which are exacerbated when away from family members and others with whom they share long term connections, language and culture.	Create a new carer visa category that has clear categories for qualification. For example, to provide care to a family member who has been diagnosed with terminal cancer, has been significantly injured in an accident or has been told by their doctor to be on bed rest during pregnancy. This could also enable caring for a very young child.
3. Culturally integrated services network to uplift and facilitate cultural and religious needs in care provision	There are underserved populations whose various cultural and religious needs are not well understood by mainstream services. This means services are not accessed at all, services are accessed less than would otherwise be the case or public health messages are not received by members of the community because cultural and religious considerations and practices are not well understood or engaged with.	A network of care providers and volunteers who help uplift and facilitate specific community needs such as cultural meal delivery, end-of-life care, funeral service support, transport for community events, pre- and post-natal care, and health education on topics like the safety of co-sleeping with babies and infants.
4. One-stop shop to assist with retirement and later life planning for care	Ageing, for anyone, is like entering into another land. Ageing when you are a migrant compounds the sense of disorientation. Without signposts, it's hard to plan for the journey. In a world increasingly focused on digital solutions, this is no less the case when it comes to care services. However, so-called digital solutions bring layers of complexity and challenge that don't always result in meaningful outcomes for end users.	Create a one stop shop that would help migrants – the Australian community, too – understand what might be ahead on the journey, choices they can make and how they and their loved ones can plan well for the future.

	Problem	Solution
5. Community health education program	Carers of migrants who are also migrants themselves often find it challenging to navigate care services efficiently and effectively, and miss out on support and services.	Provide better education and information for the community, with the community and by the community. Work with existing community service providers to co-design education programs to improve care services and literacy of carers.
6. Families network forum for navigating and activating care	Navigating and then accessing care is difficult. It's hard to know which information to trust and to find care relevant to needs. We know care services are available, but we're lost trying to find them.	Create a digital resource curated and provided through trusted public apps to help individuals and the community navigate and access care relevant to them. Make it so that there is a seamless connection between the various actors who provide care and generate links with the physical places people go to access care.
7. Creative solutions to workforce shortages	The domino effect of workforce shortages in any one care sector generates a set of pressures on households and communities and contributes to workforce shortages not just in other care sectors, but across the local labour market.	Recognise that siloed thinking about interventions in one sector may exacerbate rather than solve broader workforce shortages. Learn from successes such as student placements that have led to ongoing work in community, and considered use of technology that enables care to be supported remotely. Developed solutions need to be holistic in nature, consider the whole care ecosystem and the relationships between individual components and embedded in established relationships with community organisations and service providers.
8. Care Navigators embedded in community	Shortage of services, as well as difficulties in navigating care systems, matched with long-standing fear and mistrust of formal systems, exacerbate barriers to accessing available care and support in a location.	Working in partnership with local communities, community leaders and people with lived experience, identify new ways to remove barriers to care through community asset mapping and co-creating solutions that draw on existing community assets and knowledges. Allocate resources to community developed care navigation systems that are fit-for-place and commit to the development of new services that enhance access to care and services.

A framework for action

This first phase of the Australia Cares project has demonstrated just what can be achieved when people are given the opportunity and support required to step back from systems and policy settings as they are and to imagine what could be.

The problem definitions and solutions in this report reflect what matters to a cross-section of people involved in care in Australia and two very different communities.

The policy recommendations contained in the report are not only highly desired by members of communities who have suffered from successive policy failures but have the potential to be highly effective if refined and implemented with this same community leadership and university partnership.

Governments at local, state and federal levels now have the opportunity – and need – to look beyond their near-term agendas in which they have sought to address the most urgent and pressing failures in current systems and policies related to care. These systems and policy settings have their origins in the 1950s, yet even measured by the values of decades past they have not succeeded.

Current harms, egregious policy and governance failures must, of course, be addressed, but it's time to transition to a new way of thinking about and doing care policy. It is time to move away from a dominance of neoliberal values that drive policymaking and delivery frameworks modelled on new public management to a greater emphasis

on relationships and the relational economy that can drive innovative solutions for the future.

A coherent, forward-looking framework for action is urgently needed to enable a person-centred approach to care that:

1. is holistic, binding together care, wellbeing and health, and therefore linked to other policy reform agendas
2. listens to people throughout policymaking cycles
3. builds a relational economy
4. responds to community expectations
5. is designed around the strengths and assets of specific cohorts and communities
6. renews public institutions and invites partnerships
7. spreads capital investment across the economy, especially to the forgotten parts.



7. spreads capital investment across the economy, especially to the forgotten parts.

The Australia Cares project has demonstrated such a framework for action is desirable, feasible and viable. As a community-led, multidisciplinary project of the Sydney Policy Lab at the University of Sydney, enabled by philanthropic funding from the Paul Ramsay Foundation, we have also shown the potential for collaborations across sectors and between institutions to provide new solutions within such a framework.

In the project itself, we have piloted various forms of community-led policy development. Drawing on what we've learned, these could now provide the basis for the way forward for care policy in Australia: community-led policies developed and implemented on an iterative basis.

At the Sydney Policy Lab, we are committed to moving forward with communities across Australia on the Australia Cares project, and with this approach. Success will be when care policy enables communities across Australia to flourish in ways that are socially sustainable.

We invite governments and other partners to join us in this collaborative endeavour.



Postscript

An international perspective on care

Sir Andrew Dilnot

Warden of Nuffield College, Oxford. Chair, United Kingdom
Commission on the Funding of Care and Support 2011

Care can be wonderful, a support to living a great life, delivered by individuals, structures and communities that are strengthened and enriched by caregivers and by those cared for. But in Australia, as in pretty much the whole world, the care system is struggling.

Struggling to give care that is desperately needed, struggling to recruit and value those who provide formal care, struggling to support those who care informally and, above all, struggling for the political and public support that is essential if the system is to deliver the human flourishing that should be at its heart.

So, it is a delight to see the Australia Cares report coming to fruition and we should all hope that this marks a period of intense discussion, but above all action. For too long, care has been a neglected sector, and that is long overdue for change.

For us all to get this right, we will need the courage and honesty to face what is plain, but somehow hidden. The need for care has been growing rapidly across the world, both care for younger and working-aged people and care for older adults. This growing need follows directly from massive increases in life expectancy in older adults and great steps forward in enhanced life expectancy for people whose care needs begin early in life. These trends are things to celebrate, but

as we celebrate we must also be honest about what some of the consequences are.

It is a commonplace for politicians and commentators, and members of the public, to assert the amounts of money involved are huge and so nothing can be done. Both parts of such statements seem at least questionable to me. In most countries expenditure on adult care is significantly less than one percent of national income. This will go on rising as populations age, but the idea that this is a large amount of money when compared to, say, the wider health system or the education system is simply wrong. And to the assertion that nothing can be done, we should say that is both wrong, because as this report shows, things can be done, and unacceptable.

One of the central questions is how to balance the responsibility of individuals and the wider community. It is vital to recognise that this is in part a political judgement, so people will take different views of how to balance these two. But there are still things to be said.

Central to care is uncertainty. None of us can know before we are born whether we will be born with a care need. And even as we approach retirement age, few of us can know whether we will have a care need as we age, and almost none of us can know how long such a care need will last. Most people will not have a long or intense period of care in their later lives, but some will. Saving is not an appropriate response – most people could never save enough to cover a long and intense period of care, and most people won't need such provision. So, care is an area, like health, where we want to pool risks. In some nations, health care risks are pooled through private insurance as well as through state provision, and the balance between state and private risk pooling varies a lot across countries. But in no country is there a thriving private insurance market for care, because

the commercial risks associated with offering such insurance for many years into the future are too great. If we are to make this system work, I believe the state has to be involved in providing risk pooling for at least the very high costs that might affect any of us, although will in practice only affect a small minority. With that in place there is scope for individuals, communities and both charitable and commercial bodies to help make a system that works.

We must stop hiding from the need for care, which is why I am so

pleased to see this new report. But reports are not enough. Reports need to be followed by discussion, and discussion by action. Being a country that gets care right could not only deliver huge benefits for that country and its people, but for the rest of the world, as a model of the way in which human flourishing can be achieved alongside other economic goals, and that we can see great care given, by outstanding and properly valued staff in an industry that thrives and innovates, in a country that celebrates all of its population.



Notes

1. Bernice Fisher and Joan C. Tronto, "Toward a Feminist Theory of Care" in *Circles of Care: Work and Identity in Women's Lives*, edited by Emily K. Abel and Margaret K. Nelson. (Albany, NY: State University of New York Press, 1990).
2. Otto Scharmer et al., *The Essentials of Theory U: Core Principles and Application* (Oakland, CA: Berrett-Koehler Publishers, 2018).
3. Adrian Pabst, *Postliberal Politics: The Coming Era of Renewal* (Cambridge: Polity, 2021).
4. Martin Parkinson, Joanna Howe and John Azarias, *Review of the Migration System 2023* (Canberra: Commonwealth of Australia, 2023).



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Reimagining Care

How might citizen-led policy development improve ideas and policy to address the crisis in care in Australia?

People's Assemblies on Care: Bringing people to the forefront of policy development

"Not another royal commission!" is now a common lament. In Australia and around the world, the COVID-19 pandemic made clear that we face a crisis of care. At the same time, Australians, like many others around the world, are losing faith in democracy. They are calling for greater engagement with policymakers to address a perceived failure to tackle the serious global and domestic challenges we face as a nation.¹

To rise to the challenge presented by the dual crises of care and democracy, the Sydney Policy Lab, based at the University of Sydney, seeks to strengthen how care policy is conceived. We seek to do that by inverting the royal commission model of looking at what went wrong, and instead support forward-looking, collaborative policy development that is led by the communities and the people whose lives and livelihoods are most at stake.

Taking inspiration from consumer health movements and person-centred models of care, the Sydney Policy Lab, will convene People's Assemblies on Care to give citizens the opportunity to deliberate on the care policy matters most important to them and come up with new ideas to address the pressing problems within Australia's broken care sector with the

support of expertise from the University of Sydney.

The Sydney Policy Lab believes care-giving and care-receiving are fundamental functions of society. Policy to support these functions cuts across our most intimate and social bonds and determines the extent to which we can all live well and with dignity. The development of care policy therefore demands sustained engagement with affected communities and individuals. When there is an active role for communities in policymaking, a rich diversity of lived expertise is brought to bear on policy design, outcomes and evaluation.

By exploring the potential of deliberative democratic methods, which have been applied with increasing frequency in key OECD countries including, experimentally, in Australia, we hope to develop new means of addressing the dual crises in care and democracy.

With the support of the Paul Ramsay Foundation, the Sydney Policy Lab will initially trial two pilot People's Assemblies on Care in locations where the University of Sydney is part of the community landscape. We look forward to working with communities in Broken Hill and Westmead in New South Wales. Our aspiration is for the People's Assemblies on Care to enable members of the public to write their own agenda for care, deliberate over relevant evidence, and determine key priorities for

the future of care policy, thereby improving outcomes and, in turn, strengthening our democracy.²

What is deliberative democracy, and what can it achieve?

In Australian representative democracy, citizens elect their representatives to form a parliamentary body. Those elected representatives then deliberate on matters in parliament, including on policy made through legislation. Parliamentary democracy allows for representation and deliberation, subject to party discipline, but limits the ongoing direct participation of citizens.

Deliberative democratic methods complement and strengthen representative parliamentary democracy by creating additional opportunities for members of the public to directly and carefully weigh and discuss important public questions. What has been described as a "deliberative wave" prioritises discussion among members of the public, learning and collaborating with the support of trained facilitators and experts to form collective recommendations for policymakers.³ Possible formats include citizens' assemblies, citizens' juries and citizens' panels. Each of these provide opportunities to arrive at better solutions to policy problems because they tap into a diverse range of community perspectives that are tested through social interactions with others.

Careful determination of who participates in deliberative activities ensures that those who are normally excluded from policymaking are included. Deliberative processes can also strengthen support for policy outcomes in the broader community because people are more likely to trust, and consider legitimate, a decision that has been informed by their fellow citizens, as opposed to decisions made by government at a distance from community needs.

Piloting the People's Assemblies

The pilot People's Assemblies will be held in two locations. The first pilot takes place in the regional town of Broken Hill in far-western NSW, the home of our colleagues and research partners at the University of Sydney Broken Hill University Department of Rural Health.

The second pilot takes place in Westmead in western Sydney, where the Sydney Policy Lab collaborates with University of Sydney colleagues based at the Westmead Health Precinct.

The two phases of the People's Assemblies

Phase 1: Community agenda setting

On a mid-week evening, the Assembly members in each location will be invited to reflect upon what care means to them. The groups will then discuss the challenges in care in the communities represented.



Pilot 1: Broken Hill

Broken Hill is within the Far West Local Health District which covers almost 200,000 square kilometres of remote NSW. The District is the most sparsely populated in New South Wales, with 62 percent of its estimated 30,000 residents living in Broken Hill. The remainder of the population live in agricultural towns along the Murray River, in small remote communities of between 80 and 800 people or on stations. It also has the highest proportion of Aboriginal residents at 12 percent. The District reports that "population is decreasing, ageing and experiencing significant morbidity related to lifestyle factors and chronic illness."⁴

"Responding to the demand for greater democratic input from communities, each of the two pilot People's Assemblies will occur in two phases. In each phase, approximately 20 members of the public will come together to reflect on the most pressing public questions related to care in their everyday lives and communities. By exploring the issues relevant to participating individuals and their broader communities, we seek to uncover obstacles to the effective delivery of care, chart the social and material resources available to the communities in question, and identify new avenues for community-led reform of the care sector."

Dr Kate Harrison Brennan
Director, The Sydney Policy Lab



Pilot 2: Westmead and surrounds

Located approximately 28 kilometres from the Sydney central business district, Westmead is a suburb in the demographically diverse urban domain of western Sydney. The suburb is home to the Westmead Health Precinct, one of the largest health, education, research and training precincts in Australia. Westmead and surrounds are home to a large community of Indian-born residents. Neighbouring Harris Park, a suburb where almost half of residents were born in India, has recently been renamed Little India in honour of its diaspora communities.

By the end of this session the groups will be able to identify a care issue that matters most to them and their local community upon which they will deliberate in the second phase of the Assembly.

Phase 2: Deliberation and recommendations

On a weekend day, the Assembly members from the first phase will be reunited and provided with resources, including insights from diverse experts, to enable their development of new policy ideas and recommendations. Stipends, meals and all necessary materials for participation will be provided to participants in the People’s Assemblies.

The Sydney Policy Lab is excited to put this democratic innovation into practice. We will make every effort to ensure that participants have an engaging experience, and perhaps even some fun, as we experiment with this venture in deliberative democracy.

What happens after the People’s Assemblies on Care?

We are working to ensure that there are multiple paths to impact for the

policy recommendations developed in these People’s Assemblies on Care. Our priority is that these deliberations inform and engage policymaking processes in Australia.

We envision working with more communities who wish to hold a People’s Assembly on Care and establishing a People’s

Commission on Care, housed at the Sydney Policy Lab. The Commission would act as an anchor, a resource and an innovator for the forward-looking, community-led approach to care policy development in the People’s Assemblies, supporting Australia’s communities to play an active role in care policy development and reform.

Notes

1. Gerry Stoker, Mark Evans and Max Halupka, *Trust and Democracy in Australia: Democratic Decline and Renewal* (Democracy 2025, 2018), apo.org.au/node/208536. See also: “2023 Edelman Trust Barometer: Australia Report,” Edelman, 2023, edelman.com.au/trust-barometer-2022-australia.
2. See: Claudia Chwalisz, “Good practice principles for deliberative processes for public decision making” in *Innovative Citizen Participation and New Democratic Institutions: Catching the Deliberative Wave* (OECD, 2020), doi.org/10.1787/339306da-en.
3. Chwalisz.
4. “Far West,” NSW Health, health.nsw.gov.au/hd/Pages/fwlhd.aspx.

Project Methodology

Guiding principles

For the Australia Cares project, we designed and developed the two streams of community-led policy development around a small number of shared principles.

See the University as a key public institution

Universities are critically important public institutions that are central to our society and democracy. As self-governing communities of scholars, members of universities are united in the shared purpose of pursuit of knowledge and teaching. Ideally, a university is able to be a community of communities, inviting and supporting plurality, deliberation and formation of citizens.

Value people, relationships, Country and places

Across the Care Labs and People’s Assemblies, we held the principle that people, relationships, Country and places matter a great deal. We worked for more than a year in the establishment phase of the project to build relationships and attend to the specific experiences, needs and interests of those in the communities with which we planned to work. We integrated that commitment into our project governance with the composition and membership of the Australia Cares Advisory Group.

We convened the Care Labs with people from different geographies, roles and life experiences, doing

so online to ensure greater access to the Sydney Policy Lab. We were aware of the need to prioritise opportunities to acknowledge the specific contexts in which Care Labs collaborators live and work. We invited them to collaborate in the Care Lab not only in their professional capacity, but contributing their personal and lived experiences. Part of this process involved ethnographic follow-up interviews, where we reflected with Care Labs collaborators on the aspects of their experience and life histories that they felt unable to share in a collective space, but saw as important.

For the People’s Assemblies, we built relationships with University of Sydney colleagues at Westmead and the Broken Hill University Department of Rural Health (BHUDRH), as well as those who work at Camperdown and other campuses with related responsibilities. We then built relationships with people and organisations beyond the University in those two locations, travelling to Broken Hill and Westmead on a number of occasions.

We sought the support of the Broken Hill Aboriginal Community Working Party for the project and the involvement of members of the Working Party and Maari Ma Aboriginal Health Corporation at the Assembly. We then co-facilitated the Assembly with our colleague, Mariah Goldsworthy, who is the First Nations Project

Officer at the BHUDRH. Both Assemblies began with a Welcome to Country and we look forward to integrating the spiritual connection to and commitment to care for Country in our conversation at the second phase of the Assembly at Broken Hill.

Seek plurality, invite diverse expertise and distinctive contributions

The Sydney Policy Lab was founded on the belief diverse expertise makes for better policy. This project builds on those foundations. As a multi-disciplinary initiative of the University of Sydney, we are tasked with fostering and supporting collaborations to address some of society’s biggest challenges. This was reflected in the project design as a whole and the academics, disciplines and methods involved in the two streams of work.

The project’s academic leads, united by participatory methods, brought distinctive approaches to the work: Professor Brendan McCormack, head of The Susan Wakil School of Nursing and Midwifery, is experienced in person-centred and creative methods, while Dr Kate Harrison Brennan uses deliberative democratic and design thinking approaches. Academics from 13 disciplines were involved across the two streams.

Both the Care Labs and the People’s Assemblies invited diverse expertise and distinctive contributions. The Care Labs involved 38 people.

This included people with knowledge from personal experience, community knowledge, knowledge as a practitioner, organisational knowledge and academic knowledge. Those who took part in the People's Assemblies were randomly selected against criteria to ensure diversity of age, gender, socio-economic background and life experience.

Leaders of community groups with an interest in care policy development participated to lend their expertise as practitioners and community-based service providers. A range of interdisciplinary academics were invited to contribute, facilitate and tailor specific methodological approaches, as well as to interpret findings, so we ensured a plural process of knowledge production.

Create a positive civic experience of being and working together

Opportunities to come together and work for a common, civic purpose are increasingly rare. We identified the importance of creating spaces, whether a Care Lab or People's Assembly, which would maximise the opportunity for collaborators to have a positive experience of being and working together. Part of this process involved paying attention to the detail in how spaces were set up, and how people were invited into them. Processes such as offering food, ensuring an accessible location and time,

and sharing creative materials were essential to generating an atmosphere of belonging and openness, and to creating safe spaces for knowledge production.

In the Care Labs, we sought to do so by clearly marking for collaborators that we were seeking to enable a way of being and working together that was different from the common experience of online workshops in which collaborators can be passive recipients of dense material presented by 'experts'. For example, we sent a Care Lab pack ahead of the sessions with a guide, creative materials and a snack. The initial signalling continued in the style of facilitation and theoretically-informed modes of interaction.

For the People's Assemblies, we began with welcome refreshments and shared meals sourced from local catering popular among the community we were working with. At Westmead, we found an Indian violin player to play during the refreshments and dinner time. We drew on design thinking while designing the deliberative sessions to maximise the experience of those who took part.

For example, our InTensions activity involved us marking out a continuum on the floor in the room, sharing pre-determined propositions about care and asking collaborators to move themselves across the room to take a place on the continuum. We then engaged collaborators

to share the reasons they took their position and facilitated the conversation to broaden understanding in the room.

Enable opportunity for shared contemplation

Care is foundational to who we are as persons and as a society. Australia Cares deals in the intimacy of a person's humanity – it asks what a flourishing life is. The project then draws communities together to contemplate what is needed for flourishing. In an area of policy that is so personal but also communal, and that has been dominated by the need to do retrospective top-down analyses of policy failures, we hope this is a contribution to the life of these communities as well as an opportunity to amplify their voices

Attend to the inner worlds of collaborators and their social contexts

Because the nature of care is highly intimate and social, we wanted to be attentive to the inner worlds of collaborators and their social contexts. In the Care Labs we did so primarily by using Theory U. In the People's Assemblies, we used design thinking methods to enable collaborators to create Care Maps, use silhouettes of people as prompts to speak about people and care in their own lives, and played a guessing game – Whose Life? – to empathise with others and develop profiles of care users. We linked both streams of work to our Stories of Care stream which uses an ethnographic



method. An ethnographic approach is aimed at understanding the values, morals and expectations that shape experiences of care, and the relationships through which care is practiced. Dr Nikita Simpson, an anthropologist in the project team, attended a Care Lab and the first phase of the People's Assembly at Broken Hill. We invited collaborators in the People's Assembly and Care Labs to share their stories of care, reflecting on topics and experiences that informed their contribution to shared spaces.

Hold the space and opportunity for embodied expression of different, dearly-held values and views

While the methods and emphasis of the Care Labs, although held online, were more weighted towards embodied participation, the People's Assemblies were also guided by this principle, which was fulfilled through the use design thinking and participatory methods, alongside the more orthodox use of deliberative methods for a People's Assembly.

In the Care Labs, this looked like a dance between the use of creative individual and group methods – clay, poetry, metaphor and inflammatory essays, for example – matched with deep thinking and reflective discussions. In the People's Assemblies, this looked like systematic approaches to engaging in group dialogue through structured deliberative practices, alongside creative methods that allowed people to pen up and share intimate details of their lives without feeling exposed.

Enable emotional engagement with policy issues

Through the design of opportunities to engage, active facilitation, support and examples given, we sought to enable emotional engagement with the subject of care and the policy issues. This often required modelling emotional engagement through mini-stories told by facilitators or examples shared. When collaborators engaged emotionally with the subject, topics for discussion or

policy issues we sought to ensure spaces were able to hold emotion, and we allowed collaborators to follow up on particularly sensitive issues through one-on-one 'stories of care' interviews.

Working with flow

Through our focus on engaging with our inner world of embodied knowing about care and externalising this world through creative and cognitive processes, we enabled a flow of energy to emerge between collaborators. While we worked with structured plans for the Care Labs and People's Assemblies, we were flexible with how these unfolded based on the flow of engagement with and between collaborators. This flexible approach to engagement meant we were able to stay focused on what was important in the moment and facilitate the emergence of new insights in a systematic and thoughtful way.



Care Labs

We adapted the methodology of Theory U to inform the working of the Care Labs and the focus on ensuring meaningful engagement from all collaborators. Theory U is an awareness-based methodology for changing systems that challenges us to connect with our internal world – our beliefs, values, experiences and assumptions – to engage fully with the external world. This means we need to be aware of our own beliefs, values, biases, prejudices and assumptions before we can start to understand how best to bring about change in the world. The methodology is informed by transformative principles of ‘being before doing’ and recognising we all have blind spots when it comes to changing ourselves and others.¹

Blind spots such as lacking awareness of the influence of our values on how we behave and act or how our unconscious prejudices shape the decisions we make. Theory U contends that to act effectively we need to know the source from which we operate when we act, communicate, interpret or think. It is easy to see what we do – results – and how we do it – process – but we are usually not aware of the ‘why’ in our doing. That is, what has really influenced us in the process or the source of our influences.

It is easy to advocate for being explicit about the sources that

influence us as persons but less easy to access those sources. We are often unaware of them – they can be unconscious – or, if we become aware, we can ‘shut down’ because we are unable to cognitively process them. Working with Theory U challenges us to use

different methods of engagement that take us through a process of becoming aware over time in a systematic way by using practical methods and tools for change makers to build collective capacity. Doing this creates a new narrative for evolutionary societal change.

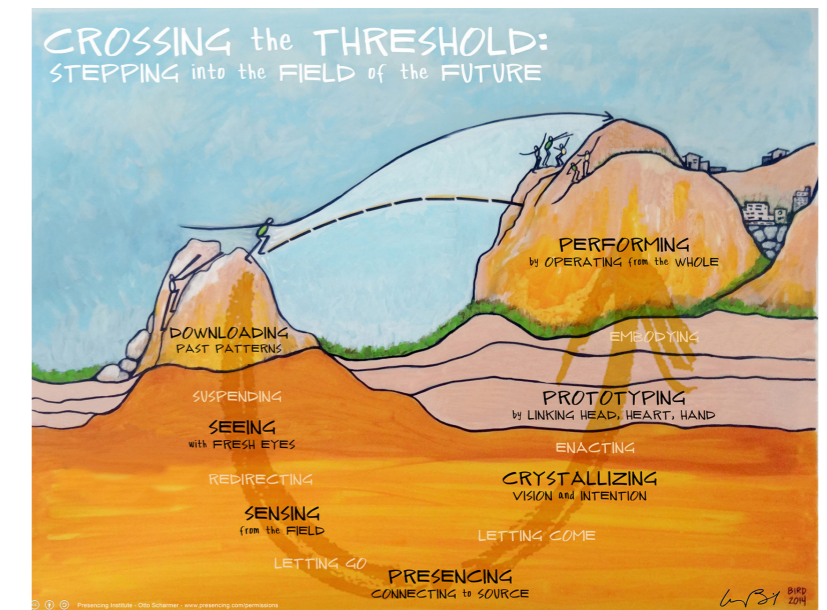
Left: Timeline of 2023 Care Labs. Right: Theory U illustration courtesy of the Presencing Institute, licensed under Creative Commons BY-SA 3.0 Deed.

Because of this deep emotional engagement with change processes, bringing about transformation is not a linear process but is instead a U-shaped movement.

In essence, Theory U combines principles derived from participatory action research, design thinking, mindfulness and civil society movements. These principles are consistent with the community and societal change underpinnings of Australia Cares and our collective intention of elevating care in society. We shaped the work of the Care Labs through the five collaborative commitments of Sharmer and colleagues, to provide us with a framework to guide our movement around ‘the U.’² Importantly, our intention was to use the labs to get to the bottom of the U – presencing – where we could all be content our collaborative explorations resulted in a shared understanding of care principles we could all ‘settle with’.

The design of each Lab was influenced by the practices that underpin Theory U and systematically take us to a point of presencing.

Co-creating: Facilitating practice processes that engage with a range of resources and forms of knowing. Our practices had a clear purpose that were continually evaluated to enable evolution and progress. We encouraged prototyping that enabled all collaborators to be inspired and creative.



Co-evolving: Continuous development of self, the team, the internal environment and the external environment. We recognised persons are in a state of becoming and will experience and voice this development in different ways. Engagement with the wider context of community and care services is fundamental.

Co-initiating: We adopted a deliberate intention to act and move forward, informed by attentive listening to others, to ourselves and to what emerged from the Labs that helped bring together individual and shared commitment for action.

Co-presencing: We committed to ‘being present’ to help us connect with our deepest sources of inspiration and stillness to learn from the past, make sense of the present and move to the future. We engaged in collective reflexive learning.

People’s Assemblies on Care

In 2023, the Sydney Policy Lab worked with two communities where the University of Sydney has

a physical presence and campus: Westmead in western Sydney and Broken Hill in far-west New South Wales to hold People’s Assemblies on Care. These People’s Assemblies formed a distinctive stream of community-led policymaking and were designed as a response to the sentiment that members of the Australian public were tired of successive royal commissions doing post-mortems of policy failures in key policy areas related to care.

Throughout the first year of the Australia Cares project we had heard there was deep interest in inverting the model of a top-down, retrospective analysis of systems and policies that had failed to deliver on community expectations. Given the failures in areas of policy related to care had been so long-running and systemic, there was also a sense it would be important to enable community-led conversations to express what they value and have reason to value, setting the agenda that would enable subsequent policy development.

Since providing and receiving care is so intimate, and also social,

we looked for methods that would allow for greater representation of groups normally more peripheral in national conversations and greater deliberation of the issues important to them.

We selected a deliberative method to create a microcosm of a local community or a 'mini public'. Inspired by a wave of deliberative democratic exercises that have sprung up around the world, we sought to design the People's Assemblies on Care to:

- maximise the experience for citizens to engage with one another and care policy
- support those gathered to decide what is important for them to deliberate upon
- bring together academic and community expertise in service of the community's agenda for deliberation
- enable those gathered to develop new policy ideas and recommendations
- enable academics taking part to learn with community members.

In prioritising the experience of community members, we purposefully chose to deprioritise rigor in the deliberative method itself. Practically this meant we chose a more informal approach without formal testimonies, designed activities that sought to enable a movement from precognitive to cognitive

engagement with the topics and subject matter and did not conduct polling of collaborators before or after the Assembly. We worked with Fred Dust, former Global Managing Director of IDEO, now Founder of Dust & Co., and Rob Healy, also from Dust & Co. to use design thinking methods to create participatory and deliberative activities for the Assemblies.

To select community members to take part in the Assemblies, we worked with Rebecca Huntley from 89 Degrees East to design the sample. In turn, she worked with a subcontractor to recruit 20 community members for each Assembly. In Broken Hill, the recruitment protocol was for a broadly representative cross-section of the Broken Hill population, using Australian Bureau of Statistics data as the reference point. We then adjusted those quotas to seek an equal representation of females and males, a higher proportion of Aboriginal and Torres Strait Islander people than in the general Broken Hill community, and people with experience of chronic illness.

In the final group recruited in Broken Hill, there were eight people identifying as Aboriginal and Torres Strait Islander – Indigenous Australians make up approximately 10 percent of the Broken Hill community – and approximately eight people known to be experiencing chronic illness. In Westmead, we focused selection

on members of the community who have an Indian background. This was informed by insights from the first stages of the Australia Cares project in which those we spoke with in government and communities highlighted the need for policy development that reflected the values and expectations of culturally and linguistically diverse communities. In Westmead and the surrounding suburbs of Wentworthville, Parramatta, Harris Park, Rosehill, Gurraveen, Pendle Hill and Toongabbie up to 45 percent of the community are of Indian descent. For the Westmead Assembly, we recruited 20 people from the Indian diaspora from these suburbs. The protocol was set so collaborators could be born in India or Australia and be citizens or non-citizens. We also sought an equal representation of females and males and a cross-section of this community by age. In recognition of the dominant cultural practice of living in multigenerational households, we specifically sought families living in such settings and defined this as more than one generation of adults living together.

The Assemblies were designed to run in two phases in each location. Phase one, a three-hour evening workshop, was an exercise in consultation and agenda setting which set-up for phase two, an all-day workshop on a weekend to deliberate on policy solutions.

In Broken Hill, Professor Brendan McCormack, Dean of the Susan

Wakil School of Nursing and Midwifery facilitated the three-hour session with First Nations Lead at the BHUDRH, Mariah Goldsworthy. The Assembly was supported by Richard Weston and Nola Whyman from the Maari Ma Aboriginal Health Corporation and Corina Kemp, a representative of the Far West Local Health District and member of the Broken Hill Aboriginal Community Working Party. Richard Weston, Nola Whyman and Corina Kemp assisted with the facilitation of small group discussions and supported our lead facilitators as community observers, providing reflection and clarification throughout the session.

The Assembly benefited greatly from their deep understanding of community needs and of care systems. Dr Nikita Simpson, an anthropologist, joined the Sydney Policy Lab team in facilitating deliberations in smaller groups. Dr Simpson was also available to document the care stories of those who gathered and wished to share their stories in greater depth.

From this first phase of the People's Assembly in Broken Hill, a key question was discerned: How

do we capitalise on community resources and forms of knowing to co-create solutions that enable effective navigation of care systems in Broken Hill?

Phase two of the Broken Hill People's Assembly on Care was scheduled for October. At the request of Aboriginal and Torres Strait Islander members of the community and the Aboriginal Community Working Party following the referendum on The Voice, we postponed the Assembly to allow them time to grieve the outcome.

In Westmead, we held the Assembly on Care at the University of Sydney's Westmead Clinical School which is inside Westmead Hospital. Professor Brendan McCormack facilitated the three-hour session with Professor of Pharmacy Practice Bandana Saini. Phase one in Westmead was supported by Mereline Murimwa-Rarami from SydWest Multicultural Services and by Sapna Lazarus from SEVA International, a not-for-profit focused on serving the South Asian community. The Assembly was enriched by their understanding of care systems and perspective

on community needs. Associate Professor Myra Hamilton joined the Sydney Policy Lab team in facilitating deliberations in smaller groups.

From this first phase of the People's Assembly in Westmead, the driving question for subsequent deliberation was developed: What transcultural issues and challenges get in the way of an effective eco-system of care and support that enables extended family systems to flourish?

The People's Assembly reconvened in early November and was opened by Professor Kathy Belov, University of Sydney Pro-Vice-Chancellor, Global & Research Engagement. The Assembly was supported by the community organisations and lead facilitators from phase one as well as by University of Sydney staff: Chandana Guha, consumer representative and research assistant, Centre for Kidney Research, School of Public Health; Dr Vaibhav Tyagi, Senior Research Fellow, School of Nursing and Midwifery; Associate Professor Murray Fisher, School of Nursing and Midwifery; and Dr Anita Van Zwieten, School of Public Health.

Notes

1. Tara Brach, *Radical Compassion: Learning to Love Yourself and Your World with the practice of RAIN* (London: Rider Books, 2020); Paul Gilbert, *The Compassionate Mind* (London: Robinson, 2010); Jon Kabat-Zinn, *Coming to Our Senses: Healing Ourselves and the World Through Mindfulness* (London: Hachette Books, 2006).
2. Otto Scharmer et al., *The Essentials of Theory U: Core Principles and Application* (Oakland CA: Berrett-Koehler Publishers, 2018).

illuminating Lived Experience

Exploring researcher perspectives on co-design through participatory methods

The lived experiences of people involved in care – from informal and formal care workers to the people they support – is foundational to the Australia Cares project. To learn from the ways people with lived experience are included in co-design and research methods, the Sydney Policy Lab initiated a reflective research program on lived experience methods.

Through a series of interviews, dialogues and collaborative writing processes, co-authors of a forthcoming report explored tensions between different approaches and core concepts underpinning lived experience methods and shared examples of those methods in practice.

This summary shares key insights that emerged from that discussion. It poses questions that may help guide researchers and policymakers seeking to engage people with lived experience and three core principles we believe are required for such engagements.

Defining lived experience research

The concepts of co-design and lived experience research are often confused or used interchangeably. Through our dialogue we explored their overlap and what makes them different.

Co-design, and other methods like co-production, seek to co-create. Co-design is a type of research

method that seeks to privilege or centre the voice of community participants with lived experience by ensuring they are equal collaborators and full partners throughout the full research process, from identifying research priorities, designing methods and data collection, interpretation and analysis, all the way to shared authorship and implementing impact strategies.

Lived experience research is a broader category in which researchers seek to privilege the voices of people with lived experience but not necessarily to co-create. For example, people with lived experience may only be involved at specific stages of a research process, perhaps as members of an advisory group, participants in workshops or subjects for data collection. Different 'levels of participation' in research exist and depending on how people with lived experience are involved in the research they may have limited power to exercise influence over the project and its outcomes.

In our report we argue lived experience research methods are not always co-design, yet co-design should always include lived experience people and communities deeply and creatively throughout the research process.

Many of us are concerned the language of co-design can be used for other consultative practices.

When engagement with lived experience participants is a tick box exercise, rather than a meaningful process that emancipates communities, it is not co-design.

There is no formula for lived experience research. To realise the emancipatory potential of recognising and building knowledge centred on people's lived experience, methods will look different for different people. Our aim is to encourage researchers to be creative in the ways co-design and lived experience are approached while being true to the critical roots of participatory methodologies.

Rather than being prescriptive, the principles and practices developed in our research are offered as a guide – a starting point for play.

Guiding questions for engaging lived experience

Through our dialogue we distilled three questions that can guide research design and elicit reflection and action from researchers and policymakers engaging lived experience, including ourselves:

1. How are we ensuring our relationship practices with persons and communities are reciprocal and not extractive?
2. How are we including people from diverse communities, at their discretion, as active and



equal members of our research teams in ways that allow them to exercise agency and autonomy?

3. How are we collaboratively identifying and evaluating tangible evidence our collaborators benefit from their involvement and the research outcomes?

Three core principles

Through our dialogue, three core principles and values emerged as foundational to engaging people of diverse experiences.

1. Critical reflection and ongoing learning

Commit to critical reflection and ongoing learning at personal and institutional levels.

Lived experience research requires researchers to question values and assumptions, be open to changing direction, and learn from the people and communities they are working with. Here we mean researchers to include

researchers with lived experience of the topic under investigation, with and without qualifications. Lived experience methodologies start with a process of critical reflection on the position of those who are initiating the policymaking or research. This means being aware of:

- our own power and social position as well as the historical and cultural context from which our privilege derives as, for example, researchers at the University of Sydney

The Language of Care

A strengths-based, person-centred guide to changing terrain

Dr Juliet Bennett

- people who have not benefited from historical circumstances
- types of skills and knowledges that have been cultivated and privileged in a western capitalist society
- ongoing impacts of racism, colonialism and imperialism.

Moreover, it means recognising the:

- ableism and stigma that overlooks the abilities of people with lived experience of disability
- ongoing injustices Aboriginal and Torres Strait Islander peoples face, the horrific impacts of white Australian policies that have denied Indigenous people their culture, languages and ways of knowing
- Country on which we work and the ways our lives are entangled in the wellbeing of the ecosystems of which we are a part
- destruction patriarchy has caused and its ongoing impact on our hidden values and assumptions.

This is the context that we live and research in. We participate in the continuing evolution of this culture and context. The first principle of lived experience research is a call for continuous critical self-reflection, learning and improvement.

2. Meaningful inclusion

Commit to sharing power and ensuring people with lived experience and communities are involved and in the lead throughout the research lifecycle. Involve people in inclusive and generative ways, wherever possible on terms they decide.

We should consider how people with lived experience are being included throughout the design or research process. This means including people with lived experience as early as possible and being open to those people or communities changing the framing or research question.

They are the closest to the topic of concern and their knowledge is to be privileged. There are many ways to do this. Our full report showcases some of these methods, drawing on our own experience with co-researchers, co-designers, lived experience-led research, power analysis and consulting lived experience advisors.

3. Evolving cultures and institutions

Commit to involving the cultures and institutions engaged in this work to properly and ethically value, respect and benefit people and communities of diverse lived experiences in long-lasting ways.

Including lived experience in research requires investing additional time and money in relationships with involved people and communities in authentic and reciprocal ways. Approaches that are tokenistic, extractive and exclusive must be avoided. Priority should go to ensuring people and communities benefit from their involvement in the research process and the outcomes.

Research culture and our institutions have not historically valued people with lived experience. This final core principle articulates the need to continually evolve cultures and institutions to ensure they value, respect and benefit people and communities of diverse lived experiences in long-lasting ways. This includes a focus on challenging systems and structures that perpetuate injustice.

The language we use reflects hidden attitudes and values. Language can make people feel good or bad, powerful or powerless. Transforming care requires us to reflect on the words we use and learn how we can use words to make people, including ourselves, feel supported to live our best lives.

This top-level exploration of the language of care draws on and points to language guides specific to different areas including First Nations peoples, disability, mental health, and recovery from alcohol and other drug addiction. We highlight a few commonalities across these areas, focusing on three principles: (1) start with the person, (2) focus on strengths not deficits and (3) reflect critically on contexts as an ongoing learning process. We recognise a map is not the terrain, all language guides are incomplete and the language of care will continue to change in our changing world.

1. Start with the person

People are more than their diagnosis, age, job or disability. These are just one aspect of a person and their identity. When making language choices we should consider not only how we describe a person receiving care or support, but all the people they are in relationships with, including family, friends and support workers. It is important to respect the rights and dignity of each person.¹

Language that reflects an orientation to people and their agency starts with the person, and descriptive labels can follow. One might talk about:

- ‘a person with disability’ not ‘the disabled’
- ‘an older person’ not ‘the elderly’ or ‘the aged’
- ‘a person experiencing homelessness’ not ‘the homeless’
- ‘a transgender person’ or ‘transgender people’ not ‘a trans’
- ‘people who are vision impaired’ not ‘the blind’
- ‘a person who has schizophrenia’ not ‘a schizophrenic’
- ‘a person with paraplegia’ not ‘a paraplegic’
- ‘a person with a dependence on ...’ not ‘an addict’ or ‘an alcoholic’
- ‘a child with learning disability’ not ‘a slow learner’

The point of this principle is to avoid words, narratives and assumptions that reduce a person to one aspect of their personhood. Instead, draw attention to the many dimensions that make each of us who we are.

2. Focus on strengths not deficits

No one wants to be thought of as a ‘problem’ that someone else is supposedly going to ‘fix’. A ‘deficit’

view of a person or community focuses on negative experiences and depicts people as in need of others to provide solutions or care. This is linked to low societal expectations of capabilities and can lead to people losing independence, choice and control in their lives.²

In contrast, a strengths-based approach focuses on a person or community’s positive experiences, such as what a person likes about their lives or when relationships are at their best. This directs attention to the many existing strengths a person or community has and their agency to solve problems that impact them.

Strengths-based approaches have been applied in many areas including recovering from sickness, drug rehabilitation, government services, international aid, people with disability and survivors of family abuse. Here are some examples of the language shifts a strengths-based approach could entail:

- only referring to a person’s disability or illness when it is relevant
- ‘person or people with disability’ not ‘person with a disability’ or ‘people with disabilities’³
- ‘a person with AIDS’ not ‘AIDS victim’ or ‘a person suffering from AIDS’
- ‘a child with disability’ not ‘a child crippled by ...’

- 'person who survived ...' not 'a victim of ...'
- 'person who has multiple sclerosis' not 'person afflicted by ...' or 'person suffering from ...'
- 'person with an intellectual disability' not 'intellectually challenged' or 'mentally handicapped'
- 'person with a conviction' or 'incarcerated person' not 'ex-offender' or 'the incarcerated'
- 'person seeking citizenship' not 'illegal immigrant'
- 'providing meaningful opportunities' rather than 'helping disadvantaged'
- 'priority population' not 'at risk' or 'vulnerable'
- 'lower income' or 'higher income' countries not 'third world' or 'first world'

Language guides on disability recommend avoiding language that suggests pity, perpetuates stereotypes or implies people with disability have a lower quality of life or want to be 'normal.'

Equally, describing people with disability or people who support them as 'inspiring' and often implying that others should be grateful that they don't have a disability, or that a person with disability achieved something 'despite their disability' assumes a low expectation to begin with. Use neutral language instead and avoid made-up terms like 'differently-abled' and 'special needs' which are ableist and patronising.⁴

This principle emphasises that the questions we ask, their framing

and the assumptions made by our word choices have a real impact on people. Focusing on a person's strengths provides a starting point for building on those strengths in creating the life that person wants to live.

3. Reflect critically on contexts

All our experiences take place in social, economic and environmental contexts. Reflecting on the context of language invites a reflection on power and the public dimensions of personal challenges. An example is shifts in language around gender resulting from feminist's critical reflection on context and power over the past century.

In disability, there has been a shift away from a 'medical model' that defines disability in terms of individual 'deficits' in relation to a medically-determined spectrum and assumes experts need to look after people with disability. The contrasting "social model of disability" defines disability in relation to specific physical, social and cultural infrastructures that inhibit – dis-able – a person's abilities.⁵

Critically reflecting on language across cultures and history reveals that the concept of disability emerged from and was defined in the context of industrialisation. This is illustrated by the fact there is no word for disability in Aboriginal languages.⁶

Another example is the public dimensions of mental health. The media, economic pressures and even climate change can trigger mental illnesses such as anxiety,

depression and bipolar. Reflection on the language we use to refer to mental health can help institutions like schools and workplaces evolve to better support neurodiversity and everyone's mental health.⁷

Critical reflection may inspire language changes, including:

- 'person without disability' not 'able-bodied'
- 'a child without disability' or 'non-disabled person' not 'able-bodied' or 'normal'
- 'brain difference' or 'neurodiversity' not 'mentally-ill'
- 'people' or 'citizens' not 'consumers'
- 'police officer' not 'policeman'
- 'human' rather than 'man' as a collective noun for humans
- 'Aboriginal person' or 'Aboriginal people', Torres Strait Islander people, or a specific language group not 'Native,' the acronym 'ATSI,' 'Aborigine,' 'Aboriginal(s),' or 'Islanders'
- adopting gender-neutral language such as 'invite your spouse or partner' rather than 'invite your husband or boyfriend'
- acknowledging diversity through use of plurals such as describing Aboriginal and Torres Strait Islander 'histories,' 'perspectives,' and 'ways of being'
- capitalising words for respect, including 'First Nations,' 'Country,' 'Land,' and 'Traditional Owners'

The principle emerging here is that gender, disability and brain differences are part of human diversity. Our social, economic

and environmental contexts and practices can help or hinder that diversity and a person's ability to thrive. The ongoing process of critical reflection about language involves building relationships and listening to people who are being described. There are exceptions to every rule and principle, including these examples. Some people choose to put identity first and say 'disabled person'. Some groups of people have reclaimed words that were previously derogatory, such as 'queer' and the 'mad movement'. However, these are in-group terms and one wouldn't refer to a person

as queer or mad unless they have told you that's how they identify. Some words, such as Aunty and Uncle for First Nations people, should only be used when invited to. Relationships and communication are key to adapting our language to each other's preferences.

Transforming how we care

Language is intertwined with power dynamics and social norms. There's value in reflecting on the words we use, what we mean by them and how others receive them. Person-centred,

strengths-based language helps to challenge and transform power dynamics for greater equality and justice. The language we use about care is always changing. Critical reflection may ask us to reconsider whether to use the word 'care' itself! Reimagining care requires a commitment to reflecting like this as an ongoing learning process.

Language guides that informed this piece

- Mental Health Coordinating Council. Recovery Oriented Language Guide. 3rd ed. 2022. <https://mhcc.org.au/recovery-oriented-language-guide-3rd-edition/>.
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- People with Disability Australia. PWDA Language Guide: A guide to language about disability. 2021. <https://pwd.org.au/resources/language-guide/>.
- Reconciliation Australia. Demonstrating inclusive and respectful language. 2021. <https://www.reconciliation.org.au/wp-content/uploads/2021/10/inclusive-and-respectful-language.pdf>.
- Sum of Us. A Progressive's Style Guide. 2016. <https://interactioninstitute.org/wp-content/uploads/2016/06/Sum-Of-Us-Progressive-Style-Guide.pdf>.

Notes

1. Brendan McCormack and Tanya McCance, Person-Centred Practice in Nursing and Health Care: Theory and Practice (United Kingdom: Wiley Blackwell, 2016).
2. Marno Retief and Rantoo Letšosa, "Models of disability: a brief overview," Theological Studies 74, no. 1 (March 2018).
3. This is because disability is an uncountable noun like tea, knowledge or beauty, not a specific condition.
4. People with Disability Australia, PWDA Language Guide: A guide to language about disability (2021), <https://pwd.org.au/resources/language-guide/>.
5. Theresia Degener, "Disability in a Human Rights Context," Laws 5, no. 3 (August 2016); Colin Barnes, "Understanding the social model of disability: Past, present and future," in Routledge Handbook of Disability Studies, ed. Nick Watson and Simo Vehmas (New York: Routledge, 2020).
6. While there are "factual references to a person's functioning capacity within a community," such as deaf or blind, these terms are not pejorative. Instead, they reflect "an acceptance of diversity and difference." Scott Avery, Culture is inclusion: a narrative of Aboriginal and Torres Strait Islander people with disability (Sydney: First Peoples Disability Network, 2018), 2, 4.
7. Amanda Tattersall, "Our collective mental health is stuffed, and it's more than just a medical problem," The Shot, August 10 2022, <https://theshot.net.au/opinion-news/our-collective-mental-health-is-stuffed-and-its-more-than-just-a-medical-problem/>.

Inflammatory Statements on Care

*Inspired by Jenny Holzer's
Inflammatory Essays*

Co-authored by
Australia Cares collaborators

15 August 2023

As she commenced a series of posters for pasting directly onto gallery walls by the hundred, artist Jenny Holzer sought out topics "that were unmentionable or that were the burning question of the day." Inspired by Holzer's work, Australia Cares collaborators working on the burning questions of care co-authored the three inflammatory statements on these pages. Like their namesakes, these statements aim to provoke, bursting with the immediacy of emotions around care and capturing the personal intensity of care experiences often elided policy documents.



Photograph of Jenny Holzer's Inflammatory Essays on display at the Tate gallery courtesy of C-Monster, licensed under Creative Commons BY-NC 2.0

LOVE LOST IN TRANSLATION. I HEAR THE PLEA. IT'S PEOPLE ASKING FOR HELP. CARE STARTS FROM THE HEART. HEART, LOVE, US, WE AS A COMMUNITY. PLEASE DON'T CHOOSE TO LOOK AWAY. SYSTEM LEVEL IS DILUTED EXPERIENCE. COME HOME TO WHERE WE LIVE, EVERYDAY. IT'S A DIFFERENT EXPERIENCE. MISINFORMED POLICIES DICTATING CARE CREATES CHAOS AND SUFFERING, SOLVES NOTHING. GREED KILLS. REGIONAL INEQUITIES ARE NOT OK. WELCOME TO THE POSTCODE LOTTERY. YOUR POSTCODE SHOULDN'T REPRESENT YOUR QUALITY OF CARE. CARE IS EVERYBODY'S BUSINESS. CARE INSPIRED IN THE WOMB. CULTURAL NORMS AND EXPECTATIONS, GOOD AND BAD. PATRIARCHY AND RACISM. DIVERSITY OF EXPERIENCES, PERSPECTIVES, CULTURES SHOULD INFORM SYSTEMS AND DECISIONS. SYSTEM LEVEL IS DILUTED EXPERIENCE. COME HOME TO WHERE WE LIVE, EVERYDAY. SELF PRESERVATION, CARING FOR SELF, BUT THRIVING. ELEVATION OF CARERS IS AN AFTERTHOUGHT. DIGNITY OF CARERS IS CRITICAL, HOW DO YOU SUPPORT THEIR DIGNITY?

GET OUT OF THE REEDS! STOP PROPPING UP A CARE EQUATION THAT DOESN'T ADD UP. MORE PEOPLE. MORE PRODUCTION. MORE CONSUMPTION. MORE CARE. MORE WORKFORCE. MORE MORE MORE. OUR PLANET DOESN'T HAVE MORE. PEOPLE DON'T HAVE MORE. WE NEED TO CREATE MORE THINGS THAT MATTER, WITH LESS. IT DOES NOT ADD UP. GETTING OLDER IS BECOMING CONSUMERIST - DO WE HAVE A USE BY DATE? - TO HELP THE MATH? RESOURCE CHALLENGES IN A 9 BILLION WORLD. CAN WE CONNECT? EXPERIENCE SHARED HUMANITY? MORE CHANCES TO SHARE - IN LATERAL AND UNCONVENTIONAL WAYS. MORE COMMUNITY. MORE BELONGING. MORE WATCHING EACH OTHER'S BACKS. SLOW DOWN. TAKE TIME.

CARE IS COMPASSION, KINDNESS, PURPOSE, PATIENCE, DISCOVERY, PRIVILEGE. DIGNITY. DUTY, EXPECTATION AND HONOUR. YET I'M ON A STRING, I GO HOUR BY HOUR. I STRAIN. NO HEALTHCARE WITHOUT INFORMAL CARERS. UNPAID AND UNTRAINED THE ONUS IS ON YOU TO FILL THE GAPS. NEVER A TIME OF SUCH ABUNDANCE STAGE 3 TAX CUTS LET'S FUND THE NEXT WAR BUT NOT CARE. WHAT IF I CAN'T COPE? BEING A CARER IS NOT SEXY. WHEN WILL YOU HEAR US? I'M TIRED OF PROTESTING. WE VALUE YOUTH, HEALTH, PRODUCTIVITY, UTILITY. ABLEISM AGEISM BURDENSOME. YOU'RE NOT VALUED BECAUSE YOU'RE NOT A \$ SIGN. BURDEN. THE WORD LIVES DEEP IN EVERYONE'S PSYCHE. JUSTIFIES LIFE-THREATENING PUBLIC POLICY. WHAT IS OUR COMMON LANGUAGE OF STRENGTH REALITY NUANCE? LET'S VALUE BEING HUMAN NOT A HUMAN BEING DOING. FLIP THE NARRATIVE ON ITS HEAD. WHY ARE WE NUMB TO STRUCTURAL SYSTEMIC VIOLENCE?

Photographs: Shuaib Yeung for
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