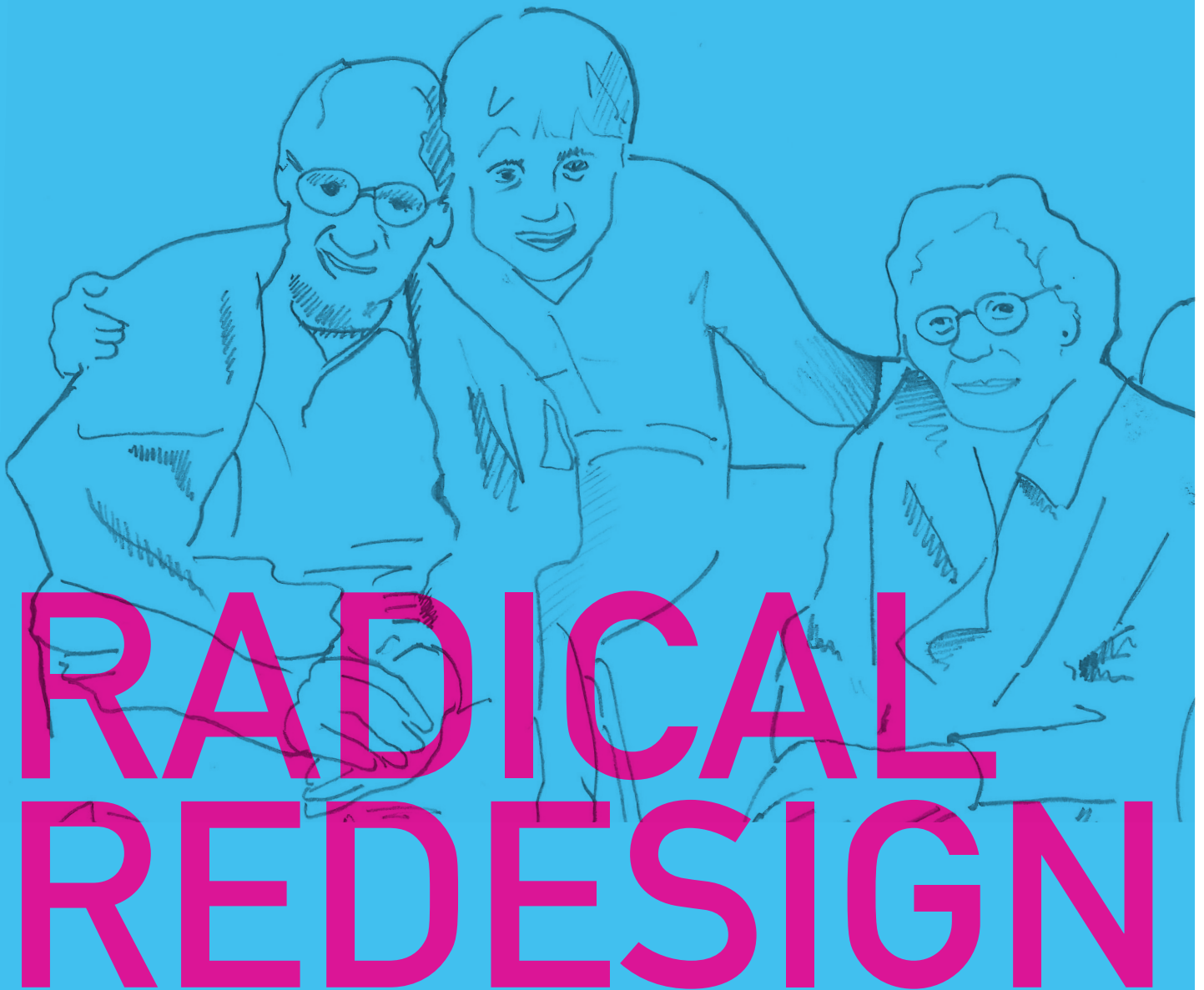


How can we
improve outcomes
for caring & cared
for older people?



A focus on caring



We know it's cliché for a report on ageing to start by describing the magnitude of the ageing population. Yes, Australia's population is rapidly ageing - no where more so than in South Australia where 1 in 6 people are over 65¹. Far from reflecting a crisis, these statistics suggest an opportunity to rethink people and system resource. Indeed, the interesting question isn't how do our current systems & services cope with an ageing population, but how do we re-design systems & services to improve outcomes for older people and society?

That's the big question underlying The Australian Centre for Social Innovation's latest radical redesign project. Together with South Australia's Office of Disability, Ageing and Carers and the cities of Salisbury and Unley, we're undertaking a 12-month process to co-design and prototype a set of solutions with older people, inside and outside of existing services & systems.

We find solutions that shift outcomes come from investing in a robust approach, having committed partners, hiring & training an interdisciplinary team, and identifying a clear problem or opportunity focus. We have an approach and partners, and for the last couple of months, have established the team & opportunity focus.

In June, we posed the question: If you could improve outcomes for one group of older people who would it be: non-joiners, culturally and linguistically diverse (CALD) older people, carers and cared for, or indigenous older people? We spoke to people in government, local services, at home and online. Most people said: every group.

¹ <http://www.health.sa.gov.au/Default.aspx?tabid=253>

² Australian Institute of Health and Welfare 2004. Carers in Australia: assisting frail older people and people with a disability. AIHW Cat No. AGE 41. Canberra: AIHW (Aged Care Series).

³ Carers Australia.

When we asked people to prioritise, carers and cared for repeatedly emerged. Non-joiners were perceived as too big and amorphous a group. CALD older people could be a subset of carers and cared for. Whilst outcomes for indigenous older people could hardly be any more inequitable, we felt the conditions weren't in place to do such a project justice. Without indigenous staff and long-term resourcing we were at risk of doing work that failed to shift outcomes.

This paper identifies the core questions that a project on carers and the people they care for would seek to answer, and highlights opportunities to shift policy, practice, and most importantly, people's lives.

Why care?

Unpaid carers are the main source of help for people experiencing challenges with day-to-day living. 46% of people in need of help with day-to-day activities, like getting around and taking care of themselves, rely solely on family and friends to get by. 48% depend on a mix of family, friends, and formal services. Only 3% depend exclusively on formal services.² Unpaid carers are Australia's largest aged care workforce. Without unpaid carers, demand on services would far outstrip supply.

But unpaid caring is not without its own costs. Carers are more likely to experience lower levels of wellbeing and increased levels of chronic disease than non-carers. One-third of all carers are severely stressed and depressed. Carer stress is a major determinant of cared for older people entering into more expensive, and often less effective, residential care. This is compounded for the 454,000 carers who are over the age of 65 and uncertain of their own ability to keep caring over the long-term.³



People's perspective

David is 67 years old, and relies on the help of his wife Pat, aged 64, to get by. It's been that way, on and off, since 1974 when David had an accident at work.

David and Pat met working at WD & HO Wills Tobacco in Bristol, UK. David was a fitter and turner. 18 months after emigrating to Australia he fell at work and crushed the discs in his back. Things were never quite the same. There were good periods: stints as a groundsman at a local school, working at a motor registration office, and working as a security guard at the South Australian Art Gallery were the highlights he mentioned.

But the pain never really dissipated, and the periods off from work gradually increased, until one day, David just couldn't go back. Some days are so bad, David spends them on a mattress on the floor. His legs have given out. Pat helps him get dressed, prepares all the meals, does the washing up, drives him to doctor's appointments, and keeps the house in immaculate order. Maintaining their big garden is a bit more of a struggle.

Pat and David have found "all these little ways to combat the problems" and try to have lots of laughs. Every day, David looks forward to sending off an email to his 14 mates around the world. He travels the world courtesy of Google Earth. When he gets particularly down, he crafts a PowerPoint presentation. These aren't just any PowerPoint presentations. They have fancy graphics, animation, and music. On Mondays, Thursdays, and Fridays, friends pop around for a visit if David is well enough. On those days, Pat volunteers as a receptionist at the local older people's centre, goes to hydrotherapy, and has lunch and a good chin-wag with the girls.

The last time they called on professional care services was when Pat went into hospital for a hip operation. She worried about David the whole time. Pat says, "We're not at the point where we need any help, but it may come some time in the future." The sign on their front door says, "Religion and charities not welcome unless called."

"It does wreck your life, I must admit. I sit down and think, what can I do? I used to do lots of volunteering work and I can't even do that any more. I look at opportunities in the paper, and sometimes I read them and think I can do that, but then I think, don't be stupid, I can't do that. Even the smallest, stupidest things"



"It gets me down to see how much pain he's in, but I'm managing. I'm just tired. There are lots of people worse off than me."



"It gets me down not being able to do things. I can't help Pat. She does it all. She makes the meal, I come in and eat, and I can't even help with the dishes."



A practice perspective

"To me going into respite would mean giving Pat some time off. But I wouldn't be able to take my computer and she would be worried"



Were David and Pat to call charities or government agencies, they would find a range of services on offer: carer support groups, information & training for carers, and respite care.

Respite care comes in several different forms - from residential or overnight care, to day centres, to in-home respite. Whatever its form, the aim of these respite services is similar: to provide a break from the responsibilities and stressors of care. But does respite really do that?

"I know he'd hate it"



Respite providers like Helping Hand Aged Care and advocacy groups like Carers Australia are calling for new models of respite care - models that are person and family centred - and which are not just temporary fixes for the ongoing challenges of providing care. The Statement for Australian Carers promotes carers as individuals with their own needs within and beyond the caring role, and goes on to call for support to be "timely, responsive, appropriate, and accessible."¹

Yet research suggests that only "slightly over half of caregivers" use respite services.² Barriers to service utilisation can be grouped into three categories:³

- Carer attitudes & role definition (e.g guilt, abandonment)
- The behaviours of the person being cared for during and after respite (e.g resistance, shifts in routines, skill loss)
- The inflexibility and quality of service provision (e.g staff training, staff attitudes, range of activities)

¹ <http://www.carersaustralia.com.au/?/article/view/1991>

² Lawton, M., Kleban, M., Moss, M., Rovine, M., & Glickman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology: Psychological Sciences*, 44, 61-71.

³ Doyle, Colleen. "Giving carers of elderly frail people a break: Perspectives on respite care." *The Australian Psychological Society*. www.psychology.org.au/inpsych/carers_respite/

A policy perspective

Not only are respite services too often inaccessible or unattractive, there are also real questions as to whether such services provide value for money.

In 2008-2009, the Commonwealth spent \$193.3 million on the National Respite Care Program, for an average annual cost of \$1,520 per episode of care. That doesn't count all the money state governments put in - or contributions from older people and families.¹

Yet the evidence suggests respite care - in particular, respite care for those with dementia - has negligible benefits for carers and the people they care for. An international Cochrane review concluded that there is, "No evidence of any benefit of respite care for people with dementia or for their caregivers for any outcome including rates of institutionalisation and caregiver burden." That said, the report struggled to find much research or attention paid to the outcomes of those being cared for, noting that, "This review has raised the possibility that studies of respite care focus too much on caregivers...a minority of the literature reported on any outcomes for the care recipient."²

New financial models - including block funding and & consumer or self directed care - open up new opportunities to empower carers and those being cared for. In 2011-2012, 1000 places for consumer-directed care will be made available across Australia. Carers and those they care for will have greater choice over the types of services they have access to - including who will deliver them, when, and where. How the 'choice agenda' actually plays out in practice isn't yet known.

"I don't mind paying for things but it's about finding it"



¹ Productivity Commission Draft Report on Aged Care. 2001. <http://www.health.gov.au/internet/ministers/publishing.nsf/Content/mr-yr11-mb-mb010.htm>

² Lee, H, Cameron MH. Respite care for people with dementia and their carers. *Cochrane Database of Systematic Reviews* 2004, Issue 1, Art. No: CD004396

Opportunity focus

People, practitioners, and policymakers seem to agree: we can do more to improve life with & for David and Pat - and the 465,000 older carers in Australia and the people they care for.

Too many carers are not using carer support services like respite care, and those that do use support services aren't always getting the most from them. Carer stress, chronic pain, and ultimately institutionalisation for those they care for, are still pervasive occurrences. There are two big opportunities to do things differently.

Opportunity Focus 1

Re-design respite care so it is more attractive, accessible, and effective for carers and the people they care for.

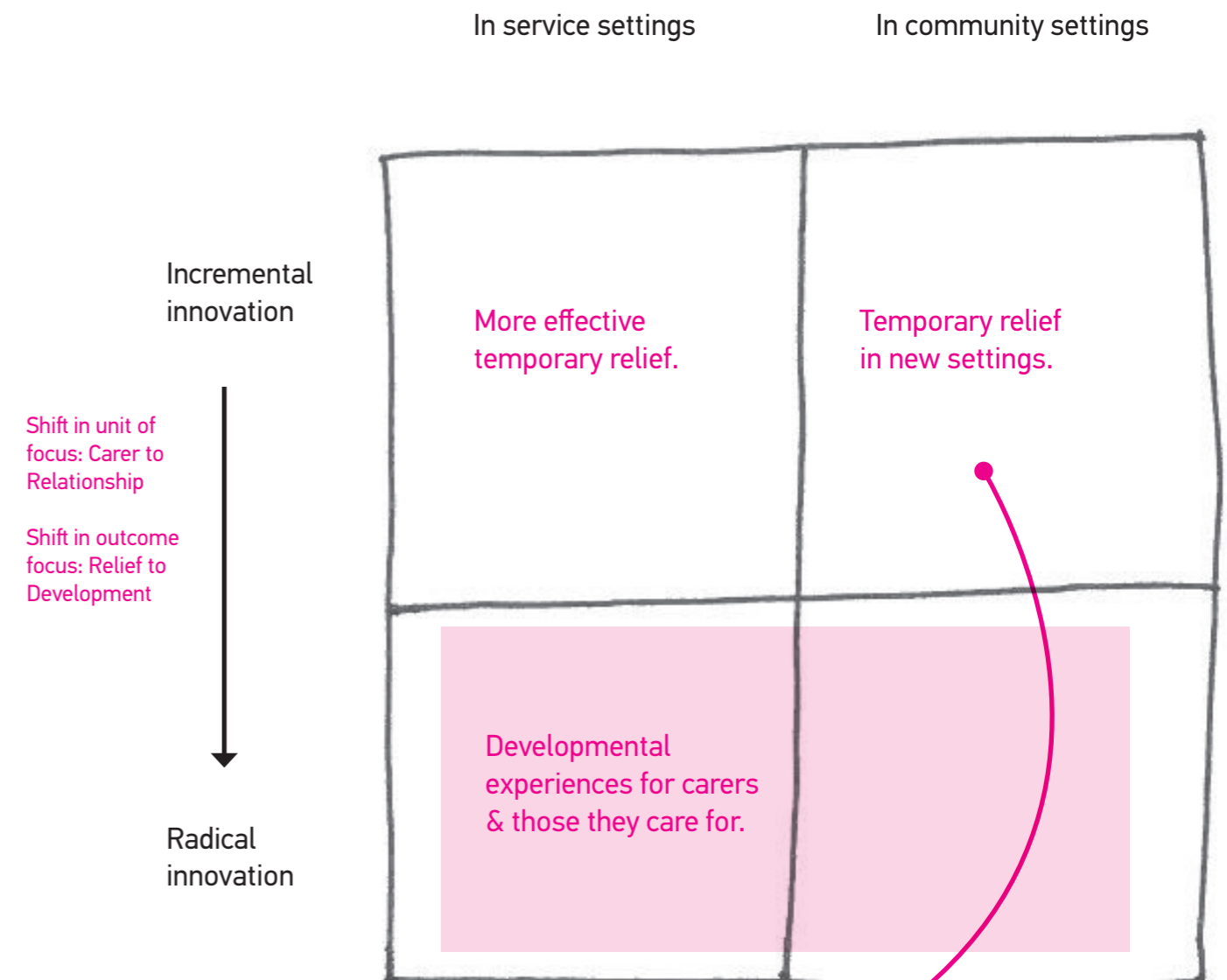
Opportunity Focus 2

Re-define and re-design respite care so it doesn't just relieve carers of stress, but creates more developmental relationships & experiences for carers and the people they care for.

The first opportunity is about incremental innovation: enabling existing services to do what they are intended to do, better. Respite is currently defined as "temporary relief from the burdens of caring". Such a definition deems the carer as the unit of focus. Incremental innovations would tweak existing services, inside institutions and out in the community, so that they work better for carers.

The second opportunity is about radical innovation: resetting what constitutes success and coming up with new kinds of networks, programs or platforms to move towards those new outcomes. Here, we might re-define respite as "improving the relationship between carers and those they care for" or "creating developmental opportunities for carers and those they care for." Such a definition deems the relationship between the carer and the cared for as the unit of focus. Radical innovations would come up with entirely new models, inside institutions and out in the community, so that they shift outcomes for carer-cared for pairs.

The LOOK phase will lay the groundwork for exploring these opportunities.



Our initial desk-based research into respite care suggests there is much to learn from different forms of respite provided to children and younger disabled people. Here's some of our favourite models:

1 Respality

Hotels offer an overnight stay, meals, and entertainment to parents whilst trained staff lend a helping hand to children.

2 Community experiences

Businesses and community groups give people being cared for a chance to do something they love (eg fishing), whilst giving carers some time to themselves.

3 Family home care

Families volunteer and receive training to provide respite in their own home.

LOOK preview

Radical redesign projects unfold over seven phases. In the next phase, the LOOK phase, we will identify what constitutes a good outcome or developmental opportunity for carers and those they care for - particularly as people's physical and mental capacities shift over time.

We will look at the problem and opportunities from the perspective of people, practice, and policy.

LOOK People

David and Pat are just one example of a caring relationship. In the LOOK phase, we'll seek out and spend time with people who have lots of different experiences of caring and being cared for.

From people like Pat and Dave - who have found ways to cope and enjoy what they can - we can learn about opportunities to live differently. We'll also talk to people who find caring an unmanageable challenge; people who have had less time than Dave and Pat to adjust to the caring and cared for roles; people with cognitive impairments; and people with weaker social networks.

Currently David and Pat do not use many services aimed at carers or cared for people. We'll find those who do and find out how those services help, or not.

The diagram opposite shows our initial thoughts on the spread of factors we'll look for when recruiting caring pairs and caring networks - and where Dave and Pat fit into the mix.

From speaking to people in a wide variety of caring relationships we hope to learn more about....

- The everyday experience of caring and being cared for
- Life before & beyond caring and being cared for
- Strategies people use to cope with challenges
- Strategies people use to enjoy their relationship and life
- How caring changes relationships
- Perceptions and experiences of existing caring services
- The outcomes people consider important over time
- The offers that are attractive and those that turn people off
- People's willingness to pay for services

Factors influencing caring:



LOOK practice

We will explore respite services, support groups and other services aimed at carers and those they care for. Through existing literature, observations of existing services, and discussions with practitioners we will learn more about local, interstate and international practice.

In South Australia

- What is the range of services on offer?
- Who do services see as their users?
- What challenges do services face?
- What do practitioners see as the opportunities for change?
- What is the theory of change?
- What is the business model?

Interstate and international

- What does practice look like that takes caring relationships, rather than carers or cared for, as the unit of focus?
- What practice has been proven to create change for caring and cared for people? What does change mean in a caring context?
- What promising practice can we learn from?
- What can we learn from respite services for children and disabled people?
- How are outcomes measured? What instruments exist?

LOOK policy

We will identify the big ideas, policy frameworks, regulatory guidelines, and resource pools that govern services for carers and those they care for. Through interviews with policymakers and civil servants, as well as document and discourse analysis, we will learn more about what shapes existing practice, and the windows of opportunity for policy change.

In South Australia & Australia

- How do resources & responsibilities flow between local, State, and the Commonwealth government when it comes to aged care?
- What policies are currently under review and why? Where is the political impetus?
- What values and principles underpin current policy?
- What are the levers for systems change?

International

- What can we learn from ageing policy in non-Western contexts?
- How does cultural context influence policy frameworks?
- What are different resourcing models and incentives?

Feedback wanted

We'd value your input to help us answer these questions and alert us to anything you think we should know about.

You can drop an email to sarah.schulman@taksi.org.au or send us a message on twitter [@ozinnovation](https://twitter.com/ozinnovation) or leave a comment on our blog.

Meet the team

Over the past few months we've been busy interviewing and hiring a new team to work alongside project leads. The team brings together social science, design, business and community as well as expertise in older people in the form of a full time secondee from the City of Salisbury. The team provides enough capacity to run two prototypes, one in-system, one in-community.



David Kelly, Strategist, Older People's Policy (Aus)

David is deputy CEO of TACSI. He is an experienced strategist, project coordinator and program manager with a twenty-five year commitment to working with disempowered communities. His career is founded on the deeply held belief that communities change for the better when citizens of all ages are active and creative participants in community development processes rather than passive consumers of services. David brings to the project many years experience in the ageing sector.



Dan Mohr, Business (Aus/Germany)

Dan has combined his passion for social justice and numbers to forge a career in business for social ventures and social justice. He studied in Germany, France and the UK with a focus on corporate finance, environmental economics and quantitative economic methods. He's worked as a business analyst for the UK Department for Business and for Social Ventures Australia, and volunteered to run a project to set up radio infrastructure for 40,000 people in Ghana.



Susan Butler, Design (Ireland)

Susan aspires to design and change the world into a system that is fair and makes people smile. She has a Bdes in Fashion Design and an MSc in Multimedia Systems from Trinity College, Dublin. She has volunteered with women's groups in the favelas of Rio de Janeiro and worked as a care assistant supervisor providing work environments for people with mental disabilities. She was a team leader on Designing Dublin, which saw her leading live prototypes in the streets of the city.



Dr Sarah Schulman, Co-lead Social Policy (USA)

Sarah holds a PhD in social policy from Oxford University where she was a Rhodes Scholar, and an MA in Education and a BA in Human Biology from Stanford University. She's worked with national, state and local governments in the UK, US and New Zealand to engage users in the design, delivery, and evaluation of health, education, child, youth and family interventions. With several failed organisations and programmes under her belt, she partnered with Chris Vanstone to start InWithFor and improve social problem-solving.



**Jenna Harrison, Older People's Services
Secondee from City of Salisbury (Aus)**

Jenna works for Salisbury Council, where for the last 5 years she has been part of the team that runs the innovative Jack Young Centre for older people. A graduate in recreation, planning and management, she has experience of working in residential and recreational services for older people. Jenna is looking forward to learning a different way of working and embedding what she learns at the City of Salisbury.



Jessica de Campo, Social Science (Aus)

Jessica is a social researcher and educationalist with a passion for social change and design thinking. She holds a Masters of Education from Monash and spent her early career teaching indigenous pupils at remote schools in the Western desert and rural Victoria before working at the Foundation for Young Australians. She is returning to Australia after completing an MA in Policy, Organization and Leadership Studies at the School of Education, Stanford University.



Sandhya Sharma, Junior Designer (Aus)

Sandhya is a recent graduate in Visual Communication and International Studies from University of Technology Sydney who wants to apply her design skills for social good. Her graduating project used information design to promote awareness of traditional indigenous fire management techniques. She has a passion for food and is currently developing an app to share the foodie secrets of western Sydney whilst helping her mum design her learn-Indian-cooking-at-home service.



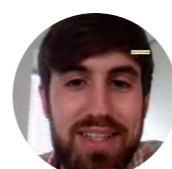
Chris Vanstone, Co-lead Design (UK)

Chris Vanstone is graduate of Central Saint Martins College of Art and Design. He's worked with communities in the UK to prototype solutions in the areas of drug use, obesity, ageing, loneliness and youth disengagement. He helped found RED at the UK's Design Council and social enterprise Participle.



Adele Liddle, Community & Organisation (Aus/UK)

Adele is a 'career hopping generalist' who's found her place in the community sector. A graduate in community arts, she worked for multinational Diageo embedding e-learning across their business before moving to Adelaide to work in HR and recruitment at the University of Adelaide. She used to run the Box Factory community centre, organising volunteers and community partnerships. She is a Red Cross 'Mate' and is currently investigating notions of isolation for a project with a local community centre.



Ryan Hubbard, Design (USA)

Ryan is a designer with a passion for social change. He studied systems engineering and is a graduate of Austin Centre for Design, where he developed an SMS platform to promote drug compliance. Other projects have included working for a web startup in London, helping Ashoka pilot an initiative to accelerate social innovation in US cities, developing products to reduce HIV transmission in Africa, and designing stoves for use in Guatemala.

The Australian Centre for Social Innovation exists to identify and support the innovative ideas, methods and people that will contribute to and accelerate positive social change.

tacsi.org.au

TACSI's Radical Redesign team blends design thinking, policy thinking, social science and business to solve social problems and demonstrate new ways of working with and for social services.

tacsi.org.au/design

The Radical Redesign Team for this report was:
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