Nothing about us without us -

older citizens co-producing residential services

six key steps



The aged care system in Australia is changing. Older people and their allies are moving from being passive to active participants in their support. These changes often referred to as 'personalisation', challenge providers to develop different mechanisms for engaging older people to both co-produce and co-own aged care services.

While some of these changes are being implemented in home care or community care, there is significant reform needed for residential aged care services to co-produce outcomes with older people and implement consumer directed support in residential services.

This short paper provides an analysis of some of the key issues for older people, families and staff living and working in residential services. It includes six key steps that older people and their families and staff can undertake to co-produce residential services with older people.

Personalisation of Aged Care in Australia

'Personalisation' refers to making publicly funded services tailored to the interests of the people who use the services (Needham, 2011). Mechanisms for how this is implemented vary from person centred practice, to individualised budgets to 'cash-for-care' schemes where people manage their funding and supports.

Nothing about me without me



Personalisation challenges the historical pillars and institutional structures of Australia's aged care system and the continued dominance of institutional care for older people. It seeks to embed the concept of 'active ageing' to support older people and their allies to age well in their community. Rather than older people being slotted into services, supports are tailored to the individual supported by more flexibility in funding.

While Australian Government policy documents are positioning older people as 'consumers', others are critical of this perspective. Some contend that rather than positioning older people and their allies as 'consumers', they should be seen as citizens located within an ethic of care that focuses on trust, reciprocity and building connections and relationships between older people, families and their support staff (Barnes, 2012, Tronto, 1993, 2010). Furthermore, some are critical of residential services because of the lack of active participation or citizenship of older people (Scourfield, 2007).

Personalisation is also challenging models of support for people living with dementia and their care partners. People are challenging the dominance of the 'medicalisation' of dementia including the 'prescribed disengagement' model for people living with dementia. Swaffer (2016) contends that the 'prescribed disengagement' model is based on the premise that people living with dementia should not expect to have the same quality of life before their diagnosis. In critiquing this model Swaffer (2016) argues for a social model of support for people to live beyond dementia that includes access to rehabilitation, technology and social support.

As part of these challenges and opportunities, services need to reflect on how they work with older people to co-produce support that enriches the lives of older people and their allies.

Co-production with Older People

The idea of co-production is a contested and debated term (Needham & Carr, 2009). At the most basic level it involves people who use services being involved in their production. There is no 'single' formula for co- production; however, it is underpinned by a number of principles:

- People are not passive recipients of support and have resources and expertise that can improve services (Needham & Carr, 2009);
- Involving the people who use aged and community care services in more collaborative relationships with frontline staff. Front-line staff should share power and acknowledge the lived experiences and expertise of service users (Needham & Carr, 2009);
- The importance of working with peer and personal support networks alongside professional networks (Social Care Institute for Excellence);
- Service providers don't just provide services they also become agents of change and redesign and facilitate services to include and support people living well. This means moving from being 'fixers' to 'enablers' to empower people to have a good life.



The benefits and risks of co-production are debated. Critics contend that co-production downplays the power imbalances between service users and services (Barnes, 2009, Beresford, 2009, Ottman, 2011). The potential to reproduce power imbalances and reproduce inequality are significant (Needham and Carr, 2009), there can also be significant institutional and staff resistance (Needham and Carr, 2009).

Supporting older people living in residential care to remain active citizens challenges existing service models and is an adaptive leadership challenge. Heifetz and Linksy (2002) argue that adaptive leadership is the activity of mobilising people to tackle tough challenges and thrive. They demonstrate that adaptive leadership challenges are those for which there are no simple, painless solutions – problems that require us to learn new ways. However, there are small steps that leaders in residential services can take to start a different conversation with older people and their allies in their organisations.

Co-producing residential services with older people – six key steps

Step One - Start with why - engage people in the issues and the solutions

Organisations that innovate and change, start with why (Simon Sinek, Ted Talks). Sinek argues that most organisations can't describe why they exist. As part of 'starting with why' it is important to engage people in a conversation about why change is needed and to engage all stakeholders. This includes older people living in the residential services, front-line staff and the allies and families of the older people. Start with small steps, pick one area of practice that you think you can change and involve all people in identifying the issues and possible ways of changing practice.

Step Two – Build connections and relationships with people and their families

Putting the person and their family at the centre of how supports are designed and provided is critical. One way of doing this is through person centred planning which is a mechanism for getting to know the person and their care partners. One of the most critical concepts is what is important to the person (for example, what brings the person comfort and joy) and what is important for the person (for example, what does the person need for personal safety).

Using person centred thinking tools and developing person centred plans can be a really important way of getting to know the person and to build connections and a relationship. As part of this it is important to match staff and residents with similar interests so they can build connections and relationships. Similarly, it is important to connect residents with similar interests and passions.



Step Three – Create a culture of engagement and active participation

Residential services are an ideal place to create a space of active participation and engagement with older people. Sometimes this may require an external facilitator to start a conversation. For example, Helping Hand (2014) invited a group of older people living in their residential facility to explore what they would like to have a better life using a co-design process. The group was facilitated by an external facilitator who explored what a better life would look like for people. The group designed a series of projects including managing a shopping cart that was run by the residents for the residents. In the Netherlands, a residential facility brought together a group of older women who wanted to improve the food that was being developed in the facility (Baur & Abma, 2012). The facility brought in an external facilitator who worked with the group to identify what they would like to do – the group formed the "taste buddies' who redesigned how the food was developed and designed in the facility. This led to people being happier and it was actively supported by management.

Fostering social connections through activities organised for residents can build connections and relationships. This should include supporting people to access activities in the local community and maintain their existing relationships within their local community. If there are people with similar interests then structure activities to connect people through their interests (eg gardening groups, cooking groups, conversation groups). Encourage people to lead groups, for example, tai chi groups, meditation classes, scrabble groups, etc.

Step Four – Engage, educate and empower frontline staff

Front line staff are the most important people in building connections and relationships with people. If they are well trained and supported by management they are often the first to understand what is important to and important for a person. Frontline staff should be encouraged to be creative and explore ways of working with people to support them to have the best life possible.

Step Five – Foster a culture of reflective practice and passionate curiosity

To engage older people as citizens, they need to feel like they are part of your organisation and that you work with them to support them to have the best life possible. In doing this it is important to reflect on how you work with people, what works for people, what does not work for people and to change what is not working. This includes being willing to experiment, try new things and explore ideas that are creative and possibly outside of the square.

Step Six – Reflect on your journey through research

When you try something new, make sure you think about how you can share the journey you have been on through research. Engage and connect with researchers. Researchers are curious about how to change practice, what works in some contexts and what does not work. Involve the people who are working through the change in the research process and allow them to reflect on their lessons. This works to build on existing research and evidence and can change thinking, attitudes and practice.



Resources and Websites

http://myhomelife.org.uk

My home life is a project that was established in the UK to create personalised residential services for older people living in the UK. It includes lots of resources that you can use with your staff

www.wavertonhub.com.au

The Waverton Hub is a membership based organisation run by people living in the Waverton Local Government Area of Sydney. It connects people together in the community and aims to support older people to age well in their local community.

Green farms for people living with Dementia in the Netherlands

http://www.who.int/features/2015/dutch-community-living/en/

http://www.reigershoeve.nl/

www.homecaretoday.org.au

Resources for service users and providers on implementing consumer directed care.

Simon Sinek Ted video – start with why https://www.ted.com/talks/simon_sinek_how_great_leaders_inspire_action?language=en

References

People living beyond dementia

Alzheimer's Australia Dementia Language Guidelines downloaded from https://fightdementia.org.au/about-dementia/resources/dementia-language-guidelines

Alzheimer's Australia (2013) Relate, Motivate, Appreciate - A guide to Montessori Activities, downloaded from

https://fightdementia.org.au/sites/default/files/AlzheimersAustralia_A5_Montessori_Booklet_WEB(3).pdf

Alzheimer's Australia NSW. (2014) *The Benefits of Physical Activity for People living with Dementia*, Sydney, Alzheimer's Australia NSW downloaded from <u>https://nsw.fightdementia.org.au/nsw/news/the-benefits-of-physical-activity-and-exercise-for-</u>

people-living-with-dementia

Mental Health Foundation, (2015). Dementia, rights and the social model of disability: A new direction for policy and practice? London: Mental Health Foundation Policy Discussion Paper. https://www.mentalhealth.org.uk/publicatons/dementa-rights-andsocial-model-disability

Rahman, S. (2015). Living better with dementia: good practice and innovation for the future. London: Jessica Kingsley.



Swaffer, K., (2016) What the hell happened to my brain? Living beyond dementia, Jessica Kingsley Publishers, London and Philadelphia

Co-production

Baur, V., & Abma, T., (2012) "The Taste Buddies': participation and empowerment in a residential home for older people, *Ageing and Society*, Vol 32. pp 1055-1078

Helping Hand (2014) Life to go on – co-designing new activities and programs at Helping Hand Parafield Gardens, Helping Hand

Needham, C. and Carr, S., (2009). *Co-production: an emerging evidence base for adult social care transformation* In Social Care Institute for Excellence (Ed.). United Kingdom Social Care Institute for Excellence downloaded from <u>http://www.scie.org.uk/publications/briefings/briefing31/</u>

Ottmann, G., Laragy, C., Allen, J., & Feldman, P. (2011). Coproduction in Practice: Participatory Action Research to Develop a Model of Community Aged Care. *Systemic Practice and Action Research, 24*(5), 413-427. doi: 10.1007/s11213-010-9181-5 <u>http://dx.doi.org/10.1007/s11213-011-9192-x</u>

Ethics of Care

Barnes, M., (2012) Care in everyday life: An ethic of care in practice, Bristol: Policy Press

Tronto, J.C., (1993) Moral Boundaries: A political argument for an ethic of care, New York: Routledge

Tronto, J.C., (2010) *Creating caring institutions: Politics, plurality and purpose*, Ethics and Social Welfare. 4(2), 158-171

Leadership

Heifetz, R., & Linksy, M. (2002) *Leadership on the Line - Staying Alive through the dangers of leading* Boston, Massachusetts: Harvard Business Review Press

