

Lessons learnt from navigators

Supporting choice and control

Who is this for and why

This resource may be helpful for the care finder line manager and the care finder as an additional resource to their existing expertise and knowledge. It is based upon experiences and reflections of Aged Care System Navigators and COTA Australia as part of the Australian Government funded Aged Care System Navigator Trial measure (ACSN).

The official operation of the National Care finder program is governed by Care finder policy documentation.

Links to the Care finder Competency Framework Domains

- Communication / Interpersonal Skills
- Access to services
- Person-centred
- Building and sustaining networks



Background

The aged care system supports consumer choice about the care and support needed. Many reforms are underway to further improve choice in aged care, especially in the context of quality of care, and navigators should be aware of and understand these to best support their clients.

For some people, this process can be confusing, complicated and distressing and require support/navigation to facilitate choice, agency, and control over outcomes.

Decision-making includes both the act of deciding and being able to act upon the decision to achieve the desired outcome. Making choices can be constrained by a range of factors, including available resources at both individual and system levels. In addition, navigators learned that a customer's choice occurred within the context of the customer's social, cultural, language, religious, spiritual, psychological, and medical needs.

Definitions

Navigators understood choice and its associated elements as follows.

Choice Choose or decide between different options.

Control Ability to influence the way choices are implemented.

The capacity to make choices tangible (This is often defined as Agency

empowerment).

This is defined in the Charter of Aged Care Rights as the right to have Dignity of Risk

control over and make choices about my care and personal and social

life, including where the choices involve a personal risk.

Informed choice and decision making are best identified within the Aged Care Quality Standards and the Charter of Aged Care Rights (Charter).

Aged Care Quality Standards Outcome Measure

The aged care service system operates within a rights-based framework.

The right of the older person to select the type of services they receive, from whom and how is central to the system's design and operation.

Standard 1 Aged Care Quality Standards Outcome Measure states:

I am treated with dignity and respect and can maintain my identity. I can make informed choices about my care and services and live the life I choose.

Lessons learnt:

Exercising choice

Effectively engaging with the aged care system including My Aged Care requires the person to:

- Understand there is an aged care system, and where to start
- Understand the registration process and eligibility
- Understand the assessment process and its different elements
- Be able to identify and articulate the level of support they believe they need
- Understand the level of funding they have been approved for and from what program
- Understand how to accept services offered and select a provider from a range of providers based upon approval level and type
- Understand and be able to choose how they wish their services to be delivered.

At each stage of the process, the person requires knowledge to make an informed choice to both gain access to and receive the support they need in a way that is consistent with their preferences.

Exercising choice depends on having access to the correct information in a way that is accessible and on having a relationship with a trusted person who can facilitate information provision.

Navigators found that effective decision--making, agency and control involved more than the provision of information. It is an active process of discussion, deliberation, and dialogue to enable the customer and those who support them to understand the service systems and options available to them.

Exercising choice: what enabled customers

- **Trust**. Customers had to believe the Navigator was working in their best interests and they had received information that was trustworthy, i.e., independent, accurate, accessible, contestable, timely and actionable. Consequently, Navigators spent considerable time staying up to date and checking information before supplying it to customers. This task is difficult in a system that keeps evolving.
- Time. Its takes time to build trust with the customer and their carers/family members. Many people and communities, such as members of the Forgotten Australians, may have limited or no trust in the government or service providers, due to their background, history, or cultural experiences. The customer may not disclose information about their past, so Navigators had to be sensitive to the possibility of past trauma or prejudice. Examples could include refugees, people who identify as LGBTIQ+, and people from Aboriginal or Torres Strait Islander backgrounds. Building trust takes time, and Navigators stressed that they had to follow through on what they said they would do.
- Taking time to listen builds trust. When meeting with the customer the first time,
 Navigators stressed the need to listen and ask clarifying questions to identify why the
 customer was seeking assistance and what they knew about the aged care system. They
 did not assume people's knowledge about their needs or willingness to follow through on
 their decisions.

Assisting Brenda with identifying, choosing and using services

Brenda contacted the navigator for assistance to find a provider. The navigator first assisted Brenda to clarify the support she needed at home.

Brenda does not own a computer and lacks digital literacy skills.

The Navigator organised a home visit and took their laptop computer to Brenda's home. Together Brenda and the navigator used the 'Find a provider' tool on the MAC website to perform a search for providers with availability in Brenda's area. The tool enabled them to quickly ascertain which providers had the capacity for the services Brenda needed.

After several phone calls, a provider who could deliver both house cleaning and a social support service was found. Brenda was surprised how easy this was after her own experience and indicated that not understanding how to approach providers significantly affected her confidence. Brenda appreciated having someone with knowledge and expertise supporting her through this process.

Brenda was anxious about the provider fees involved. The provider assured her that she would not have to pay a contribution fee if she could not afford to. With Brenda's consent, the Navigator arranged with the Service Coordinator for someone to visit and assist her with the paperwork involved in commencing her Home Care Package. Brenda was so pleased that she could finally access some support and has just started receiving a much-needed service.

Brenda's experience demonstrates the many steps involved in exercising choice.

Barriers to agency and choice

- A lifelong inability to exercise agency creates significant challenges in old age.
 Navigators noted customers who had limited opportunities across their lives to exercise tangible agency and control also had limited capacity to actively demonstrate agency and control in their old age, for example, some older women. Navigators reported that they needed to respond in ways that respect the customers' capacity and willingness to take control. In doing this, navigators needed to agree with the customers what tasks each should undertake and set clear expectations.
- **Dignity of risk**. Navigators identified that in some cases, the customer's right to make their own decision and live as they wish posed a challenge. In such cases, they sought to actively apply the principles of 'Dignity of Risk'. For example, a customer wishes to continue walking in her local park by herself but has a considerable risk of falling. Her family would like someone to walk with her in case she falls.
- Limited availability of services. This was a challenge for navigators, making their role at times a balancing act between helping the customers to understand the system and identifying choices within the constraints of the system. Navigators reported they had to be open and transparent in their communication to ensure the customer was aware of the limitations and scope of the aged care system. This includes limited or no services within an area.
- Customers need to be skilled consumers. Navigators stressed that the process of selecting an aged care service and understanding budgets to determine the value for money and quality, required the customer to be a skilled consumer.

Navigators noted that many of the customers they assisted had limited experience in this area and consequently, the navigator role was to empower clients to acquire these skills. This included showing people how to use the My Aged Care Find a Provider tool including sitting beside them while they did this, explaining what the various levels of care meant and the dollars associated with packages and the fees of services. Navigators are dealing with the most vulnerable and most navigator clients did not use computers.

How navigators encouraged choice: some strategies

- By working respectfully with the customers to determine how much prior knowledge they had of the aged care system and their beliefs about ageing. It was clear many people believed they had limited choices and that residential aged care was their only option as they aged.
- Engaging with customers about their individual circumstances, rather than starting in problem-solving mode. This enabled the navigator to gently challenge the customer's beliefs and remove psychological barriers to receipt of aged care and choices they could make. Customers would often articulate these barriers, such as "I will be all right," I don't want to make a fuss," "I don't want strangers in my home" and "I am sure there are other people worse off."
- Navigators said they needed to be persistent in following up with customers, as well as respecting the time taken by customers to make choices or come to decisions.
- Navigators noted that some people became overwhelmed when trying to select providers from a service finder, particularly when there were limited vacancies. In this situation, the navigator created a list of providers for the customer to choose from rather than the customer undertaking that task.

Needing the right information to choose services

Geoff first phoned the aged care navigation service in November 2019. He was concerned about his brother-in-law Stephen, who lived alone in a small rural community. Geoff explained he had noticed a decline in Stephen's self-care - that his house was untidy, and the gardens were overgrown. Geoff made an appointment for Stephen to meet the navigator face to face at the local hospital to discuss options. Stephen was guarded on engagement and reluctant to accept support.

During the discussion, it became apparent that Stephen was not aware of any services available to him to remain living at home.

After the navigator sat down with him and explained his options, Stephen became more open to the idea and gave the navigator permission to call My Aged Care (MAC) to organise an assessment. The navigator supported Stephen during the assessment and clarified issues about the range of services available to support him.

The navigator spent a total of 6 hours working with Stephen. Most of this time was spent on the initial face-to-face meeting explaining the aged care system and the options available to him. Stephen had Commonwealth Home Support Program services implemented following the assessment. He was later assigned a level 2 Home Care Package in November 2021.

Stephen initially did not want services. He was isolated and unaware of his options in a small regional town. He welcomed support once his choices were clearer and presented in a way that he could understand and act on.

Tips from navigators

Appropriate information provision

- People rely on their networks and friends to test information and make choices. Navigators gave customers the time and space to do this as the decisions the customers were making had life course implications.
- Use positive framing. Navigators were clear that framing the discussion in the positive such as, "What would a good life look like?" gave customers permission to envisage different ways of living, reflect on their strengths, imagine choices, and reclaim control of their lives.
- Navigators noted they had to curb their enthusiasm and learn to provide the necessary information in ways that did not flood the customer and overwhelm them which effectively disempowered them. More is not necessarily better, when enabling people to understand and act upon information.
- In presenting the information, navigators reported that they would use clarifying questions to test what the customer had understood or misunderstood or why the customer could not proceed. Navigators stressed the importance of never assuming.
 - Navigators stressed the need to understand the person's capacities and preferences. For example, did they have digital skills, what was their level of literacy, and could they understand how to select services from an online portal?
 - Navigators noted having family members or a friend present when information and options were being provided meant the customer could clarify information later or try engaging with MAC.

Needing assistance to exercise choice and stay in control

The navigator worked with the customer to select the customer's preferred service provider. A home visit was scheduled with the customer, the service provider and navigator present. The customer participated fully in a discussion about her care needs, and care plan and signed the agreement.

This meeting also included a discussion about the timetabling of the service provided. The customer, with support from the Navigator, explained she was unable to read. The service provider agreed that the care worker would mark the customer's calendar in a way that the customer understood when the next visit for Domestic Assistance was scheduled. The case manager was also made aware that the customer would require support with completing forms etc and the care manager offered support with this as required.

The customer was happy with this arrangement and felt she had been supported in making her choices and decisions known.

Understanding the client's capacity and preferences

- Navigators stressed that customers had to begiven opportunities and permission to say
 "No" to choices or actions proposed by the Navigator. This included posing questions in a
 way that enabled the person to give alternate ways of saying no to a suggested course of
 action. For example, asking 'How do you feel about someone coming into your home to
 clean?" rather than "Do you need a cleaner?"
- Navigators reported that practicing contacting MAC could assist customers to make decisions. This experience was an effective way of enhancing customers' confidence when dealing with services and government. For example, doing a role-play exercise of talking to MAC.
- Navigators stressed the importance of modelling decision-making so that the customer could learn from their actions, such as for example, the customer listening to how the Navigator spoke to services about customers preferences for service delivery.
- Navigators needed to be aware that some people will not tell you that they do not
 understand something or cannot do something. They may do this for cultural reasons,
 shame, or not wanting to offend you as the worker. They may have limited literacy, or a
 previous history of engaging with the government and its agencies. It was important for
 navigators to display empathy and think about why people may be struggling with their
 answers and responses.
- Navigators stressed the need to understand the person's capacities and preferences. This
 could include having family members present when information and options were being
 provided.
- Navigators reported breaking down the key steps required to receive a service was
 important for people with cognitive impairment or those overwhelmed by complex
 administrative systems with many different people undertaking distinct roles. For
 example, being clear about the difference between registration and assessment. They
 also stressed the need to explain the language used within the aged care system and
 where people would be required to make choices about the support they wanted or give
 permissions.

Persistence in identifying and working with barriers

The navigator received a phone call from a woman concerned about her friend Nev who is paralysed down one side of his body and has just had a knee replacement on his good side. Nev lived alone in senior public housing. The navigator visited Nev at home. Nev was 74 years of age, fiercely independent, in a lot of pain, and struggling to move around, but his attitude was "she'll be right" and "there are people a lot worse off than I am."

The navigator suggested that Nev get assessed for some help, which he agreed to. The navigator assisted Nev in organising registration and assessment. Unfortunately, when the Aged Care Assessment Team (ACAT) visited Nev at home, Nev said he was fine and didn't need any help, so nothing happened.

A few weeks later, the navigator received another phone call from Nev's friend and realised that Nev had declined help. The Navigator called the ACAT manager and organised a joint home visit, as the navigator had an established relationship/trust with the client.

During the home visit, the navigator asked the ACAT manager to describe the assessment process and explained to Nev what would happen and the type of support he could receive to enable him to live at home independently. The Navigator explained terms that Nev did not understand. Following this, he agreed to the help which has now been organised.

This case study demonstrates the importance of ongoing conversation and engagement. It is important to keep revisiting and following up with people to understand what is going on for them.

Useful resources

Specialist Homelessness Services Assertive Outreach Good Practice Guidelines.

This provides a good overview of working with disempowered people and steps to work with them. Available at: http://homelessnessnsw.org.au/wp-content/uploads/2021/03/Assertive-Outreach-Practice-Guidelines.pdf

This article provides an overview of current policy thinking and research into providing information to older people and their role as consumers in social care. At the same time, the UK is very applicable to Australia.

Harding, A. J. (2021). Older people, information-giving and active agency practices in health, social care, and housing: theory, evidence, and reflections. Ageing & Society, 1-13. DOI: https://doi.org/10.1017/S0144686X21001884

Aged Care Quality & Safety Commission: Aged Care Quality Standards

Charter of Aged Care Rights

What is Dignity of Risk? Consumer Resources

Supported Decision-Making In Aged Care (Aged Care Royal Commission)