



Deciding where I'll live.

Supporting choice making with younger people living in residential aged care

Introduction

Resolving the issue of younger people living in aged care was a key focus of the Royal Commission into Aged Care Quality and Safety.

As an outcome of the Royal Commission's work, the Australian government endorsed the Younger People in Residential Aged Care (YPIRAC) Strategy, which has 3 Targets:

1. no people under the age of 65 entering residential aged care by 2022;
2. no people under the age of 45 living in residential aged care by 2022; and
3. no people under the age of 65 living in residential aged care by 2025¹.

To achieve the third Target, the NDIS has initiated conversations with NDIS participants living in residential aged care (RAC) to ask if they would like to explore community-based support and accommodation options. Many of these participants have not had sufficient information to make a clear decision and have not felt confident to engage on this topic.

In response to concerns that younger people are being asked to indicate their preferred living arrangements without decision making support or the opportunity to consider possible options, the Young People In Nursing Homes National Alliance (The Alliance) investigated choice and decision making processes with younger people living in RAC in two states through the My Future My Choice project.

The Alliance has significant practical experience working with both younger residents in aged care and with residential aged care providers. We understand the complexity that younger people living in residential aged care confront when making decisions about future living and support; and the capacity building required to ensure people are confident, trust the process and can effectively communicate their choices.

¹ To read more about the YPIRAC Strategy and the targets see: <https://www.dss.gov.au/disability-and-carers/programmes-services/for-people-with-disability/younger-people-with-disability-in-residential-aged-care-initiative>

The My Future My Choice project implemented a choice making model that involved those people who had been working separately with each young person, coming together as a support team. As well as the younger RAC resident, this included their decision supporter/s, family members, key staff from their RAC facility, allied health personnel, health and disability service providers and the person's support coordinator.

Using a comprehensive approach that prioritises trust, transparency and collaboration, the Alliance has identified the gaps, barriers, and challenges involved in engaging with younger people living in RAC settings. We have also seen first hand, the benefits that can result when younger people are supported appropriately and given the opportunity to consider their options and make informed decisions.

The project's choice making model and its team approach was not only used to arrive at an actual decision, but remained in place to guide transition planning and address any issues that arose following the person's move to their chosen home.

This comprehensive guide and its descriptions of how to successfully engage in choice making processes with younger people living in residential aged care, is a tangible outcome of that work.

Who is this guide for?

This guide has been written for people who facilitate decision making support for younger people in RAC.

It provides guidance for Support Coordinators, System Coordinators, NDIS planners, appointed Guardians and RAC providers in the use of a collaborative practice that builds respectful working relationships with the younger person, their residential aged care provider, their network of formal and informal supports and services; and delivers improved outcomes for these younger residents.

Resources needed to improve engagement, communication and activate the choice and decision making processes that younger people living in aged care settings can apply successfully, are also included.

Why choice making processes?

Many younger people in RAC have limited opportunity to consider choices and make decisions. Others may have limited capacity to do so or lack family involvement or informal support networks to assist in supporting their choice making.

Through its work, the My Future My Choice project has developed a choice making process that acknowledges the diversity of capacity that exists amongst these individuals and those around them.

Starting with where the individual “is at” and canvassing a range of topics important to them, the process enables each younger person to work through risks, goals and preferences and be in a position to have an informed conversation with an NDIS planner about their current and future living arrangements.

The project has also developed a set of resources that

- Guide the younger person and their decision supporter/s through a choice making process
- Address potential risks that need to be considered by younger people weighing up their options
- Improve SDA providers’ understanding of disability and the complex presentations of younger people in aged care; and
- Identify the need to develop bespoke accommodation and service options that respond directly to this diversity of need.

As well as developing a collaborative choice making process, the My Future My Choice project has built the capacity of all actors involved with the younger resident to acknowledge the importance of learning about the younger person and their formal and informal relationships...factors that are so important for transparent and successful engagement.

The project has also identified where and how to successfully begin the conversation about current and future living arrangements.

Choice making is not straightforward for younger people in RAC

Intended for older people in the end stages of life, RAC facilities are highly controlled environments where younger residents are often isolated and subject to institutionalisation. RAC facilities have a service model that is different to disability services and do not uniformly offer opportunities to residents to make decisions about the many activities of daily living. As a result, younger people living in these settings can lose the capacity to have agency in their lives.

Younger residents are highly unlikely to have chosen to live in residential aged care and their journey into aged care has a significant bearing on their confidence to make major life choices. Involuntary placement in aged care is disempowering in and of itself and results in younger people not believing they are able to make decisions. Many younger people who were part of the My Future My Choice project, did not identify as decision makers in any part of their lives.

This underscores the need to invest time and care into supporting people with choice making. An expectation that people who do not see themselves as decision makers could independently make complex choices about where they live and how they want to be

supported, is unfair and underestimates the impact that living in aged care can have on people's identity and confidence.

Where people have chosen to move to aged care, it is likely to be because of particular family or location circumstances, such as being in a remote area with no suitable disability service alternatives; the breakdown of support arrangements; or the lack of community accommodation following hospitalisation. The conversation about future choices will be strongly influenced by these previous contexts and the experiences people have had that led them to be living in RAC.

The decisions facing younger people in aged care are complex, they are far reaching, and they are challenging. This is especially so when the housing and support solutions younger people need in the community are not available. Managing the expectations of all actors involved becomes a critically important part of the process in these circumstances.

What does good decision making support look like?

Facilitating successful decision making with people who experience personal and structural barriers to making decisions, means addressing a range of factors that contribute to effective decision making.

Our experience is that the following factors contribute to strong outcomes when supporting people with their decision making.

1. Building positive working relationships

Developing and maintaining good working relationships is the basis of successfully working with a younger person living in residential age care. It's also the basis of successfully engaging their formal and informal supports in the decision making process.

Where people need decision making support in aged care, a team approach is critical. While you'll need to develop a solid working relationship with the younger person, that's not the end of the story.

Key staff in the aged care facility can play a critically important role in supporting the younger person when considering and discussing their options. Family members and significant others with whom the younger person has rapport and trust are also an important part of the younger person's support team.

Building and maintaining positive working relationships with them all is the bedrock on which all else stands in the aged care context.

As with any relationship, developing trust with a younger resident and those around them takes time. Weekly meetings involving the younger resident and their decision supporter/s has proven to be an excellent way of building a good working relationship and ensuring that trust in the relationship exists.

2. Be prepared

The aged care sector is undergoing significant change and those providers supporting NDIS participants have also had to contend with two separate regulatory systems – the NDIS Quality and Safeguards Commission and the Aged Care Quality and Safety Commission – and the additional workload this has delivered.

Before introducing yourself to a Residential Aged Care Service Provider, ensure you know about and understand the aged care environment and be clear about your own role and what you have to offer.

As well as an awareness of the aged care sector ‘landscape’, be sensitive to the pressures that residential aged care providers are subject to, including with their workforce, standards compliance and the way the NDIS impacts on their service.

Things to know about aged care services who provide care to NDIS participants include

- Residential aged care is intended and resourced to care for frail older Australians in the end stages of life. It was never meant to support younger disabled Australians with very different support needs and expectations.
- Aged care is a very contested space in which residential aged care providers are under resourced and time poor. As example, without mandated staff to resident ratios, a RAC service may have ratios of 12:1 or 8:1 compared with ratios of 3 or 4:1 in disability residential services.
- Each RAC facility is funded by the Australian Department of Health (DoH). The NDIS reimburses the DoH for the funding the RAC provider receives to deliver services and supports to NDIS participants in their care. This means the NDIS becomes the sole funder of its participants living in aged care.
- The RAC funding model is not individualised in the same way as the NDIS. The funds that providers receive from the DoH to deliver services to residents, are aggregated or shared across all residents. In other words, aged care funding is not ‘provided’ to individual residents.
- The lack of mandated staffing levels can mean only one registered nurse is on shift to care for 60 to 90 residents or more. The bulk of the RAC workforce is made up of poorly paid ‘personal care workers’.
- Aged care services standards do not address specific disability needs.
- Familiarise yourself with the role and functions of the NDIS Quality & Safeguards Commission; and how it can support NDIS participants in RAC and RAC providers.
- In December 2020, RAC providers caring for NDIS participants were automatically registered as NDIS providers. Already subject to regulation by the Aged Care Quality and Safety Commission, these RAC providers are now also subject to regulation by the NDIS Quality and Safeguards Commission. The cost of this dual regulation and

the administrative load it has delivered has led many aged care providers to refuse to accept NDIS participants into their services.

Finally, familiarise yourself with the aged care service you'll be working with. Are they, for example, a specialist provider supporting a specific group of people? Does the provider support just one younger person or do they have many younger people in their care? Are all their younger residents NDIS participants?

The choices available to people are very different depending on whether they are NDIS participants or not.

3. Working with RAC providers

Establishing and maintaining a positive working relationship is key to working collaboratively with a RAC provider.

The provider may not be aware of the YPIRAC Strategy and Targets and the fact that the federal government has endorsed these as central to addressing the YPIRAC issue in Australia.

The provider and their staff may also have little knowledge or understanding of the NDIS and may see the possibility of the younger resident moving to the community as an unspoken criticism of their care and concern for that person. So...

- Get to know the RAC staff who support the younger resident. As well as knowing the younger resident well, they can be invaluable in supporting the decision making process. Make sure RAC staff are aware of what you're doing and why and seek their commitment to assist.
- Ask the staff to tell you about their service and any concerns they may have about a younger resident leaving their service.
- Ask how you can best support and work with them and the younger person/s they support. Ensure their knowledge of the younger person's needs are shared and that the service is engaged in supporting the younger person to make an informed decision, whether that is to move to the community, or stay in RAC at that time.
- Assure the provider you are keen to work with them and will make sure they are kept up to date and directly involved in the process.

4. Before meeting the younger person

Gather all available information about the individual you are about to meet.

This information should be available from the aged care provider, the support coordinator, and the person's NDIS plan as well as their aged care record. Look for information that indicates

- How long the person has lived in residential aged care.

- The pathway that led the person to move into residential aged care.
- How long the person has been an NDIS participant and what goals are included.
- Their formal and informal supports.
- Whether the person makes their own decisions, has the support of others and/or likes the support of others to make choices and decisions.
- Ask the aged care provider to help complete the template, *Initial information about younger people in residential aged care*, about the younger person in their care.

5. When meeting the younger person with or without a decision supporter: presume nothing!

- Do not assume the person knows why you are there. Some younger people living in residential age care have no idea they are NDIS participants and have an NDIS plan. They are unlikely to have heard of the YPIRAC Strategy and Targets.
- Do not assume that younger people living in residential age care are able to engage independently. Many will require supported decision making assistance to engage in considerations of their current and future living arrangements.
- Do not presume younger residents can easily make choices and decisions or that they see themselves as decision makers. They don't!
- Understand that, for a younger resident, the decision to move involves trusting in the unknown and that for many, the devil they know is preferable to the unknown quantity of community living.
- Be aware that for younger residents, considering such an option can be highly anxious making.

It's critical that you take the time to establish a relationship of trust with the younger person so they can rely on the information you provide as you begin to discuss their current and future living arrangements.

But... **do not begin the conversation by asking if the person would like to move.** Instead, start by finding out a little about the person and their life before aged care.

Talk about what the person does like about their current living arrangement and what they'd like to change.

The template *Guide to gathering information through conversations* includes conversation prompts to help you learn as much as possible about the younger person. But it is best to start the conversation with 'where the person is at'.

As you build your relationship with the younger person, gather information that can answer the younger resident's questions such as: What are the things I need to know before I consider anything? Who are the people I would like to have involved who can help provide this information and help me with my choices and decisions?

Things for the younger person to consider can include

- Preferred location
- Safety concerns
- Preferences, such as living on one's own; returning to the family home; or sharing with others and if so, with how many
- How support services will be organised and delivered
- Type of housing: apartment living, share house, duplex/villa arrangement, shared supported setting, communal living
- Community amenity required: close to shops, supermarket, public transport, hydrotherapy pool, library, family, social networks, health services
- The person's likes and dislikes. For example, sharing with compatible others who don't stay up late or have wild parties
- Preferences for managing food in a shared setting.

6. Encourage collaboration across the board

It goes without saying that the best outcomes and solutions occur when collaborative partnerships with the younger person, their service providers and the younger person's formal and informal support networks are established and maintained.

As well as NDIS support, many younger residents will require support from a number of other service systems including health, mental health and housing. To promote the integrated service response younger residents commonly require, encourage all service systems that the person needs to use to share information and collaborate.

Assist the younger person to identify their support network, each person's role and how they provide support; and understand the value their support network provides.

Help the support network members to develop a shared understanding of the person's disability and how it has impacted their life. For example, will the person's disability and any disability related health supports influence the alternative accommodation and support options they may choose to explore? As example,

- Younger people living with psychosocial disabilities may not meet eligibility requirements for Specialist Disability Accommodation (SDA) and Supported Independent Living (SIL) settings.
- Younger people with dual disabilities i.e., a person living with Down syndrome, young onset dementia and fragile diabetes; or acquired brain injury, unpredictable epilepsy and mood disturbance will require very different support and housing responses if they choose to move to community living.

It's also important to consider how any new living arrangement will meet the younger person's physical, social, emotional and community needs and connections.

Accommodation requirements, individual preferences and support needs should therefore be considered as parts of a whole, not as stand alone items.

7. Building and maintaining the support team

A team approach is a vital part of good practice in supported decision making. Bringing the younger person's formal and informal support network together to work as a team is an important part of the choice making process.

People that can be included in a team around a younger person can include

- The RAC provider and their staff
- Disability, health and mental health providers already involved or who may need to be recruited to the team
- Allied health personnel already involved or who may need to be recruited to the team
- Support coordinators
- Disability support workers
- NDIS planners
- SDA and SIL providers
- Guardians
- Advocates
- Family: parents, siblings, other family members
- Friends
- Acquaintances
- Colleagues
- Other people in the community.

In the first instance, the younger person and their trusted decision supporters work through the conversation topics outlined in the [Guide to gathering information through conversations](#).

Once this information has been gathered, the team is brought together to provide any additional information including allied health reports, disability support worker input, or aged care provider information.

This information is important to help translate the support the younger person needs, from an aged care context to that of community living. It will also assist with developing an integrated service response if the person decides to remain in RAC for the time being.

Once the younger person's choice or preference has been expressed, the team then plays a central role in validating that choice and helping to develop and sustain a transition process that supports the younger person to turn their choice into reality.

Regular meetings with the younger person and their support team are important to secure trust in the work being done by ensuring everyone is kept up to date on progress, problems and concerns that arise are addressed early and the team continues to collaborate to achieve the chosen outcome. These regular team meetings remain in place after the younger person has moved to their chosen home to support a 'settling in' period and manage any concerns that may arise.

For younger people who choose to remain in RAC at that point in time, the team works to integrate supports from other service systems, such as health, mental health and the NDIS, with the supports the aged care service provides.

The team's aim here is to support delivery of a comprehensive integrated service response that addresses the younger person's needs while they remain in RAC.

Should the younger person indicate they wish to reconsider their decision to remain in RAC, the support team works to support this new choice making process.

8. Preparing for an NDIS Plan Review

Two templates that can ensure a shared understanding exists of the person's circumstances and records any choices and/or decisions they make are

1. *My Social Story*
2. *Statement of the decision I have made about my current living arrangements.*

Both have prompts to guide what to include. Some of this information may have already been gathered if the conversation template *Guide to gathering information through conversations* has been used.

If a decision about current or future living arrangements **has not been made**

- Ensure the younger person understands the planner may ask about their living preferences.
- Discuss what the younger person might say in response.
- Ensure the younger person's preferred supports are involved and available to attend the meeting and that the required resources are available to assist them to communicate their preferences, choices and decisions.
- Notify the aged care provider and ensure they are available to attend the meeting and have prepared any documentation that may be required.

If a decision about the person's living arrangements **has been made**, whether that decision is to move to the community or to remain in RAC

- Make sure the younger person understands the planner may ask about their living preferences.
- Discuss what the younger person might say in response.
- Ensure the younger person's preferred supports are involved and available to attend the meeting and that the required resources are available to assist them to communicate their preferences, choices and decisions.
- Notify the aged care provider and ensure they are available to attend the meeting and have prepared any documentation that may be required.

Where a decision to **move to the community** has been made

- Ensure the planner understands that a dedicated transition process will commence that requires appropriate funding in the plan, including additional support coordination hours, funding for OT and physiotherapy assessments and assistive technology.

Where a decision to **remain in RAC for the time being** has been made

- Funding and capacity to engage with other service systems must be included in the plan as well as additional support coordination hours, funding for OT and physiotherapy assessments and assistive technology.
- For younger people who choose *at this point* to remain in RAC, ensure they are aware that this question will be asked again at the next plan review meeting.
- Ensure that the younger person knows that they can change their decision, and that they just need to tell their support coordinator or their trusted supporters to do so.

Finally...

This guide has described how younger people in residential aged care can be supported to exercise choice and make decisions about their current and future living arrangements.

Fundamental to this approach is a belief that each person has a right to make their own decisions and to access skilled supports to assist in this process.

Because each person will require a tailored approach, the resources, practical assistance and time they require will obviously vary from person to person.

No matter how the process works for each younger person, they need to be confident that their supporters and their team are present for the entire process, including transition to new living arrangements.

Further information

To find out more about the My Future My Choice Project or this guide, contact info@ypinh.org.au



Guide to gathering information through conversations template

This template provides conversation prompts aimed at gathering information to inform the development of a person’s social story; and to record their choices, preferences and decisions about their living and support arrangements. There is no order to gathering this information, the conversation is best to start where the person is at.

PERSONAL DETAILS			
Name:			
Date of Birth		NDIS # (if relevant)	
Preferred contact details			
Name of Aged Care Service			
Person/s assisting & Relationship			
Are there other people you would like to have involved in the conversations			

Gathering information

1. What I like people to know about me

Guiding note to gather the information.

The following conversational points may help the person to share information about themselves for others to learn and understand more about them and help to shape their social story.

- *How would you describe your personality (good sense of humour, easy going, strong willed...)*
- *What values are important to you (honesty, respect...)*
- *Who are the people who are important to you*

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- *What interest or, hobbies do you have? What do you do, where do you go on holiday?*
- *What experiences have you had that have made an impact, or are important?*
- *Do you have cultural needs and interests? Can you tell me about these?*

2. About my background

Guiding note

The following conversation questions are to learn about the person's life & experiences including work, family, housing /accommodation, holiday, adventures, and other pursuits.

- *Can you talk about your background and tell us about where you grew up, about your family, study and work. Situations and circumstances that have made a difference/created change in your life*

3. Previous living arrangements

Guiding notes

The following conversation questions are about understanding the person's previous accommodation and living situations and their experiences of these living arrangements including places they don't want to live or cannot live in.

- *Where have you lived in the past?*
- *What did you like about any of the places you have lived in? Why did you move?*
- *What didn't you like about places you lived? (tips: safety, transient residents, not long term accommodation, too many people, not enough support, in the middle of nowhere etc)*
- *Where were you living before moving into residential aged care?*
- *Were you living with anyone?*
- *Were you receiving support or needing support?*
- *Why do you think that you came into care? What was the situation before aged care?*
- *Did you feel you had a choice about where you live now? Did you have family or friends who made decisions for you or assisted you with the decisions?*

4. Current living and Support arrangement

Guiding notes

The following conversation questions are about understanding what makes their current living arrangement right for them and what improvements or changes would help. Try to take a holistic approach of who the person is, their background and the risks in any current and future situation.

- *What do you like about where you live? What is important about the support you receive here?*
- *What changes would you like and why. How would these changes improve your living and support arrangements?*
- *Have you thought or talked with anyone about not wanting to live here and wanting to know if there are other places that might be possible for you to move to?*
- *Do you know what other options there might be that could meet your needs?*

5. Choice and Decision Making

Guiding notes

- *What are the types of choices and decisions you make every day?*
- *Do you get many opportunities to make decisions, or do you leave it to others?*
- *Are there bigger decisions that you receive support with or like to have support to talk through matters with? Are there people you like to have support you to do this?*

<i>The types of choices and decisions I make independently</i>	
<i>Decisions that I make where I need support or like to have support with.</i>	
<i>Choices & decisions that other people make for me or I feel they make for me</i>	
<i>The people that support me with choices & decisions and the types of decisions they support me with</i>	
<i>What I would like to change about how I make decisions.</i>	

6. The support you need or like to have with making choices and decisions

Guiding notes

- *Would you like to be involved or be more involved in choices & decisions?*
- *What is the support you need or would like to make choices and decisions?*

For example: to have a regular support person who can get you information, take the time to explain the information, give you time to think about the information and ask questions. To have sufficient support of a speech therapist to build my communication skills and resources where required. This may include easy to read prompts or summaries of information.

7. Knowledge of NDIS and your NDIS supports

- *Do you know how your NDIS funded supports assist you?*
- *Do you feel you are involved in planning & making decisions about how to use your supports?*
- *Would you like more involvement in planning meetings with the NDIS?*
- *Would you like to know more about the NDIS and other supports they could provide?*

8. Is there anything you would like the NDIS, the residential service, or significant others to know about your preferences about your living arrangement?

- *Do you want to make any change to your current living arrangement? Are you at this point in time happy with where you live?*
- *Will you tell us if your choice changes?*
- *Would you like to consider other options?*
- *Do you need more time and information to think about this?*
- *What information might be of help?*



Social Story Resource

The aim of a social story is to give the younger person the opportunity to share information about themselves that is consistent, accurate and reflects the person's personality and interests.

Stories will often include quotes and can include photos of important people and events in the person's life.

Guiding note

- *Write the story in the person's voice and include their quotes and words where possible.*

The headings can be tailored to the individual. The aim is to succinctly capture the

- *information gathered from conversations so that it provides a comprehensive, well-rounded story.*

Suggested Headings

- **Introduction to who I am - (My name, age and something to introduce who I am, where I live)**
- **About my background**
- **What I like people to know about my personality, values & culture that are important to me**
- **Activities I like that are meaningful and important**
- **What makes me feel safe**
- **Things that I don't like and people I don't like being around**
- **What makes me laugh**
- **When I am sad What makes me sad**
- **What annoys or frustrates me**

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Peta's Social Story

Hi, my name is Peta and I am 46 years of age.

I was born in PilPil and lived in Treetop for most of my life.

My father bought me and my sister a pony when we lived in Treetop.

I was previously a kindergarten teacher and valued my work with young children to help them learn and contribute to the world.

I had to stop working due to my deteriorating health and at the time a lack of support to assist me in the workplace. The loss and grief I have experienced having left work has had a big impact on my life. My identify and purpose has been eroded.

I live with a neurodegenerative condition so the assistance I need changes and I am become less independent.

I am generous, knowledgeable, and smart.

Activities I find interesting are cooking, craft, reading, writing, going out and socialising as well as movies.

My family makes me feel safe.

For me funny movies and being around upbeat people make me laugh.

I am frustrated by drama and arrogance.

I value my family, sense of humour, my independence and spending time alone to pass the day.

Culture, and opportunities to be myself are important. When I am sad I try to see the funny side of things.

I look forward to trying new things in the house which will become my home.

I have always liked meeting new people and look forward to getting to know the other residents in the new house and them becoming my friends. Spending time together and learning together are important.