



This Guide is part of the National Alliance of Capacity Building Organisation's (NACBO) My Home, My Way project.

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Printed version: info@ric.org.au

PDF: Download from

https://www.myhomemyway.com.au/

# Thank you

We acknowledge the traditional custodians of the lands on which this book was produced. We pay our respects to Elders past and present. We acknowledge the profound knowledge and kinship that Aboriginal and Torres Strait Islander peoples have to Country, and how they have continued to nurture the lands where we live, create community and call home.

For that we are truly thankful.

Thank you to all those who generously shared their stories, to help others imagine the possibilities. We acknowledge the tremendous leadership of people with disability and their families, who have pushed the boundaries for us to learn from and take the necessary steps to support someone to create a home of their own, and live life on their own terms.

This Guide has been created by the National Alliance of Capacity Building Organisations (NACBO)

















# How will you make this happen?

Moving out and deciding to live in your own home is a big decision. This Guide will provide you and your family, friends and allies with information and exercises to help you plan this life-changing step. We encourage you to take your time to work through the Guide. You may even find it helpful to keep a journal of your journey. This Guide is intended to be accompanied by the My Home, My Way Workbook.

Complete exercises in the Workbook

To download the My Home, My Way Workbook visit https://bit.ly/MHMW-Workbook

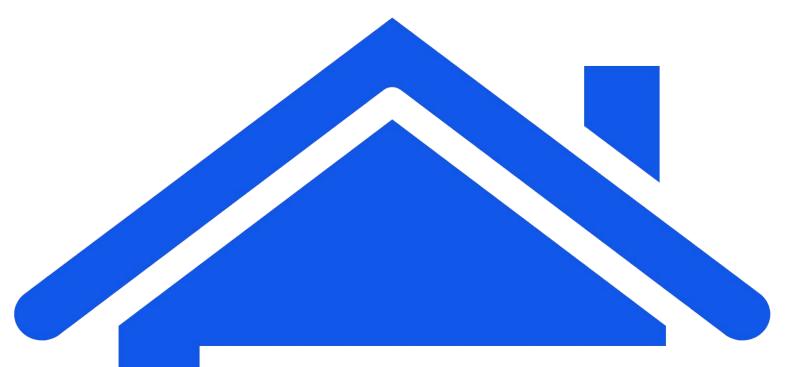
This Guide forms part of NACBO's My Home, My Way project, which offers practical advice, activities and stories of people with developmental disability living in their own home, making a home on their terms with support from their allies and families. There are plenty of videos, podcasts, tip sheets and other resources for you to explore! Visit www.myhomemyway.com.au

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For most of us, moving out of the family home is a rite of passage into adulthood. While it can happen at different ages, when it does happen it provides us with an opportunity to develop and explore our sense of self, separate to our parents.

Growth is ongoing and our ideas of home can change many times throughout our life. Home changes just as we do. What worked for you when you first moved out at 18 is different to what it looks like at 25. It may be very different then to what you want from home now. As relationships, interests and sense of self change over the years, home also changes to reflect this.

A home is developed and supported over a lifetime.



## What is a home?

### Home is a place just for ourselves, where we can grow.

A home is more than just a physical, accessible and affordable space.

Home is about who we are, and how we choose to live in the privacy of our home.

Home is where we feel grounded, secure, comforted. Where we feel safe to process our thoughts and emotions. A home of our own doesn't mean living alone. Although it can, most of us seek companionship.

Home gives us a place for making memories, a place for relationships and to explore who we are.

For all of us, moving into our own home is a **rite of passage into adulthood**.

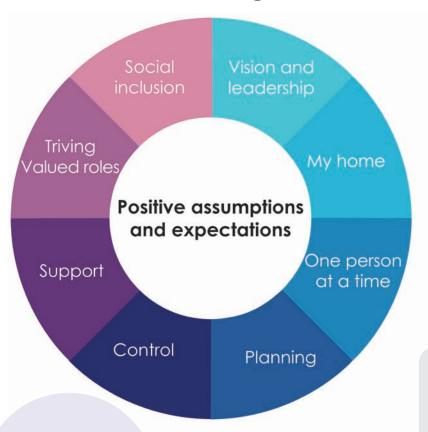
There is no such thing as being completely prepared to live in our own home, as often we don't learn the skills necessary until we start to live in our own home!

A home of my own means I get to decide who I live with, how I live and where.

Everyone's home is unique.

# Australian Research: Individual Supported Living (ISL)

### Australian Research gives nine elements for a successful home



Pictured in the diagram are nine elements that are needed to create and maintain a thriving home for a person with disability.

This diagram is drawn from research that followed the journey of 130 people with disability already living in their own homes, in a unique and individualised way. The research was conducted by a joint team of Australian universities from Curtin, Deakin, Sydney and Melbourne universities. (Cocks, E. et al., 2017).

Cocks, E. et al. (2017) Quality and Outcomes of Individual Supported Living (ISL) Arrangements for Adults with Intellectual and Developmental Disabilities.

https://bit.ly/IndividualSupportedLiving

You can use this framework to think about your home



#### Plus

- Individual Supported Living (ISL) Manual 2nd Edition https://bit.ly/IndividualSupportedLiving2
- Individual Supported Living (ISL) Report for Participants https://bit.ly/IndividualSupportedLiving3

### PART 1: FIRST STEPS

### Ask yourself:

What makes a place feel like a home?

What are the essential elements of a home that are important for all of us?

What would 'unmake' a home and how do we avoid this from happening?



Community Resource Unit (August 2019) CRUcial Times – What It Means To Create A Home Issue 55 https://bit.ly/CreatingAHome

Mamre Association. Pave The Way (2013) A Place to Call Home https://bit.ly/PlaceToCallHome1

Belonging Matters (2019) Tip Sheet - Home! https://bit.ly/HomeTipSheet



### A Typical and Ordinary Home

### Thinking typical

Regardless of whether you have a disability, what makes a place feel like a good home is likely to be similar for all of us.

With this in mind, what is the starting point when designing and planning for a meaningful home?

We suggest using the lens of 'thinking typical' before beginning. Consider the questions "What makes a place feel like a home?" and "What features of home do we all appreciate?" and use them as a guide throughout.

#### Person-centred

Work with the person with disability to design a home that reflects what they want, their unique personality, interests and needs. Ask them "What would work best for you?" or "What would make your ideal home?" including any specific things to consider about the person's disability.

### Home 'unmaking'

Take care to watch out for things that could unmake a home, leading to situations where a person feels

- · uncomfortable, regimented, unsafe, not in control of their own home
- like a guest in someone else's home or filling a vacancy
- like their home has become someone else's workplace, e.g. a clinic or medical facility.



For more on this, read:

Notes from Michael Kendrick Workshop held on 22 April 1991. *Quality Criteria – Accommodation.* Notes taken by Wendy McGlynn. Family Advocacy Inclusion Collection No. 10157. https://bit.ly/MHMW-Kendrick



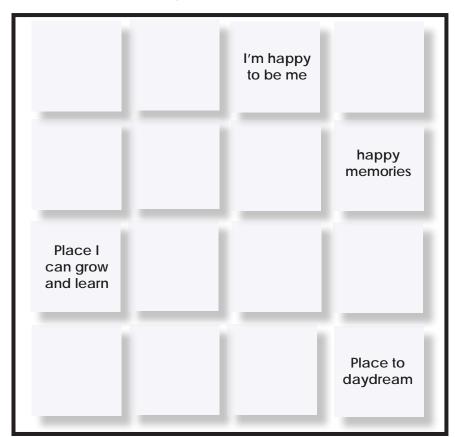
### What makes a 'good' home are largely universal ideals.

The functional and material features of a home would be different, as that reflects our unique style and needs. But deep down, what makes a home means much the same for all of us.

### Use the following exercise to brainstorm with others.

"For all of us, what makes a place feel like a home?"

### What makes a good home for you?



# What happens when it is not a typical home environment – when home 'unmaking' occurs?

"A group home does not solve issues of loneliness and isolation but can actually accentuate people's difficulties and sense of isolation. Vacancy management, poor matches, inadequate supports and poor need assessment can create and exacerbate a range of emotional, communicative and behavioural difficulties. The alternative to group homes is not necessarily living alone, or living a lonely life. Instead of investing in group homes, funds need to be invested in a range of ordinary housing options, alternative supports and the strengthening of the skills of support people."

- Family Advocacy Newsletter, Autumn 2008, Volume 3, Issue 5 https://bit.ly/FamilyAdvocacyNewsletter

"People with disabilities would not be well served in the limited life options available within group homes, particularly those gathered together in institutional sites. This is because they will be deprived of a wide variety of everyday, but rich and diverse life options that are freely available to ordinary citizens of our communities but denied to people with disabilities in the name of abstractions like 'care' and 'service', but which provide largely only custodial existences compared to what is possible when people with disabilities have authentic access to the fullness of community life."

#### - Michael Kendrick



Michael Kendrick (2017) Why Group Homes are No Longer Optimal: A Commentary https://bit.ly/MHMW-Kendrick1





"Jacob has really taken to living on his own and being in charge ...you can see he is up for a social gathering that he has initiated with support and he is doing a lot more on the weekends, and you can see how engaged he looks on his face. I feel like it's made a difference to the people around him because we know it's what Jacob wants." Melanie, member of Jac's circle of support

"One thing that I've noticed, from my perspective, and I know it happened with me when I moved out of home, and a lot of my friends when they moved out of home, was how much Jacob and Linda's (his mum's) relationship has changed since she's moved out and he's been living independently ... living without his mum around all the time ... I think the friendship side of their relationship has deepened a lot more. The dynamic's changed." Jac's crew

### Vision

### Importance of vision

Having a vision of what makes a Good Life lets you take control and be clear about the direction you are heading. A vision directly influences our imaginations of what is possible.

This is why it is so important that the vision not only reflects the person, but also offers a life that is rich with hope, possibility and potential.

"To craft the Good Life we need to do the hard work on clarifying and sustaining our vision of what we want, not what others tell us are the limits of what is possible. If we try to choose in a vacuum, not know what it is we really want, others will choose for us."

Jeremy Ward, parent advocate



### What is a vision?

A vision can consist of simple, clear statements about what you consider important for the person with disability to have a Good Life. The clearer the vision, the easier it will be to plan and, importantly, the easier it will be to stick to the plan.

You don't have to know how the things in the vision will be accomplished right away, as more planning can come later. You just need a sense of what would make an ideal home life for the person. This will help to guide your decision making.

"A vision is a mental picture of life in the future that is life-giving, helps us to reach our full potential, and builds on our strengths, interest and gifts." - Michael Kendrick

### Cameron's vision

### My vision for the future

To have a full, meaningful and inclusive life in my local community.

This means having the same opportunities as everyone else.

A home of my own [not a group home] in Warragul that reflects my tastes and preferences.

A housemate I can go to the pub with.

Be a valued and contributing member of my community.

A paid part-time job.

Get to know people in the community through my interests and passions.

Friends who care.

A dog.

Being independent, getting out more.

Being healthy and content.





#### Vision for home

Complete the exercise in the Workbook page 3

#### Think about:

- Where close to transport, shops, work, connections, neighbourhood
- Type of home unit, apartment, house, multilevel
- Size of home number of bedrooms, living spaces, bathrooms
- · Features garden, decor, accessibility, light, style
- Who with alone, housemates and their qualities, pets
- Price budget, how to make it affordable
- Supports, natural and paid
- Community and roles
- Preferences; likes and dislikes.



### Leadership - Who can be the vision keepers?

Complete the exercise below in the Workbook page 4

It's important to gather a number of people who know and care about the person, to help create and bring the vision to life. These people will also provide an important safeguard for the person's future.

#### **Brainstorm**

- 1. A list of people who would be great at providing leadership, both now and in the future.
- 2. A list of people who can help you create your vision and who to share it with.

### Trust your gut instinct and be creative.

If you think someone could be great at this role, write down their name, even if you think they may be too busy or are located in another state or country. You never know!

### Overcoming fears

For those of us who have moved into our own home – when we think back to that time in our own lives, chances are both we and our parents had some concerns and worries. A lot of these were probably very justified and reasonable.

We all share feelings of missing family, the family home and friends, and of feeling lonely, stressed or anxious that there's too much to manage.

All these feelings are normal. But it's important to move beyond fear.

"Too many of us are not living our dreams because we are living our fears."

- Les Brown

### Whose fear is it?

### What if the person with disability does not want to move out?

They might be having thoughts such as this:

- "But I'm afraid to move out ..."
- "What do you mean 'move out'?"
- "I live here, this is my home already. I like it here."
- "Don't you want me here anymore?"
- "If I move out, does that mean I can't come back?"
- "I can't manage on my own."



### The person with disability's fears



It is a big choice to move out. Perhaps the choice is overwhelming. Perhaps the idea of moving out is too unreal for the person you're supporting. For so long, people with disability have often not been given the choice of their own home or even been allowed to think it was possible.

How can we better understand the anxieties and fears that the person might be going through?

How can we better support the person to name those anxieties and fears, and to communicate and share it?

Tips for family/allies to support the person with disability overcome their fears

### The person with disability's fears

- If the person is involved in the planning and decision making, is able to move at their own pace and has space to talk about their fears, they usually do well.
- As allies, it may be helpful
  to reflect on our own
  experiences and feelings
  when we first started living
  in our own place, and to
  share it with the person
  with disability "It was an
  exciting time for me, having
  my own place, but I was
  also worried too."
- Consider asking other family and friends to also share their experiences.
- Arrange for someone who the person knows well, to show them their home and how they have set it up.

- Support the person to test it out! Get an idea of what it means to have their own place, especially if the person has never had that experience before (see stories from Lincoln, Gus and Cameron for examples of this). This may also assist you to figure out the supports needed when the real move comes. This is a useful strategy for overcoming fears.
- It may help to leave the person's bedroom in its original state in the family home until they are clearly settled, and to have a conversation with them about it.

### Other people's fears

For a person with disability, it may be the fears of others that can be the most significant barrier to moving out. Understandably, family members and professionals may be concerned about the impact of the person's impairments, their physical and personal safety, or a perceived lack of readiness: "Will they be safe? Are they ready to move out?" Anxiety can protect in the right amounts, but it can also stop a person with disability from

living their daily life, their full life potential.

In having those fears, family members and others might assume that congregate living arrangements (like group homes) are safer options. Unfortunately, there is much evidence that living in such settings exposes the person to loneliness and the risk of abuse. Australia's Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020) found



### Other people's fears

that group homes are still places of abuse and violence for people with disability, <a href="https://disability.royalcommission.gov.au/">https://disability.royalcommission.gov.au/</a>

Try not to focus on "When will the person with disability be ready?" Instead, remember back to the time when you first moved out of your family home; it was only once you lived in your own place that you learnt many of those life skills.

### Tips for overcoming fears

- It is important to know who's fear it is and to support each person to work through those fears.
- Write down the fears, anxieties and barriers. Then break it down into clear, manageable parts to come up with ways to address each one – do the exercise in the Workbook page 2.

- Ask and learn from others:
  - How they overcame their fears and anxieties.
  - o Do they recall the time when they first moved into their own place; what did they learn about themselves; what life skills did they learn quickly?
- Learn about safety. Try to get specific and then identify learning strategies.
- Problem-solve as you go, but agree that not everything has to be (and can't be) solved at once.





### Parent's fear: a mother's reflection

Story by Brodie's mum, Justine

https://bit.ly/ MHMWBrodiesStory

"No-one is ready to move out of home, until they move out of home" Brodie recently became a qualified personal trainer and has a job as a fitness trainer in Victoria. Brodie lives in a three-bedroom house that he rents with a long-term friend of his. It has a large garage they have made into a gym, because fitness and bodybuilding are Brodie's passion. Like any young adult, Brodie moved out of home in his early 20s. He's been living in his own place for about four years.

Brodie's mother, Justine, remembers the day that he moved out:

"I didn't really feel prepared at all, probably because it all happened quite quickly. The predominant feeling was fear, – fear of things going wrong, but over and above that I was really excited for Brodie. It was such a big milestone and he was so ready in terms of what he needed for his own happiness and his growth as a person.

"There's been trials and errors, and things that have gone wrong just like anyone, just like life.

"I've needed to learn how to let go of control – over needing to know everything that's happening and everyone that's there. And so, stepping back and releasing, I saw it as handing Brodie the reins to his own life

"It's the moving out of home that enables the independent living skills. That's how we all grow and develop.

"There're a few different strategies I've found really helpful. The first one is talking with Brodie and perhaps



with others, maybe in his circle, maybe his housemate as well. I put forward my wonderings around different ideas now. But being careful not to project my fears onto him at all. I try to put it in neutral terms like 'I'm a little bit worried about this' and then just seeing what his thoughts are. Most of the time, he's already thought through those things and he's already come to his own conclusions, and that's a really good way for me to relax.

"Quite often as well, when I run it through other people – this is one of the advantages to having peers around who don't have disabilities, but are similar age to Brodie, that I get their feedback from a point of view of a young person.





### Overcoming fears: Test and try

### Three stories of how people have overcome fears

A really useful strategy is to test it out! There are lots of ways to do that.



### Lincoln's Story

https://bit.ly/ MHMWLincolnStory

### Imagining my own home

Lincoln was unsure about moving into his own home until he had the opportunity, at a planning meeting, to express his vision for his own home. This video captures the planning, his Airbnb stay and moving day.





### Cameron's Story

https://bit.ly/ MHMWCameronsStory

#### The Housesitter

Cameron explored what life in a home of his own could look like by housesitting for a family friend. His experience showed that he's was ready to move out with carefully-crafted support in place.





### Try a staycation like Gus!

April 2021: Beach getaway, 3 days/2 nights-stay booked via a holiday rental website.

- Gus spent a beach holiday with his mentor to practise living away from the family home. This was Gus's first time away without his parents.
- The experience was to gain (supported) self-sufficiency: writing a groceries list, restocking the empty fridge, cooking healthy meals, learning recipes, first-time experience as a housemate, and troubleshooting problems together (e.g. blown fuse).

May 2021: Local getaway, 11 days/10 nights-stay in his local area.

- A two-bedroom townhouse was booked through another holiday rental website.
- Living in his local area, Gus was able to continue his routines but from his own place.
- Two mentors and his brother visited and took turns staying overnight, continuing the experience of living with new housemates.
- Gus embraced living in 'his pad' and he invited his parents over, hosting them twice for afternoon tea and dinner.

#### To achieve this:

 Gus had a goal of moving out in the next few years and



### Try a staycation like Gus!

planned to test options in the meantime. He used the following funding from his National Disability Insurance Scheme (NDIS) plan:

- Daily Activities Short-Term Accommodation and Assistancefunding 1:3 for weekdays and Saturdays.
- o Flexible core funding.
- Arrangements with mentors:
  - o Mentor 1 was found via an online platform that helps find and match support workers and mentors. They were paid according to the platform's formula for hourly support, overtime, evenings and sleepovers.
  - o Mentor 2 was directly employed by the

family and was paid according to the Social, Community, Home Care and Disability Services (SCHADS) Industry Award covering ordinary hours, overtime, evenings and sleepovers.

During the COVID-19 pandemic lockdown:

- Gus and his family looked online for houseshare listings to get an idea of the types and costs of local accommodation.
- Gus focused on building his skills while still living with his parents, including cooking his meals, washing clothes, cleaning etc.
- Gus also bought a couple of pieces of his own furniture to bring into his new place.



### My biggest fears, barriers and resistances

Complete the exercise in the Workbook page 2.

- What are your current fears, barriers and resistances about moving out of home?
- What steps could you take to overcome these?
- Have you heard any useful tips from others?

### Useful tips/strategies from others

Use this space to write down useful tips you've heard from others!				

## Belonging in the Community

#### **TIP**

Do things at same time at the same place, frequently. This can invite conversations, reciprocity, and, finally, connections. A home is more than just the physical property and more than just a shelter. Our homes are embedded in our communities, and so home is often a launch pad into community.

**Belonging happens when** the person is well known to others because they have

- a regular, visible and predictable presence in the community
- valued social roles (page 34) where they are actively participating and contributing to their community, workplace, places of learning, recreational activities and social environments.



Read this beautiful chapter on how Neil Barringham goes about developing connections between ordinary members of neighbourhoods and individual people wanting a greater sense of belonging. His work is distinguished by simplicity, the importance of spirituality, and the importance of solidarity.

Barringham, N. (2005) Assisting Communities To Be Welcoming. Taken from chapter four, page 44, Community Resource Unit (2005) Like a sweet cup of tea: shared lives, neighbourhoods and communities. https://bit.ly/WelcomingCommunities

# Community happens because we are active in it

Explore typical community places that are connected to the person's interests.

Here's an exercise on how a person's interest or pastime can be strengthened from merely being present, to actively participating in community and ultimately making a contribution.

	Being present	Actively participating	Making a contribution
Neighbour	Be physically present next door, know their name.	Greet or chat to the neighbour every so often.	Be a good neighbour by sharing recipes or food, picking up their mail, feeding their pets or watering their plants etc.  Organise regular walks together, or other social catchups.
Football Game	Sit in the stands at games as a spectator.	Sit with loyal fans and join the cheer squad.	Join the supporters club and attend regular meetings to support the team.
Shopping	Be taken to a store and have someone purchase items for you.	Select items from the store for yourself and present them for purchase.	Shop regularly at a local store and become known as a valued customer. Greet staff by name and be greeted by name.





#### **Developing Community Connections**

In the Resourcing Inclusive Communities workbook, learn sixstrategies that can enable people with a disability to be active and contributing members of their communities and create the possibility of friendships (PDF)

### **Valued Social Roles**

### Valued social roles are roles that are typically valued by a society. Holding valued roles generally affords people the good things in life.

Tips from families about Valued Social Roles:

- Look for roles that are valued by society.
- Start with a person's interests, passions, strengths and gifts when exploring a range of possible valued roles – dream big – and support the person to build their competencies for that role.
- Make a list of community places where the person can contribute their gifts and interests.
- The more valued roles a person has, the more experiences they'll have and greater opportunities to develop reciprocal and genuine relationships.

#### Things to avoid:

 Avoid activities and arrangements that do not offer pathways into a genuine role or can limit a person's growth because of low expectations. For example, 'special' work or community arrangements, or special places that are specifically only for people with disability.

### PART 2: MAKING MY HOME

"You can help someone to make a home; you can't simply give a person a home." - Janet Klees



### Making My Home My Own Means:

- Home is unique to me e.g. my routines, my roles, my supports.
- Home is my private and personal space, not public or someone else's workplace.
- I can choose who I live with.
- I have natural authority and control in my home. I have direction over my life.
- Home is where I learn, grow and develop. I get the chance to explore just how capable I am.
- Home is where I solve problems, and also make mistakes that I can learn from.

# Preparing to Move – Things to Think About

When a person with disability is given the chance to make their home their own, and to have typical adult roles like tenant or host, they can thrive and grow!

Leading up to the big move, encourage the person to take up more valued roles in their current living situation.

As a parent or support worker, you might think "it is easier if I just do it". For example, taking the dirty plates to the sink, washing up etc. Consider where the person can be provided with more opportunities to take on some of these day-to-day roles. Perhaps the person may already be expressing a desire to do something with more independence. Being open to opportunities like this can be an important stepping stone to many more things.

However, try not to get stuck on notions that the person has to continually train until they are 'ready' to move out.

It may not be realistic to expect someone to learn all the life skills while still at home. There's something about learning as you go or learning on the job. This can bring a sense of pride and achievement. For many of us who have gone through the experience, we know that we only learned to live in our home when we actually started living in our own home!

#### Valued roles in the home

In this part of the planning, supporting a person to take on valued roles in their home is an essential element to making a home.

People grow and develop into a range of new roles that are likely to come along with having their own home. Think about some of the typical roles a person might take up in and around their own home – roles that allow a person to have as much responsibility and control over how their own home is run, e.g. primary householder, homeowner, tenant, housemate, homemaker, host and neighbour.

Roles are usually accompanied by

- responsibilities or duties
- expectations
- · behaviours or activities
- obligations
- privileges.

#### Roles can change over time

Consider how both the person's roles may change over time, but also the roles of those closest to them. Over time, as the person takes up their newfound roles and skills, and thrives, this can be a wonderful opportunity for family and allies to adjust their roles and actions to match the person's progress as they take on more responsibility within their home.

#### Valued roles in the home

Role example: Homemaker

Duty example: Maintaining the garden

**Responsibilities** keep the home space tidy inside and outside.

**Expectations** garden is maintained regularly;

**Behaviours** person regularly waters, weeds, mows the grass

(or a person is supported to do so).

**Privileges** the person decides what grows in their garden,

how it is maintained and how frequently, and who to do it – either by the person themselves

or hiring a gardener.





#### **Making My Home**

Complete this exercise in your Workbook page 5.1. In doing this exercise, think of the valued roles and skills for both

- · the person with disability and
- those closest to them or providing the support.

#### Start by writing down

- 1. What new roles might the person take up in their new home?
  - What new roles might others have?
- 2. What comes with these new roles? You may want to consider breaking the roles down further.
  - What are the typical responsibilities, expectations, behaviours, obligations, privileges are associated with that role?
- 3. What **new skills** will the person need to learn in their new home. Include skills that a person does not need to be able to do independently, but which can be done with the right support, if needed.
  - What new skills might others need to learn to be able to better support the person in their new home?



#### Making My Home

Complete this exercise in your Workbook page 5.1. In doing this exercise, think of the valued roles and skills for both

- the person with disability and
- those closest to them or providing the support.

	What new roles might the person take up in their new home?	What comes with these new roles? Eg. Responsibilities; expectations; behaviours/activities; obligations; privileges.	What new skills need to be learned in their new home? These can be skills that a person does not need to be able to do independently, but which can be done with the right support, if needed.
Person with disability	Dinner Host	Sending out invitations.	Creating a fun guest list; learning how to send an invite; following up on confirmations; deciding menu, dinner party atmosphere; opening the front door safely.
	Renter	Arrange regular bank transfer to pay the real estate agent the rental amount.	Setting up bank account, learning how to budget to pay rent and bills, learning the language of renting, knowing how to contact the real estate to check rental payments and receipts etc.
Others closest to the person	Visitor	Visitors and guests don't drop in unannounced.	Parents learning to contact the person before arriving.



Story and activity: Dee's home

https://bit.ly/ DeesHome



What did you notice made Dee's home her home?

What did her home tell you about Dee's interests and likes?

Think about how a person might express their tastes, and their natural authority and control in their home.

#### For example

- choosing furniture and decor
- · the colour of the walls
- where things go
- the mood
- the routines: when to go to bed/get up, what and when to eat
- who comes and goes
- · garden, pets
- collecting mail.

## Who's Really in Control?

Research shows that a person with disability is more likely to thrive in their own home when the person has

- control over their own life, with the support of those closest to them. For example, on how funding is spent and who provides support
- control over their own home, with the support of those closest to them. For example, who comes into the person's home, who holds the key
- self-determination the person has opportunities to make decisions and change their mind, including the dignity to take risks and make mistakes.

(Cocks, E. and Thoresen, S. and McVilly, K. and O'Brien, P. 2017).

### **Supported Decision-Making**

The dilemma of supporting choice for people with disability has always been complex and nuanced (and perhaps even more so since the NDIS). People with disability can sometimes be at risk of losing their right to decide, or at the other extreme, be abandoned to their 'choices'. For all of us, choices and decisions are sometimes hard to make, and we often seek the support of others to consider all our options and weigh up the pros and cons. For people with developmental disabilities, they may have few life experiences to draw on to make informed decisions, or find it difficult to relate consequences to a particular decision.

Supported decision-making is an approach to give a person with disability the support they need, to understand, make and act on decisions about their life, and have those decisions be heard and respected. In turn, this strengthens a person's decision-making and problem-solving abilities.



In this video, Emily Raymond explains how to best support her to make decisions

https://bit.ly/ EmilyMakesDecisions



#### Think about some of the important decisions made at the person's home.

For example, who comes into the home and when; money and finance; what happens and when; who has the keys; decor; routines; what is done at home; choosing support workers; going out (when, where and who with); clothes; personal care, etc.

#### Now think about:

- Who is currently in control? For example, support workers, parents?
- Whose responsibility is it really? For example, the person's, the housemates?
- · What steps can you take towards shifting control?



Do the Exercise on Supported Decision-Making – My Home My Way Workbook pages 6 and 7.



## Settling in

#### Moving at the person's pace.

Moving and adjusting to a new home is different for all of us and there can be many things to deal with at once. These things can be exciting, momentous or stressful. There are likely to be new people, new sounds, smells and lights to get used to, and new routines to create.

#### **TIPS**

- Plan what will make the transition easier? For example, staying one–two nights per week in the beginning.
- Plan what are conditions for success?
- Support people through change it's part of life.
- Review, reflect, communicate, plan again don't give up.
- Tweak supports where needed.
- Think about what needs to happen before and during the move, and as the person gets used to their new home.
- Support the person to meet their neighbours they're an important safeguard and connection.





Helpful Tip Sheet by Belonging Matters: 'Settling in to Your New Home!'

https://bit.ly/NewHomeTipSheet

## **Thriving**

### How do you know when the person is thriving in their new home?



- "The more opportunity to thrive, the more the person will develop and contribute. Once they have some of the good things in life, they will want more, and more will come to them."
- Belonging Matters

## What if the person is *not* thriving in their new home?

"If someone is not thriving after a settling-in period, don't give up. Review and reflect – what's not working, what needs to change and what support is required?"

- Margaret Rodgers



https://bit.ly/ CameronsStory2



### Home and Belonging by Belonging Matters (8 mins)

Cameron Skinner lived with his parents, Maggie and Greg, but always knew he wanted his own home. With the support of his folks, his friends, and some brilliant housemates, he is now thriving in his own home.

In this video, notice what natural and paid supports Cameron has.



#### Michael Kendrick

https://bit.ly/MHMW-Kendrick2



### The importance of Home and **Fulfilment**

Michael says, when making a home, "your level of disability is not the important issue, but is the home arrangement helping you thrive?"

"The happiness factors are rarely functional only ...Happiness is the engagement of the person and the fullness of their life potential."

The real question is – is the person fulfilling their true potential in their current home? When creating a home, we can always do better.

### **PART 3: SUPPORT OPTIONS**

With or without disability, we all require support and rely on others to live in our homes.

Most of us do not live a life that is completely 'independent' of others. Rather, our lives are full of **inter**dependence – we all rely on our families, friends and acquaintances, our neighbourhood and communities, and services.

Supports based on natural relationships and trust might be referred to as **informal** or **natural supports**. Sometimes informal supports are complemented by supports that we pay for – **formal** or **paid supports**.

There are risks associated with having supports provided by just one service, and by having only paid supports in a person's life. This is because services are paid to be in a person's life and they may disappear once the payment ceases. Having a mixture of formal and informal supports in a person's life can provide stability and an important safeguard.

## Support Options TIPS



- There is no one 'right way' or model of supports to achieve a home of your own home.
- Support should be flexible and tailored to the person's needs.
- Supports should not place too many restrictions on a person, nor should they be determined by rosters created by an agency or service. Rather, support workers, assistants and others should be available when the person requires them.
- Think creatively, no matter what funding you have available.
- Have a mixture of informal and formal supports. Informal and natural supports are important for keeping people safe; therefore, it's useful to avoid an overreliance on formal (paid) supports.
- Look beyond disability-specific supports. You might consider businesses and professionals with skills or tools, who are set up to deliver the required services. For example, a laundry service, a gardener, a meal-delivery service



### **Informal (Natural) Supports**

When we talk about informal supports, we are talking about companionship, friendship, and relationships that offer knowing, familiarity, social interaction, a sense of belonging, and connectedness. And there is very real value in these supports, for all of us. They help to keep people safe, happy and well, and to know that we have people in our life who care about us and who we, likewise, care about. Informal supports can add to and enhance paid supports in a person's life.

Informal supports can be neighbours, friends, family members, or community members who know the person well. By definition they are unpaid, but it is different to being a volunteer.





### Good neighbours, housemates, and dinner circles

Here are a few creative examples of informal supports that have really worked for families:

Creative examples of informal or natural supports that people use:

#### **Helpful Neighbours Housemates Dinner Circles** Derek and his neighbours Jessica was 16 when she let her family When Mena moved into her own home, know she didn't want to live in a her family created a dinner circle. Mena's Derek's neighbour helps him disability share house. With Jessica's dinner circle is a roster of friends, family, to put his meal in the vision in mind, her family explored the community members and neighbours microwave during the week idea of Jessica living with regular who join her for dinner on certain nights of and his friend at the football housemates who are a similar age to the week. Sometimes they cook together club picks him up to go to the Jessica. Jessica loves living with her or the guest brings dinner to share. local match. housemates and living in community. She loves to entertain and have friends Read more about Mena's story and her dinner circles in The Shouted Goodbye over. Jessica met her housemate Coralie through church. Jessica's housemates pay the rent and Cameron's neighbour Sally split the living costs. As housemates, invites Cameron over for a they have dinner together three times a cuppa. She has also got him week and provide each other with Read involved in the street companionship and friendship. They go gardening working bee and to the basketball, football and beach local farmer's market. Sally is together. Jessica's housemates also also an important safeguard if provide her with a few hours of support something went wrong. each week, and they are reimbursed for Listen to Mena's parents' this support. interview on podcast https://bit.ly/ Podcast MHMWMenasStory See more of Jessica's story on page 51.



#### Jessica's Story

https://bit.ly/ MHMWJessicasStory

- "(Jessica)'s with people of her own age, doing things that people of her own age do. I'm not going to provide that. I don't know what 30-year-old wants to do. But other 30-year-olds do" -
- Jessica's mum, Julianne, on why living with housemates of similar age can be beneficial.

**Video: Planning for Home: Putting Trust in Others.** Jessica's mum, Julianne, talks about how Jessica's homeshare came to be.

**Video: Homeshare: Doing Home with Jess.** Jessica and her housemate Coralie interviewing each other about life together.





Homeshare



#### Homeshare tips from families and housemates

- Start the planning early. Take time and care to plan.
- It's not just about finding the right housemate, but also making sure everyone is happy once they live together.
- Involve the person in the housemate selection process.
- Don't 'settle'; wait for the right housemate who gets along well with the person.
- Think about how people would typically choose a housemate. For example, personal qualities, values, attitude or similar age.
- Traditional homeshare relationships are usually based on mutual exchange. For example, "I have a spare room and in exchange you provide me with some support."
- Be clear about what type and amount of support the housemate will provide. For example, be specific about the roles and how many hours per week are required. In most homeshare arrangements, a reasonable recommendation could be that a housemate provides no more than 11 hours of support per week in exchange for free rent.
- You should avoid turning it into a paid or employment relationship and seek advice on associated employment laws if you decide to pay for extra support.
- If advertising, craft the advertisement carefully. People may jump at the mention of 'cheap' or 'free' rent, but may not understand what is expected in the role. You do not need to divulge a person's diagnosis but identify their qualities and what is required.



#### Homeshare tips from families and housemates

- Always complete and lodge a bond agreement, lease agreement and homeshare agreement with each housemate.
- Have a strong induction process for housemates so they get to know and understand the person. For example, what the person likes and doesn't like, and how best to communicate and support the person.
- Support housemates to discuss and create their home together. This may change over time.
- For the living arrangement to feel safe and sustainable, all housemates need to all feel that this is their home.
- Create regular space for housemates to discuss what is working well and what needs improvement. This enables problems to be solved quickly. A neutral third party (not parents) could be helpful.



For more excellent tips on living with housemates and flatmates, read: Anita O'Brien's article (2015) My Home, My Choice, My Housemate which includes some Guidelines on the process finding and selecting Warren's housemates. https://www.19stories.org/goingaboveandbeyond

Maggie Skinner's article (2015) Housemates - A more typical way of living and the importance of clear expectations, open communication, and discussions around private spaces for each housemate. https://bit.ly/19Stories2

Follow Adam's blog and his journey from early stages of planning to moving out with housemates and flatmates. www.adammovesout.wordpress.com.

Belonging Matters (2015). *Thinking About...(Housemates)*, Periodical Issue 23, Melbourne. https://bit.ly/BelongingMattersHousemates





#### Homeshare



### Homeshare example agreement for KellyB, Jo and Justin's home

Jo and Justin are very pleased to have KellyB living in their house but they are worried about a few things and they think KellyB might be too.

- KellyB will not go into Jo and Justin's rooms unless they ask her.
- Jo and Justin will not go into KellyB's room unless she asks them.
- KellyB will not talk to other people about Jo's and Justin's private business, unless she thinks they are doing something dangerous. If she thinks they are doing something dangerous, she will tell a parent.
- Jo and Justin will not talk to other people about KellyB's private business.
- KellyB will not tell Jo and Justin what to do, unless they ask her for help.
- Jo and Justin will not tell KellyB what to do, unless she asks them for help.
- If Jo and Justin do not like something that KellyB is doing, they will talk to her about it. If that doesn't fix it, they will talk to a parent.
- If KellyB does not like something that Jo and Justin are doing, she will talk to them about it. If that doesn't fix it, she will talk to a parent.
- Jo and Justin will not ask KellyB to do their jobs (dishwasher, bins, laundry and so on) for them. If they need help, they can ask KellyB to show them what to do or to help them decide who to ask.
- KellyB will not ask Jo and Justin to do her jobs for her.
- Support housemates to discuss and create their home together. This may change over time.
- For the living arrangement to feel safe and sustainable, all housemates need to all feel that this is their home.
- Create regular space for housemates to discuss what is working well and what needs improvement. This enables problems to be solved quickly. A neutral third party (not parents) could be helpful.

Source: CRUcial Times (2020) Issue 56 https://bit.ly/CRU-56

## Formal (Paid) Supports TIPS

#### Consider using role-based recruitment.



- Identify the need: "What does the person with disability need support with?"
- 2. Identify the role you are looking for: "What skills, values and qualities do I need to recruit for?"
- Instead of looking for 'support workers' consider the right person for a specific role or need. For example:
  - "I need assistance to cook so I'll recruit an experienced cook or professional chef."
  - "I need assistance to shave every day, so I'll recruit a barber or visit a barber regularly for a shave."
- Relational skills Look to recruit more broadly, focusing on skill, values and attitudes.
  - Ask, "Do they get along well with the person with disability?"
  - For example, someone who is great at hospitality may be good at working under pressure and are natural hosts and networkers who can help the person build their community connections. Someone who works in social justice or in the music industry may be good listeners and observers, able to communicate creatively, and serve as good communication role models.
- An important part of the role might be to assist the person with disability to grow their friendships and social networks. This may mean looking for someone who does not define themselves with a particular job description or title, knows the community and how to connect people.

## Formal (Paid) Supports TIPS

#### Compare a wide range of services.



- Include mainstream services, not just disability-specific. By focusing on the need, it might become clear that the best way to meet that need is through using ordinary and typical community or mainstream services.
- For example, someone who has difficulty with fine motor skills in their hands may pay a local dry cleaner to do their ironing, or a hairdresser to wash their hair. Someone who needs assistance with some gross motor skills may hire a gardener to mow their lawn, or a cleaner to do the major cleaning tasks. Consider the benefits to using a local business it's another person in the community who will get to know your loved one because of their regular interaction every week.

"[Paid/formal] supports sometimes have the unintended outcome of supplanting rather than augmenting natural supports that the rest of us take for granted in our own lives. Families, neighbours, community members who might want to be more involved, often shy away because of a perceived lack of opportunity for engaging with the supported individual, or worse, a perception that they aren't needed. Nurturing voluntary, reciprocal relationships in community requires us to step back, to create a space for others to enter in. The challenge before us is to honour the ways in which our formal supports are working, while also recognising the ways in which those supports may in fact be inhibiting relationships."

(Community Living British Columbia, 2009). https://bit.ly/PersonalSupportNetworks

## Formal (Paid) Supports TIPS

## TIP 3

### Balance between natural versus paid supports in someone's life.

When a person's every day is surrounded completely by paid staff, it may not lead to a fulfilling life experience. The financial nature of the arrangement may mean that the relationship ends when the payment ends. This makes it hard for the connection to extend to a level of real friendship. The Good Life is one when we have people in our lives who genuinely care for us and are not paid to be there.

Friends, who are not paid to be there, are important to all people. Often, people with developmental disabilities have few unpaid people in their lives. Invite more people into the person's life. A larger circle of friends and community connections can provide stability and consistency during the transitions between paid staff, and for major life moments such as moving home.

If required, paid supports can have an important role to play and can supplement natural supports. Paid supports can assist with things the person doesn't want their friends or housemates to do; for example, personal care. They can also have an important role to play in developing skills, fostering valued roles and nurturing natural relationships and friendships.

Take the time to consider who is best placed for specific tasks. For example, housemates typically provide friendship and companionship to share a meal in evenings, and contribute to house chores and bills. It is unusual for a housemate to provide daily personal care to another adult housemate.

## TIP 4

#### Consider managing your own funding.

Self-managing your own funds offers more choice and control over the supports and services you engage.

Self-managing allows you to be more creative and flexible about the type of services you purchase. This opens greater opportunities to achieve your goals and get access to the many good things of life.

### Creative paid supports people use to live in their own home



#### Coordinator of Informal Supports (e.g. lifestyle coordinator, etc.)

As well as a key worker who is responsible for managing paid workers or formal supports, one family chose to employ a part-time Coordinator of Informal Supports. The coordinator's role involves helping the person to maintain existing relationships and seek out opportunities to build new connections. Having a dedicated team member means that this very important part of the person's life gets the same focused attention as the oversight of paid support.



#### **Coordinator of Home Supports**

Some families chose to employ a part-time coordinator for the homeshare arrangement. The coordinator's role oversees the houseshare living arrangements, including advertising, selection and induction process of housemates, supporting all housemates to adjust and maintain relationships, overseeing bill payments and resolving any issues relating to the home.



Sally\* lives in her own home. She has her lawn mowed by a local gardening service (recommended by a friend). The gardener is out and about in the neighbourhood during the day and is another person in Sally's neighbourhood who knows her and can look out for her if something happens while she's on her bike to and from work. \*name changed

### Creative paid supports people use to live in their own home



One mother hired a professional interior stylist to help her daughter style her own home when she first moved in. A professional and neutral third party, the stylist gave guidance to develop and express the daughter's own style as an adult, rather than having the home reflect her parent's style.



Craig\* has support to shave every day. Originally, his parents thought of hiring a support worker, which was quite expensive. Instead, they found a local barber who could provide a professional trim in a comfortable setting. They negotiated with the barber if he could open up the store a little earlier and provide Craig with a quick shave every weekday, at a discounted price.

It is great for Craig, as it is like being pampered every day. Because they see each other most days, Craig and the barber got to know each other really well and a friendship grew. It also provides extra business for the barber. \*name changed.

It is great for Craig, as it is like being pampered every day.



#### **Your Supports and Thriving**

Think about what supports the person needs each day. It can help to:

- plan through an entire day from morning to evening, then the overnights
- list everything. Think about all aspects of regular human needs, not just needs relating to the person's disability. You may be surprised at how much support is actually required. Then consider these life areas as prompts to check for things you have missed.

When thinking about who could provide support, consider:

- what is most natural and typical
- needs for privacy, autonomy and adulthood
- who could best provide the support, then match what you require with unpaid, paid or funded options

Some needs identified in these lists may only require short-term support. It is helpful to keep in mind that the person may take on more of these roles and tasks over time. Setting up the supports with this in mind may enable the person to grow, build their skills and gain more control over certain areas of their life in the long term.

This is not set and forget; it will change over time.



#### Supports and thriving

Complete the Exercise on Supports and Thriving in the My Home My Way Workbook pages 10 and 11.

In the exercise, think about what supports the person needs. Some examples of life areas are provided already, but you may wish to add more.

Wh	nat are your	What do	Describe the	Who is best	Hours of	Hours of
ne	eds? (Life	you need	support	placed to	natural	paid support
Are	ea), E.g.	support with	needed	provide that	support	needed
		at home?		support?	needed	
•	Nutrition	(Be specific)				
	and meals					
•	Shopping					
	ооррg					
•	Cleaning					
	_					
•	Personal					
	care					
•	Financial					
•	Developing					
	valued					
	roles at					
	home/in					
	community					
•	Health and					
	wellbeing					
	<u> </u>					

# PART 4: RENEWING AND SAFEGUARDING

"People keep people safe."

"When people are well known by their neighbours and communities, it is people's individual relationships that keep someone safe. It is not service systems, not financial institutions, not doctors or nurses ... they are important, but it is people who love us, who know us well, who advocate for us, who keep us safe into the future."

Michael Kendrick

## Safeguards TIPS

- Inviting people into the person's life is an important safeguard. People who love and care about the person are more likely to keep them safe, rather than services and systems.
- Have multiple safeguards If leadership relies heavily on one person or one service, this can be risky.
- Consider how the leadership can be shared how can others be invited in? To have multiple safeguards means intentionally inviting and bringing in trusted people around the person throughout their life, not just relying on paid support.
- Sustaining the arrangements over time and ensuring there are others to take up roles and continue to support the person over time is crucial.
- Circles of Support is a group of unpaid people who come together to support a
  person with disability to achieve their goals, but can also provide an important
  safeguard for the future.
- A Microboard is similar to a Circle of Support, but is a legal entity around one person.
- There are also formal safeguards that have legal and financial structures. These
  include:
  - o Estate and financial planning: Having a will is important as it's a legal document that can offer some safeguards for the future and can prevent delays. Special Disability Trusts can allow family members to plan for current and future needs of a person with disability. Look for a solicitor in your state who might have experience in creating wills and trusts for people with disability.
  - o Powers of attorney.
  - o A legally appointed person to work alongside the person to help make decisions such as banking, legal matters, rental assistance.

(Remember that even these legal and financial structures depend on good people to implement them.)



### Renewing: Change is a constant

It is useful to apply the principle of 'good, better, best'. Even if the home may seem okay now, what could make it better? Renewing can also help the person with disability to refresh and share their vision with more people, to focus on the gaps, learn new skills and provide a renewed sense of energy. Renewal is different for everyone!

Some useful planning resources to think about reviewing and renewing: https://bit.ly/RenewalAndSuccession



### Story: Creating Matt's home: It's not set and forget

Matthew Holles first moved out of home 15 years ago. In this video, you will hear from Matt's mum, Jill, about how she has worked with Matt and other key people in their lives to keep things on track over the years through intentional and thoughtful planning. Jill touches on topics of renewal, safeguarding, and bringing in other people so that it's not just her as part of the picture of Matt's future.



### Renewing: Change is a constant



### Home as a safeguard for my daughters

This episode is about safeguards - the things that protect you from harm, abuse, neglect or exploitation. And we'll join the dots between how living in your own place can help keep you safe, as well as be a place that helps relationships and networks happen - some other big safeguards. You'll meet Bobby Noone, mother of twin daughters, Tammy and Kelli Noone. You'll hear about safeguards that Bobby has in place for her daughters now. And how Bobby is making sure those safeguards stick around into the future.



### **Circles of Support**

**Circles of Support** is where you intentionally invite people who care about the person with disability, to come together in friendship and support for that person. A person can have one or multiple circles for different reasons.

- Each circle is unique to the person and holds the person at the centre of all efforts.
- The circle can be an intimate number of three to four people; or an expansive circle of 10 to 12 people.
- Even if you have established a circle around the person before, it is well worth considering refreshing the Circle of Support to focus on home, as well as inviting people in who could assist.
- A circle is not a team of paid professionals meeting to develop a support plan in the context of a service. Members are unpaid and regularly meet to plan, to action, and have an active role in the social life of the person.





Here are some great resources guides, workbooks and manuals on how to build a Circle of Support!

Rouget, D and Micallef, T. (2021) A Guide to Circles of Support. Belonging Matters. Melbourne.

https://bit.ly/MHMWCircleOfSupports

#### Adam's Circle of Support

"The Circle is also giving us the confidence and the mental space to think about the bigger picture. Last year (2014) we held a five-year planning meeting. This involved exploring the idea of Adam moving out of home. This is a daunting thought for any parent and it's been wonderful to have other people to offer to help consider the possibility." Karen, Adam's mother.



#### **Next Steps**

Complete the Exercise on Workbook page 12. List steps or actions you can take right now that can assist you to move towards your vision. These might be small or big steps!

- List steps or actions you can take right now. Taking one clear step towards your vision.
- Who can assist you with this step?
- When will this action be completed?



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This Guide forms part of the My Home, My Way project which offers practical advice, activities and stories of people with developmental disability living in their own home, making a home on their terms with support from their allies and families.

There are plenty of videos, podcasts, tipsheets and other resources for you to explore! Visit www.myhomemyway.com.au

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