



# Speaking up about where I want to live

A future planning guide



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### Why was this guide developed?

The Alliance has worked with a number of people with Down Syndrome at risk of being placed in a residential aged care. These people were either relinquished to hospital when a change in their functional capacity led to house staff admitting them to the emergency department; or when changed circumstances resulted in people being admitted to hospital from their family home. Both groups faced the same challenge of an unclear path home and the risk of aged care placement.



Health services reported that individuals from group homes had presented to emergency departments with the advice that they could not return to their homes because their needs had changed and the service was no longer able to provide the support required.

### The main reasons for relinquishment to the health service included:



Insufficient resourcing to meet the individual's increasing care and support needs including number of hours, lack of funding, poor built environment access



The service did not have sufficient training to support the individual's care and support needs



Poor built environment access was seen as sufficient reason for relinquishment



The service was unable to consider changes to staff rosters and implement improved training to deliver the support the individual's changed circumstances required.

With issues relating to guardianship and accommodation needing to be resolved, the extended periods these individuals spent in hospital led to crisis situations where they were given no choice in where they lived. And while service providers and health professionals looked for what they thought were 'safe' accommodation options, the preferences, experiences and voices of the people caught up in these relinquishment processes were often routinely ignored.

This was devastating for individuals and families alike, as well as for support staff who knew these people well. If strong advocacy wasn't involved or there weren't clearly expressed statements indicating how the individual wanted to live as they aged, placement in residential aged care was seen as the appropriate option.

*"In the 1950s children born with Down Syndrome in Australia had a life expectancy of 15 years; now it approaches 60 years.*

*The longevity of people with Down Syndrome means more people experience the conditions of aging.... Alzheimer disease occurs earlier in people with Down Syndrome, with an average age of diagnosis in the early to mid 50s."*

## Residential aged care no longer a destination for people under 65

Prime Minister Scott Morrison announced in November 2019 that no younger person with disability would be placed in a nursing home after 2022. This will remove residential aged care as a relinquishment option for people with Down Syndrome and others with disability. Without aged care as a relinquishment 'destination', the spotlight turns firmly back to the NDIS and the need for service providers to proactively adapt to their client's changing needs.

To enable people to have their voices heard, avoid aged care placement and indicate their current and future living preferences, the Alliance undertook a project funded by the NDIS Independence, Linkages and Capacity program.

This guide is the result of that work. It enables people whose needs are changing and who need the assistance of supported decision making, to have a voice.

Developed by the Alliance in collaboration with people with Down Syndrome, families and providers, the guide describes how preferences, choices and decisions can be protected and actioned by a person's network of support when changes in an individual's communication and cognitive capacities risks diminishing the importance of their voice.

Together with practical tools that help clarify and communicate people's wishes and preferences, the guide introduces a practice that supports people with disability to have their voice recognised more fully in NDIS planning processes and in responses to individual plans in group home services.

Though developed with people living with Down Syndrome, the guide is applicable to any individual wanting to indicate their housing and support preferences, now and in the future; and make decisions about accessing or delivering these options.

Ensuring that people with disability can make their wishes clear in decisions about their lives and that these decisions are acknowledged and acted upon, is not yet routine practice for professionals, service providers and government programs.

The **Where and How I Want to Live**, and **Speaking Up: Where I want to Live** templates included with the guide, can be used to record the wishes and preferences of individuals in real time and to inform future decisions should the individual be unable to express their wishes at that time.





## A human rights approach

### Participation in decision-making

All people have the right to participate to the greatest extent possible in decisions about their lives.

### Respect for values and preferences

All people have the right to have their values (including cultural values), life experiences, preferences and opinions respected by others.

### Access to information and support for decisions

All people have the right to accessible information and capable support to enable them to make choices and communicate those choices clearly.

### Self Determination

All people have the right to determine their own lives, associations and futures, and have authority over their own lives.

### Accountability

Disability and other service providers are accountable to people with disability for their practice, and for the consequences that arise from service delivery for people with disability using their services.

### Adherence to legislation and other instruments

The practice of supporting people in decision making and planning must be consistent with legislative and policy frameworks including Guardianship and Administration legislation, the NDIS Quality and Safeguards Commission Code of Conduct, and be consistent with relevant articles of the United Nations Convention on the Rights of Persons with Disabilities.

## Undertaking future planning discussions...getting ready

Supported decision-making and biographical storytelling can help people with disability to develop, record and communicate their opinions, preferences and wishes.

These are important for both current and future planning, particularly if people have rapidly changing needs and are in a situation where they may be at risk of others making decisions about their lives without reference to their choices and preferences.

Establishing current and future support preferences when an individual's needs are changing may not straightforward so...

### 1. **Nominate someone who knows the individual well to lead the information gathering process.**

This could be a family member, support staff person or an independent advocate. This person's job is to ensure the individual's voice is heard and their preferences and decisions are accurately recorded.

They will also lead the meetings with the individual and their support network to discuss the person's preferences and choices about where and how they want to live.

### 2. **Engage with the person's network or circle of support.**

Supporters who know the individual well and are trusted by them, should be included in discussions so that a range of views and understandings about the person can inform the decision making process. If there isn't a formalised circle of support, assist the person with disability to identify their allies: people who can and want to support them to 'speak up about where and how they want to live'. This might include friends, current housemates, family, support workers and service providers, guardian, advocate, doctor or their NDIS support coordinator.

The aim in bringing this group together is to gather more information to help the person explore their options and indicate their preferences.

### 3. **Don't rush...take as much time as you need.**

Trust, accessible information and good communication all take time and patience to establish. It may take several sessions to work through issues to establish the person's wishes and preferences so be prepared to have several meetings if need be.

### 4. **Engage advocates or independent representatives.**

Major life changing decisions such as those concerning future support arrangements, should involve more than a single person or a closed staff group. If the person doesn't have trusted others to engage in the process, involving an independent advocate can ensure the individual's voice is heard.

### 5. **Supported decision making competency.**

Anyone who engages in supported decision making with individuals, including support staff, must be trained in these processes. If residential services staff lack this capability, engage an experienced supported decision making practitioner.

### 6. **Get the time and place right.**

Choosing the right time and place to support the individual's engagement is important. People are at their best in their favourite environments and with people they trust. Having conversations in advance of a crisis situation allows time to establish an individual's preferences and decisions and confidence in the decisions they make.

## Before you start any discussion



### Is information and support appropriate to the abilities of the person and their cultural and linguistic background available?

If providing culturally specific or easy English materials, make sure the person has sufficient time to become familiar with them before starting the discussion.



### Can you record individual preferences exactly as the person has expressed them?

When changes occur in an individual's support needs or questions are raised about their future living arrangements, the individual's previously expressed wishes must be taken into account.

It's vital that you (or staff or advocates facilitating the discussion) know how the person best communicates so that wishes and preferences can be accurately recorded.



### Are you familiar with the range of accommodation and support options available?

See the Accommodation and support options supplement that comes with this guide. Use the comments section to note questions in relation to any of the options listed.



## Discussion prompts

Choices are informed by an individual's likes, dislikes, cultural and social needs, everyday supports and financial circumstances. Discussing why choices have been made enables a comprehensive social history to be compiled of a person's preferences and choices concerning their living arrangements.

The following discussion prompts will help build that social history and indicate 'What I need for a house to be my home':

- The relationships in my life that are important
- What things I like to have around me
- The values that are important for me
- My cultural needs
- What makes me safe
- What I like people to know about my personality
- The things I like and don't like so much about my current home are...
- Where I have lived before and what I liked and did not like.
- The physical environment that will best support me
- The right location for me to pursue my vocational, leisure and social interests
- What my daily support needs are and what might change
- How my finances are managed
- Who I like to support me with the different areas of my life
- The choices and preferences I have already made are
- Things I like and do not like



## Using the templates

- **About me**
- **Speaking up: my preferences and choices**

*Using these resources can also complement or enhance existing tools.*

These templates provide longitudinal records of each individual's preferences, choices and decisions and are of particular value to individuals with disability as they age and face the potential loss of their ability to share their own history and express their own wishes.

Using the templates creates a document with a unifying thread that describes an individual's relationship to home, family and networks and their choices to preserve these connections. Because they reveal a chronology of events and life situations and what these mean to the person, the information captured in the templates and the record that results can provide a more holistic and comprehensive picture of the individual with disability, the choices they have made and the reasons behind these choices.

Using these resources can form part of an individual's NDIS plan review or, if the individual lives in a group home setting, their individual program. As well as strengthening the individual's voice, using these resources offers an opportunity to share functional changes as well as aspirations and plans for the future.

**Speaking up: my preferences and my choices** records an individual's social history and their preferences and choices about where they want to live, now and in the future.

**About me** records the person's skills at a particular point in time including living skills, mood, triggers for anxiety or frustration, communication and mobility skills and self management capacities that may influence their preferences, choices and decisions. This is not intended to be a static record but provides the opportunity to capture changes that occur over time.

## Further information

The following documents and links are available for people to undertake further reading and investigation about supported decision making and future planning for people with cognitive disability.

### **Down Syndrome Victoria**

**"Ageing and Future Planning", Voice Magazine, December, 2017.**

Available at <https://www.downsyndrome.org.au/voice/issue/ageing-and-future-planning/>

### **Finkelstein, A., Tenenbaum, A. and Bachner, Y. (2019).**

**"I will never be old': Adults with Down syndrome and their parents talk about ageing-related challenges, Ageing and Society, 1-20, Cambridge University Press, March 2019**

Available at [https://www.researchgate.net/profile/Adi\\_Finkelstein2/publication/331938475\\_'I\\_will\\_never\\_be\\_old'\\_Adults\\_with\\_Down\\_syndrome\\_and\\_their\\_parents\\_talk\\_about\\_ageing-related\\_challenges/links/5d5d49b592851c37636fcc65/I-will-never-be-old-Adults-with-Down-syndrome-and-their-parents-talk-about-ageing-related-challenges.pdf](https://www.researchgate.net/profile/Adi_Finkelstein2/publication/331938475_'I_will_never_be_old'_Adults_with_Down_syndrome_and_their_parents_talk_about_ageing-related_challenges/links/5d5d49b592851c37636fcc65/I-will-never-be-old-Adults-with-Down-syndrome-and-their-parents-talk-about-ageing-related-challenges.pdf)

### **Office of the Public Advocate Victoria**

**Guide to NDIS decision-making. When a decision can be made by, with or for an adult with significant cognitive disability. 2018.**

Available at <https://www.publicadvocate.vic.gov.au/resources/booklets/ndis-1/608-guide-to-ndis-decision-making-tagged-accessible-pdf/file>

### **Office of the Public Advocate Victoria**

**Supported Decision-Making in Victoria - A guide for families and carers, 2017. Available at**

<https://www.publicadvocate.vic.gov.au/resources/booklets/supported-decision-making-1/447-guide-to-supported-decision-making/file>

### **Queensland Advocacy Incorporated**

**Decisions about my Life? The Choice Should Be Mine. 2014**

Available at <https://qai.org.au/wp-content/uploads/2017/10/QAI-Paper-on-supported-decision-making-.pdf>

### **Speak Out Association of Tasmania**

**Decisions. (video)**

Available at <https://redjelly.com.au/cache/blitz/redjelly.com.au/work/decisions/index.html>

**Tracy, J. "Australians with Down Syndrome," Australian Family Physician, vol 40, no 4, April 2011: 202-208.**





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