

It's My Choice!

A Guide for People
with a Disability,
their Family
Carers, Friends
and Advocates

**It's My Choice!
Toolkit**

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It's My Choice!

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2

Contents

<i>Using A Guide for People with a Disability, their Family Carers, Friends and Advocates</i>	2
<i>How to read A Guide for People with a Disability, their Family Carers, Friends and Advocates</i>	3
<hr/>	
1. Get ready to change your life	4
Communication and Support	5
<hr/>	
2. Telling others how you feel	6
Support the person to share feelings	7
<hr/>	
3. Think and talk about your most important choices	8
Pervasive life choices	9
<hr/>	
4. Some other important choices	10
Getting serious about choices	11
<hr/>	
5. My lifestyle and comfort	12
Learning more about choice-making	13
<hr/>	
6. Try new things to get to your dreams	14
What supports can create the pathway?	15
<hr/>	
7. The individual life plan meeting	16
The planning meeting	17
<hr/>	
8. Understanding your choices	18
There are always limits on a person's choice	19
<hr/>	
9. What should my services and supports do?	20
Ensuring the choice journey is successful	21
<hr/>	
10. Has your life changed for the better?	22
A model that may help you think through the steps of choice-making	23
<hr/>	
11. Some problems	24
Problems and conflicts	25
<hr/>	
12. You have human rights!	26
Human Rights	27
<hr/>	
13. My Choice Journey	28
<hr/>	
Stories that may help you think through choice-making:	29
Glossary of terms	32

Using *A Guide for People with a Disability, their Family Carers, Friends and Advocates*

Welcome! What is this guide trying to do?

We hope that this guide will help you to make choices.



This is what I want

It should help you to make sure your life is heading in the way you want it to go.

It will help you and those you trust to make choices about your future, about your lifestyle and day-to-day choices.



To the future

The guide should help you to work towards the life and lifestyle you want.

It may also be used by people who support you, such as family, friends and advocates.



How to read *A Guide for People with a Disability, their Family Carers, Friends and Advocates*

Each double page has two sides. The left hand side of each double page with **big blue writing at the top** and black text is in easy words and pictures. The right hand side with grey writing at the top and black text uses more words and stories.

You can read just the pages on the left hand side (easy words and pictures) or just the pages on the right hand side (more words and stories) or both. The right hand page has been written for those you trust like families and friends. You can follow the advice on these pages if you choose.

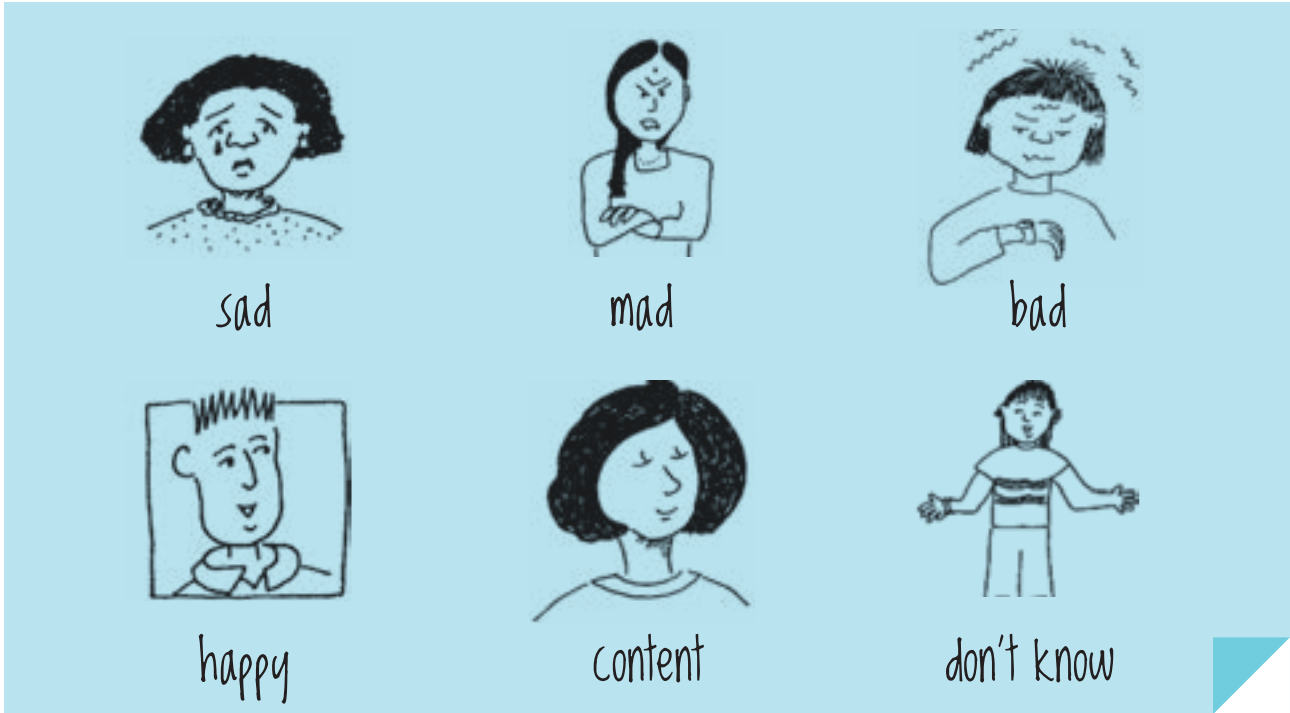
Some of the words may be hard to understand. If you want help to understand the resource, then work with someone you trust. The pictures on the left hand page will help the person supporting you explain the points being made.

It is good to talk about how you can make the best choices and get the life you want. You might also choose to write down some of your plans and write answers to questions about your life and your wishes. Keep this information safe because it is your information. *Good luck!*



1. Get ready to change your life

How's life for me? Am I ...?



Have you talked about your life with people who are important to you?



Have you talked about this to people who can help you change things?

1. Communication and Support

You have probably spoken with your friend or relative with a disability about their life on several occasions. Sometimes you have been a spectator while they have carried on with life. Other times you have joined in and shared experiences with them.

You know how they express their feelings. You want the best for them. If you are a parent you may want to plan for when you may not be around any more.

Before you support them to make changes to their life, services, supports, and community connections, you will want to be sure that your relative or friend is supported in their choices.

To help them make choices you must make sure that they have the chance to speak up for themselves.

Has everything been done to support the person to communicate to the greatest extent possible? Where needed, does she or he have access to technology or therapy?

There is no point communicating if nobody listens. Who is listening to what the person is telling you? Is he or she telling you things without speaking? Who else needs to listen to him or her?



Maximise communication

Personal observation:

We had a situation where he was assaulting people at home every morning when his lunch was being made. He was having issues with attending the service... and I suggested he come to the day service and purchase his lunch items and make it himself and they put that in place... He now goes into the supermarket every day... he's learned to use the automatic checkouts... and he is now not assaulting anyone at home in the morning...

2. Telling others how you feel



Tell someone what's good and bad



Write down what's good or bad



Photograph what's good and bad



Record what's good and bad



Write a story about your life - Copy this story and change the things you want to change. Use faces to show what you are happy with and what you are unhappy with.

2. Support the person to share feelings

People often get recognition from other places which they share with their families and friends: a school report, a driving licence, a commendation and so forth. When you are involved with organisations designed to support your relative or friend to fulfil their capabilities you may have a vital role in sharing information with them and on their behalf.

Sharing emotions and lives is only done where there is a *trusting and respectful* relationship. It may be that the person has to share more with you than other people will. They need space and understanding. And they need to know they can say anything without being judged. Sometimes your role may be to support the person to make their views

known or speak on their behalf. Some of the ways you can support them to express their thoughts and feelings are to:

- Give them a camera and photovoice their lives
- Use themes in films, books and other media to explore their feelings
- Be aware what their non-verbal behaviours are communicating
- Help them write a story or record something about their lives.
- Provide new experiences and use their reactions to choose future options
- Talk to your disability service about using social stories

Personal observation:

I've had 40 to 41 years with [my son], you know. You can read them like a book and especially if you're observant. You have to be observant and case workers don't have the time to be observant... He loves the pool but is with his own support now... They removed him from the group because of his epilepsy...

This carer knew just how much her relative loved the pool and so made sure he still used it even if services did not support her relative to do so.

3. Think and talk about your most important choices

What needs to change?

- What do I want more of?
- What do I want less of?
- What could be done differently?



Think about.....

What do I want to do with my day now and in the future?



What will keep me healthy?



How can I see more of my family and friends?



Where do I want to live now and in my dreams?



What personal and intimate relationships do I want?



What connections do I want with the community?



3. Pervasive life choices

- Explore pervasive life choices with your relative or friend
- With permission share these with others who have a role in the person's life, such as their circle of support, microboard, support workers or services
- Explore ways of widening the person's experiences so they can make a more informed choice
- Build bridges and bonds with others who may provide natural supports
- Build *pathways* to the person's dreams. Each step should be short and practical. Expect your relative to extend themselves and grow through the experience.

Write down:

- Dreams, hopes and aspirations around pervasive life choices
- What does a person want less of, more of and what could be done differently?



Pervasive life choices:

Some life choices are very important because they affect all other areas of a person's life. It is important to identify the person's ultimate goals and their short term preferences. The following are a guide to pervasive life choices:

Health: *Being fit for life, sports and leisure, diet, emotional well-being, medical and health needs, medication.*

Meaningful activities: *Long term and short term: what activities? Employment? Volunteer work? Community involvement? Self advocacy or advocacy? Relaxation and respite?*

Home: *Long term and short term. Where? With whom? Why?*

Family and friends: *How much contact? With whom? When? Special occasions, special events, routine meetings and schedule. Why?*

Personal and intimate: *Do I want a personal relationship? How to support widening the person's contacts? What training? Do they want to be intimate? What training? Access to contraception? Keeping the person safe. Engaging other friends, relatives and advocates who disagree.*

Community: *Where to go? With whom? What can the person contribute? What bridges need to be built and links made? How can bonds be sustained? Are there any community development initiatives?*

4. Some other important choices

Can I do more with my body?



Can I use my touch, taste, smell or hearing more?



How can I feel good and have a happy life?



Do I have the time to fit everything in?

How can I make my relationships stronger?



Can I have pets and be closer to animals?



Can I do more of the things that keep me interested, make me laugh and smile?



4. Getting serious about choices

You identified pervasive choices earlier. Here are some additional ideas about how a person can fulfil his or her potential. They are called capabilities.

To help you support your relative or friend you might use, or support the person to use, the following chart to think through pathways to a person's dreams and whether present services have the right pathways.

	HOPES AND DREAMS: <i>THE PERSON'S VIEW</i>	HOPES AND DREAMS: <i>THE FAMILY CARER/FRIEND'S VIEW</i>
Good things in my life		
Bad things in my life		
Things I want more of		
Things I want less of		
Most important things		
Where will I be treated with dignity and respect?		
Health		
My day		
Where I live		
My family and friends		
My personal relationships		
My community links		
My body		
My senses		
My imagination and thought		
My emotions		
Trying out through doing things, practical reason		
Relationships I'd like to have		
Relationships I'd like to develop		
Animals, pets and plants		
Control of my surroundings		
Am I happy with my service? Can unhappiness be resolved?		
Am I growing in my present services? Can this be resolved?		
Other steps to consider once you have completed the table	<p><i>Consider the following:</i></p> <p>Are there any differences of opinion between you and our relative/friend with a disability?</p> <p>What are the small steps I can succeed in doing that will lead me on a pathway to my dreams and goals?</p> <p>Does my present service help me take these steps?</p> <p>Can my service change to support my pathway or do I need to look for another service?</p>	

5. My lifestyle and comfort

There are things that make you comfortable. There are also things that may be your chosen style. Here are a few examples. Can you think up any more?

What are my routines? How do I like to get up? What's my night time routine?



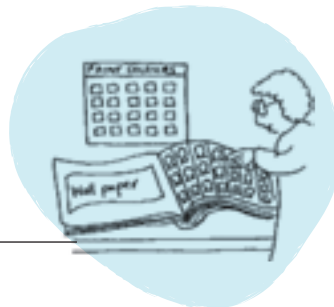
How do I like to relax?

How do I like to spend my weekends?



What clothes do I like wearing?

What posters and decorations do I want on my wall?



What TV shows and music do I like?



5. Learning more about choice-making

With your friend or relative, view the accompanying films, *David's Artful Choices*, *In Sara's Own Time* and *It's not simple. It's not that easy*. Use the accompanying guide, *It's My Choice! 4: Film and Discussion Guide* (see web addresses to right). Work your way through the booklet with your friend or relative.

In the Discussion Booklet you will find information about *pervasive choices* like the ones we have already discussed. As well as these big choices all of us make hundreds of choices each day. These are choices about what we might like to drink; what sort of dinner to have; whether to get up straight away or sleep in; what TV program to watch and so forth. These are *everyday choices*.

There is another type of choice. These choices are about who we are, our identity, our rituals and routines, our culture and our style. Look at the case studies to the right. These case studies show such *lifestyle choices* as they are called.

Lifestyle and *everyday* choices should not conflict or disagree with a person's pervasive choices. For example, if I want to be in a sports competition (*pervasive choice*) I may go to the gym (*lifestyle choice*) and not eat certain foods (*everyday choice*).

The links between pervasive and other choices help people know how to be responsible if they want to achieve their dreams. It's their choice!

To view all videos go to:
www.inclusionmelbourne.org.au/resources/choice/

To view and download a PDF version of *It's My Choice! 4: Film and Discussion Guide*, click on the link.

Case studies:

I wear white shirt and apron for cooking. I dress for the occasion.

(Focus group - self advocates)

I love going shopping, I feel like I'm getting clothes to make me feel good. It improves your sense of wellbeing about who you are. Makes me feel good inside.

(Focus group - self advocates)

I got a cross. I'm a Christian.

(Focus Group - Self advocates)

Moved from home to a CRU... Went from tracksuit everyday to very fashionable clothes... Confidence grown... Making friendships. Their whole life has changed.

(Focus Group excerpt - Support workers)

6. Try new things to get to your dreams

You may not know how to make sure your choices and dreams come true. If you do, great! Go for it and good luck!

If you don't then you will need to find the service and supports that will help you get to your dream. You will get the best results if you share all the ideas you have thought up so far. Ask someone to help you write these down.



Trying a new home.

You might need to go and try a few new services out.



You might need to be brave.



You may meet new people.



You might do different things.



You might feel some things are very hard or a bit scary.

**Give it a go!
You can only say
what you think if
you give it a try!**

6. What supports can create the pathway?

You will want to make sure that your friend or relative is on the pathway to their goals and a pathway to being as comfortable and as independent as possible. You may have already mapped out a pathway during Stage 4 (see above). Now you and the person need to track down services that can deliver the pathway successfully.

You may find there are some issues to address – now and maybe in the future. It is not always in the interests of present services to find new services for the person. Sometimes it could be important that you have someone independent to help you as the choice

will affect you too. You may find (parents') support groups, friends, advocacy or brokerage organisations or a circle of support helpful to you.

This stage of decision-making will take a lot of work. **DO NOT LEAVE THIS UNTIL THE LAST MINUTE.** It should be an ONGOING feature of life. It is NOT planning for a meeting. It is planning for a GOOD LIFE. As you visit and find out about different services you may want to use the table below and discuss this with the person, with the circle of support, advocate or broker, if you have one.

RATING SERVICES	PRESENT SERVICE	SERVICE B	SERVICE C
What need will this service fill on the pathway to reaching goals?			
Has this service delivered or failed to deliver in the past?			
What is the cost?			
Is it accessible?			
Are additional supports required?			
Is the service available?			
What is the cost of the service?			
What cost are any additional supports?			
Will this service treat me with dignity and respect? Do I trust this service?			
Is additional training required (e.g. travelling, budgeting)			
Who will administer the budget?			
What sort of service is this? (government, NGO, commercial)			
Is it likely to fit with the NDIS service criteria?			
How will this choice affect the family?			

Another way of scoring services that has been developed in 2013 is to be found at the following address:

www.inclusionmelbourne.org.au/resources/choice/ and click on the 'scorecard' link.



Make sure that if the person visits new services she or he has time to experience them properly, that you make time to discuss the service and that you provide them with emotional support. Change is never easy!

7. The individual life plan meeting

Sometimes people will talk to you about whether you are pleased with your life. They will ask you if you are moving towards your goals in life. They will decide what funding you get and who will look after your money.



It is really important that you take part if you can.



If you have written about the good things and bad things in your life then take these along.

If you have written about your dreams, your style or the things you like best each day, then take these along.



Make sure you have a say and you tell people what you REALLY think! It's your meeting.

7. The planning meeting

Attending a planning meeting is your friend or relative's chance to get the services that will move them step-by-step towards their dreams and goals. If you have used this resource consistently since you last met with a Case Co-ordinator or Local Area Co-ordinator (LAC) then you will have prepared the following for discussion at the meeting:

- Future goals and proposed pathways for achieving those goals
- A list of potential services that move the person on the pathway to their goals.

At the meeting you will also discuss:

- The level of funding available
- Deciding which of the services and supports will be purchased
- Who will administer the payment. A relative or another person or organisation may take on the role of administering the payment. The National Disability Insurance Scheme has online advice on administering payments at <http://www.ndis.gov.au>

Your role is to ensure that your friend or relative has the chance to speak up. If they cannot speak you should bring evidence to the meeting that will confirm what your relative wants, thinks and needs.

Your role as a de facto decision-maker lies in your commitment to the person. Of course you should also have an open mind so that you have the chance to learn from others too.

The person may also want to take an advocate along to this meeting. In some circumstances a Guardian or Plan Nominee may also attend and it is useful to have spoken with them before the meeting.

A personal reflection about a planning meeting from a family carer whose relative has an Individualised Support Plan:

We start with the now, what's happening now. Then we look at the dreams. And then we work towards them. And we put in who's going to be responsible for what barriers are there and this really makes you think of the risk and the things you need to deal with on the way...

This [meeting] was for first steps and I [also] added values because he wanted a job and not to attend a day centre during the day...

8. Understanding your choices

After the meeting things should start to happen.

You may have new services or you may be in the same service you had before.



my new service



my new skills



You may be using more services in the community

If you have personal support you may want to be involved in choosing the person who will support you.



This may be a time of change. Keep talking to people about how you are feeling.

Keep telling people what you think about the service you are getting.



I don't like it here



If people do not listen then tell somebody else until someone listens to you.

8. There are always limits on a person's choice

There are a number of reasons why a person's choices will not all be met. Nobody is completely free to choose (See **Principle 6**). This can be exasperating and disappointing for the person and for you. You may need to decide if you want to support your friend or relative to complain if he or she is very dissatisfied with the

outcome. Below is a table setting out some of the reasons why a person's choice cannot be met. This may help in the meeting but you may also work with the person to find other ways of addressing the shortfall. A longer list of limitations and responses can be found in *It's My Choice! 3: A Guide for Disability Support Providers*.

To download
It's My Choice! 3: A Guide for Disability Support Providers
 PDF go to www.inclusionmelbourne.org.au/resources/choice/
 and click on the link 

LIMITATION	REASONABLE?	APPROACH TO RESOLVING THE ISSUE
Funding availability	Reasonable	<ul style="list-style-type: none"> • Reconsider level of assessed need against funding available • Consider the human rights implications, especially economic, social and cultural rights • Inform systems advocacy and government department of shortfall
Discrimination	Not reasonable	Use disability discrimination legislation
Blanket service for all clients affects the person's choice	Not reasonable	It is not legitimate to sacrifice the person's <i>pervasive</i> and <i>lifestyle</i> choices because they do not suit the group. Negotiations must take place around those <i>everyday</i> and <i>lifestyle</i> choices which are acceptable for the group to negotiate. Further, no human rights should be infringed (such as freedom of movement or privacy) in relation to everyday or lifestyle choice limitations.
Risk	Can be reasonable	<p>Make sure <i>risk</i> is not <i>hazard assessment</i>. What more can be done to reduce likelihood of hazard occurring? Break activity into smaller bits.</p> <p>Make sure the benefit to the person is weighed up against the risk.</p> <p>Make sure there is a dignity of risk. Use the 'Benefit of the doubt' rule</p>
Education/ intellectual ability	Reasonable in certain circumstances only	If education and intellectual ability are seen as preventions to moving forward then break the steps on the pathway down into smaller parts so there is movement to the goal or adapt the timeframe. Over time work with the person to adapt their end choice and what they will settle for. But always move forward.
No technology/ aids/ equipment	Not reasonable (except where costs are prohibitive)	Hoists, wheelchairs, walking aids, eating aids, communication devices, ramps, and hearing aids are vital to produce as normal and as enriched a life as possible. They should be provided or a plan devised to purchase them over time.

9. What should my services and supports do?

Your services, support workers, family and friends should:



Help develop your skills to achieve your goals



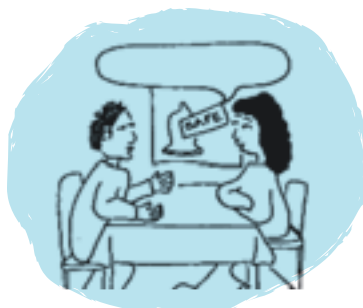
Keep checking to see how you are going



Respect your rights as a person



Make sure they support your choices



Allow you to take risks and support you to have new experiences

Always tell your services, support workers, family, friends and others to respect your choices and your rights, support you to take some risks, develop your skills and be your own person!

9. Ensuring the choice journey is successful

Once services and supports are in place their role will be to support the person to attain *set targets* to be produced in a *set timeframe* on the journey to accomplishing the person's choices.

You might support the person to ask the following types of question if they

are unable to do so for themselves. You may also make some assessment of whether the services and supports are meeting the person's *agreed* goals. This will have an important impact when you start the whole process again as you did at the start of this guide.

	YOUR RELATIVE'S VIEW	YOUR VIEW	HOW CAN THIS CHANGE?
Is your life fulfilled?			
Do you feel challenged to get the most out of life?			
Are you getting closer to your goals?			
Do you look forward to your day?			
What are the barriers that stop you having a full life?			
Are there things, people, services that I do not want in my life?			
Do I feel comfortable in my surroundings?			
Have I taken some chances and done some exciting things?			
Could I get out more?			
Do I have all the friends I want?			
Am I trying new options?			

10. Has your life changed for the better?

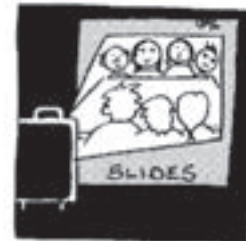
You have spent a lot of time reading and following this guide about choice.



We hope this journey has helped you achieve what you have chosen for yourself in life.



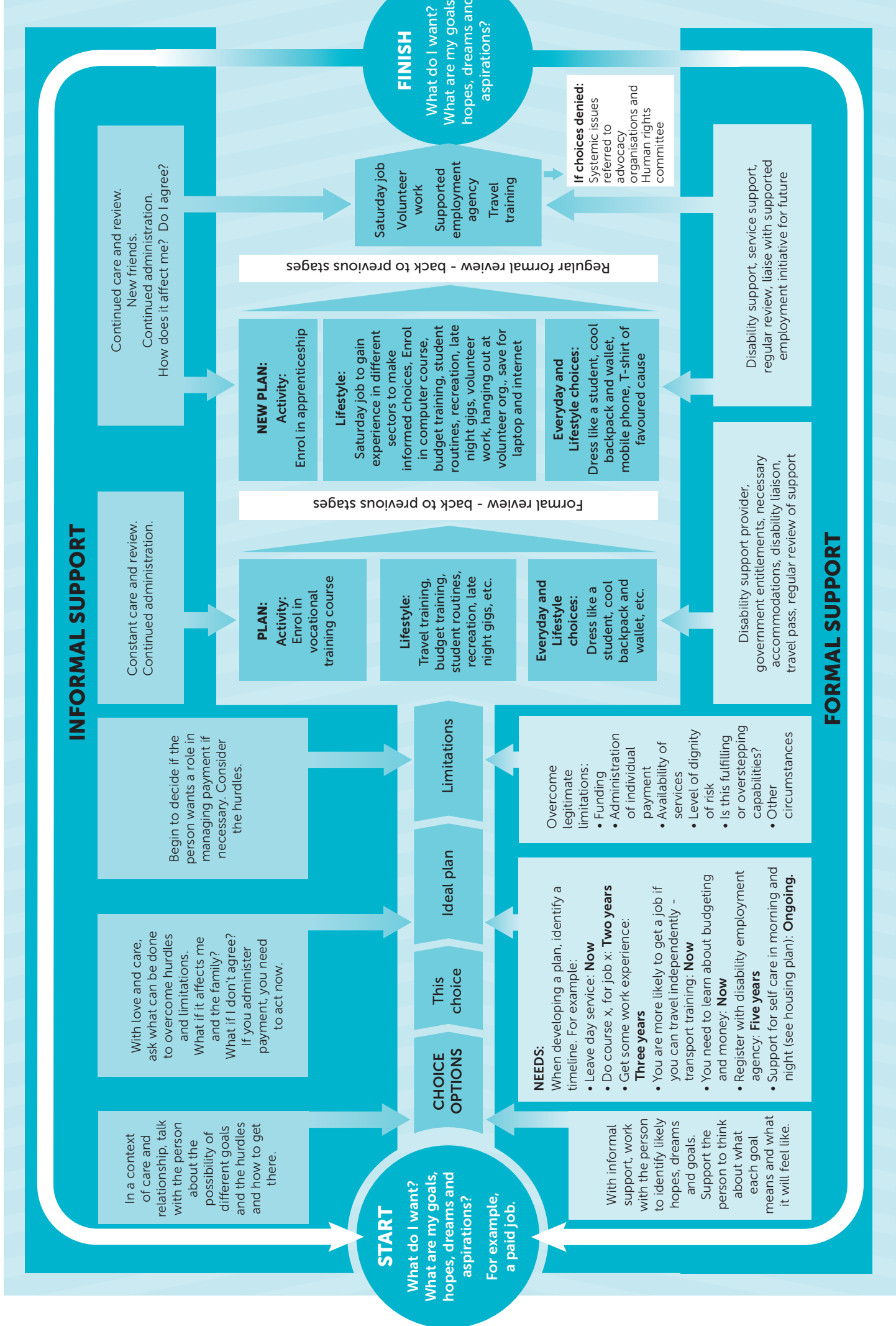
We hope you feel your life is full and more exciting and you have new memories to treasure.



If you are unhappy about anything you must remember that you have a right to complain.



Remember. Speak up. It's your choice!



10. A model that may help you think through the steps of choice-making

11. Some problems

You might find that your choices affect others you care about, especially your family or your partner. They may not agree with your choices.

Talk, discuss, negotiate, seek advice from close friends, suggest a half way point, move more slowly, agree a trial, get some support... and take responsibility for what happens. It's your choice and your responsibility!



You may find it very hard because nobody has given you the chance before. You might be scared because of things that have happened to you in the past.

Take things at your own pace. But always move forward. Build trust into relationships with people who treat you with dignity and respect. Try small new experiences and become more daring! Get help for things that have happened in the past.



You might find it hard to live the life you choose because you are a woman, because you are from a different culture, an asylum-seeker or from an Indigenous population. You have the same human rights as everyone else!



I have human rights. I should be treated the same and not discriminated against because of my disability, my culture or beliefs.




11. Problems and conflicts

There are likely to be problems, issues and sometimes conflicts with a person and their choices. This is part of life so you will need strategies to address and manage these when they occur. The following table gives some examples and how these might be addressed.

ISSUE	RESPONSES
Person does not know and cannot express their future choices	Have you maximised their opportunity to communicate? What does their past life communicate to you? What do their present preferences communicate?
	Have you, using educated guesses about the person, tried to support new experiences and taken the time to record responses?
	Have you taken into account whether they like lots of social relationships or smaller closer ones?
	Have you considered what will fulfil their capabilities, what will make them most independent and what will leave them with the sense of a fulfilling life?
Disagreement with your friend or relative over a choice	Do the <i>everyday</i> and <i>lifestyle</i> choices challenge or contradict the pervasive choice?
	Have you tried talking, discussing, re-scheduling, splitting the choice into smaller steps, creating a 'bigger picture' for the person?
	Have you pointed to examples, modelled what will happen, and provided training and support for the person?
Appointment of Nominee or Guardian?	Have you pointed to your rights as a parent?
	Have you had a say in whether an appointment is made and the choice of Nominee?
	Are you clear on their legal duty and what role you have?
	Have you involved an independent advocate?
A history of physical, sexual or emotional abuse or control because of gender, ethnicity or culture	Have you supported the person in counselling where that is possible?
	Have you suggested Trauma Informed Care and Practice(TICP)?
	Have you established trusting relationships based on human rights (see below)?
	Have you tried building confidence and assertiveness?
	Have you explored widening experience slowly to establish capabilities and trust?
Transitions (to school and adult services, into work, into old age)	Have you thought through a plan built of known steps? Have you spent enough time doing an option appraisal? Are all those involved working together with the person? Do you have the right information and contacts?
Services not fulfilling the person's plan	Warn, warn a second time then either complain or change service. Bad quality services are unacceptable. The person's life is the most important thing!
Aversion of services to risk	Make sure risk assessment is not confused with a hazard assessment. Make sure they have: taken into account benefits to balance out risk; broken activities into smaller step; been inventive about replacement options, and given the person a chance to experience the activity themselves.

12. You have human rights!



You should not live in fear! You should not be afraid. It is against the law for people to abuse you, torture you or lock you up!




You should be able to move about freely and be supported to do so.




Your private things are private to you.

You have the right to have treatment when you are ill.






You should not be excluded from the community because you are a person with a disability.




You have the right to have a family life and you have sexual and reproductive health rights too.

You have a right to meaningful education and something meaningful to do with your days.

You should not be very poor and live in bad housing.



You have the right to complain.

12. Human Rights

All people have the same rights. Australia is signatory to the UN Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol (*see websites below for more information*).

[www.un.org/disabilities/
default.asp?id=150](http://www.un.org/disabilities/default.asp?id=150)



Here is a way of remembering human rights principles (CRPD). You can see the first principle includes choice and self determination!

Human rights must be *respected*. This means public authorities (government or organisations doing the work of government) must recognise and deliver human rights.

Human Rights must be *protected*. This means that organisations must take steps to prevent infringements to human rights.

Human rights must be *fulfilled*. This means that staff must ensure everyday experience is human rights-based.

There is more about human rights and assessing human rights in *It's My Choice! 3: A Guide for Disability Support Providers*, for those who provide services and supports to people with a disability.

I RAN FREE

Individual autonomy including the freedom to make one's own choices and respect for inherent dignity

Respect for difference...human diversity and humanity

Accessibility

Non-discrimination

Full and effective participation and inclusion in society

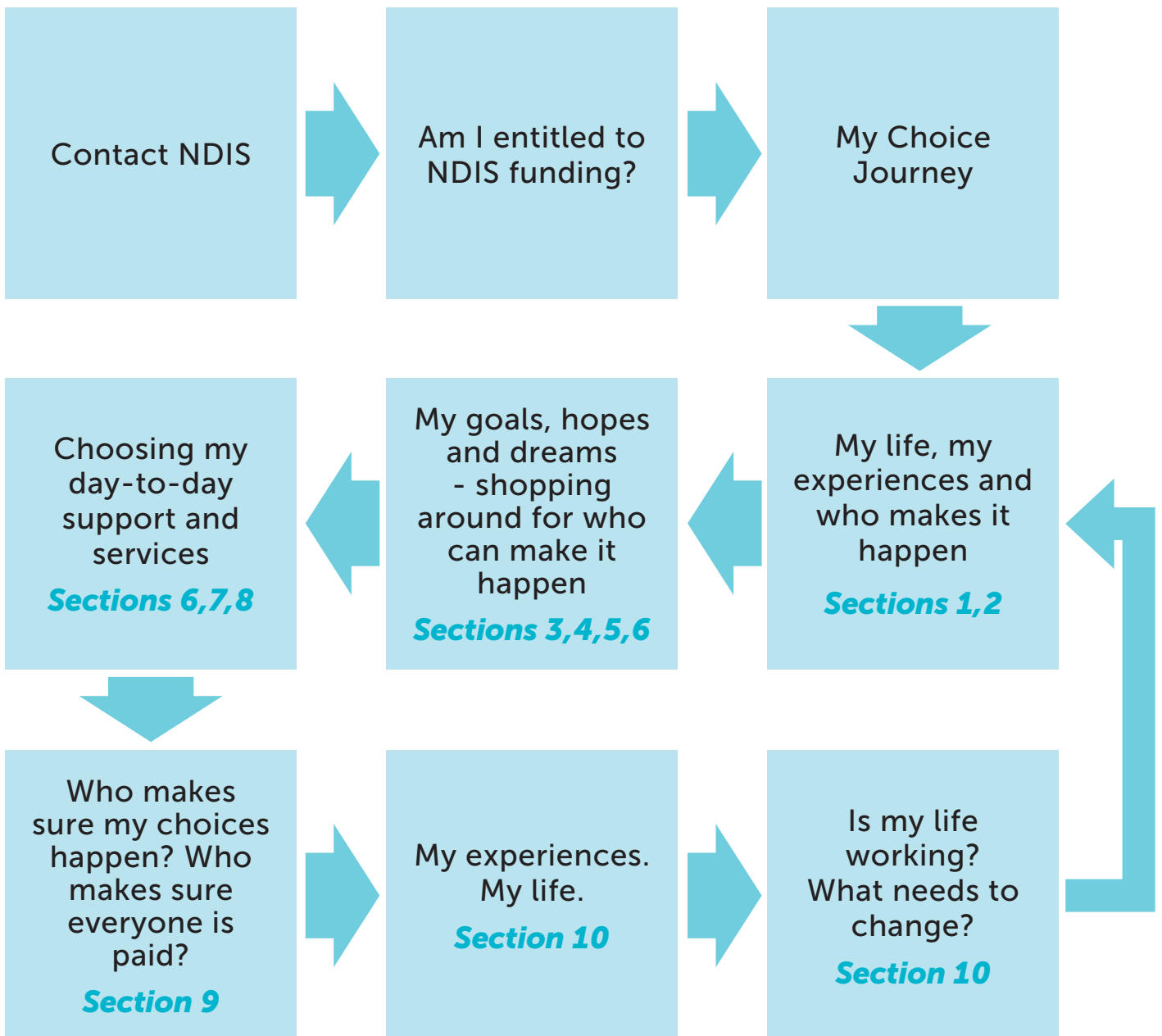
Recognise and respect for evolving capacities.

Equality of opportunity

Equality between men and women

13. My Choice Journey

Below is a diagram of your choice journey under the National Disability Insurance Scheme. Next to each phase we have put section numbers from this resource to help you plan how to get the most out of the National Disability Insurance Scheme.



Human Rights and facing problems *Sections 11,12*

Stories that may help you think through choice-making:

Sometimes people make choices that may not be good for them. You may eat too many chips or chocolate. Here is one manager explaining to a person how they deal with such issues. Remember it may be that pointing to contradictions between everyday and pervasive life choices may be a good option:

*"Yes we try to give people the understanding that if you are going to eat crap every day it is their choice, their money, but try to explain the affect it will have on them and on other people. So you need to tell them "if you want to get a job you need to keep your health good. What is the outcome if you are going to eat sugar all day?" Explain to them the possible outcomes of them doing that."
(Manager, day service)*

*"Also respecting the person as well. Don't bombard them or forbid them, but talk to them about developing a strategy to balance it out. So it's about saying "if you have a cream bun every day you will not make the basketball team".
(Support Worker)*

Lifestyle choices can effect so much else in life. Have a look at the place of a belief in God in the following quotation from a person with a disability. Note how the church provides inclusion, support, and a feeling of belonging.

*Why is the church important?
"Because God is part of our lives. Because I have my friends there. We get lunch there. We can go to services. Family time, friendship time. It helps me through a lot of stuff, it is a support network as well."*

The importance of testing the menu by providing people with new experiences is highlighted in the following quote from a family carer:

*"I was very stressed about choosing a school for (my son), and my sister said: "Just make a choice and go for it and if it does not turn out good then enrol him in another school". So there is not always a wrong and a right, it is not black and white. You have to try things and see how they go."
(Family carer)*

Remember. Speak up. Be heard and GOOD LUCK with all your choice-making, and achieving all your hopes and all your dreams!

The following quote shows how experiencing new things can contribute to confidence and to a person growing in their lives and their capabilities:

“This little bit of funding to do these extra activities – horse riding ... piano, means my daughter has a fabulous self-image and has great self-confidence. This has helped her ...to tackle things...Now I see possibilities for my daughter’s future.”

(Family carer)

The importance of really knowing a person cannot be overstated. An LAC meeting a person for the first time cannot possibly know sufficient to furnish him or her with sufficient personal preferences and history to make informed decisions. In the second quote the importance of seeing planning as a constant activity and not something arranged haphazardly prior to a meeting is exemplified. It is why those who know the person, including family and friends, are so important to decision-making:

“Are there complex behaviours preventing them from expressing what they actually want? Some support workers here know their clients through and through and can really advocate for them. So skilled communication is very important to ensure the person is really making the choice – that the choice they are expressing is really what they want.”

(Service Manager)

“In order for someone to make a choice you need to really know that person well, understand their needs and who they are as a person. We can sit down with someone and have that plan done in 60 days and they will be saying they want to do XYZ, but some of that, after getting to know them, you realize is not going to be achievable, but they are really long term goals, as there is a lot of things they need to learn to do before that.”

(Service Manager)

The following is a good example of the ways in which planning becomes an active and ongoing project and where choice is developed out of working inclusively:

“We did his planning meeting weeks ago, and I realised after doing his plan that some of those things are not going to be achievable as there are so many other issues going on in his life. But actually hanging out with him in that shopping centre has been amazing. I have met a customer who has known him for many years and taken him under her wing. I’ve got a good relationship with the cleaner and found out a lot more. I have got these 2 on board together to help me help him. Because at the moment he is not going to make decisions as he is quite fearful of things at home, so they have agreed to be part of it. So I am encouraging a kind of circle of support for him. And that ‘hanging out’ has been amazing. And he is happy to discuss things with

this other lady. This takes a lot of time and sometimes there is such a push to make a plan for people that you run out of time. And it was much better to make the plan in this setting as this is his space, whereas taking him into a sterile environment he would shut down."

(Support worker)

Sometimes the level of funding may not stretch. In situations like this difficult decisions have to be made about what is likely to most benefit the person concerned:

"But it's difficult as there is not the understanding from the businesses and we do not have the staff to supervise them all the time. Example – one guy was working well independently but he wandered off from the job a few times and got a few warnings and then was fired as we cannot supervise him all the time. So that's a big problem – they can make the choice but there is not the support to actually help them with implementing the choices."

(Service Manager)

Many people who used services and their family members were at a loss as to where to look for services and how to make judgements about them. Here is a typical comment:

"Key issue is helping people negotiate the system and having someone available who can advise where to go for what."

(Family carer)

Glossary of terms

Advocate

Somebody who speaks on your behalf.

Capability

You are able to doing so many things. Life is about learning and using new skills, reaching your goals and not being held back for any reason.

Convention on the Rights of Persons with Disabilities (CRPD)

This is a set of rules about what rights you have. The rules were made by the United Nations and Australia has agreed to these rules. You have the same rights as every other person in the world.

The National Disability Insurance Scheme

The name of a new organisation that will provide your funding, help you plan and help you choose supports.

Discrimination

When a person is treated differently because of a disability, being a man or a woman, their sexuality, their colour or their religion.

Everyday choices

Small choices that we make all the time, like deciding to go for a walk, choosing what to eat, or choosing what TV show to watch

Lifestyle choices

Choices about what you look like, how you decorate, what pets you like, what your routines are for getting up, going to bed and so on. They are the choices you make about being happy with yourself and your surroundings.

Limitation

Something that stops you on the pathway to your chosen dreams. We cannot achieve all our choices. This may be because there is not enough money or enough time. It may be because there isn't a service available.

Local Area Co-ordinator

Someone from the National Disability Insurance Scheme who will try and help you achieve your choices and talk to you about the services and supports you need.

Nominee

Someone who has a role in making decisions for you if you can't make them for yourself.

Pathway

Your plan to reach your goal. It is usually made up of small steps. As long as you're taking these steps, you'll reach your goal in the end.

Pervasive choices

Choices that will have an effect on every area of your life. These choices include things like work, school, family,

health, and where you live.

Plan Nominee

Like a Nominee but they have the important role of developing your plan. They must follow the National Disability Insurance Scheme's rules when they do this so that your plan will help you reach your goals and dreams.

Planning meetings

The meetings were people talk about your life and your future and what steps will get you there. It is important you have your say in these meetings.

Photovoice

Taking pictures of things that are important to you with a camera. This can help you when you talk with other people about things you like or don't like or things you want to do.

Resource

Things that you read or watch – like books, posters or videos – that help you know how to do things. This is a resource about making choices.

Review meeting

A meeting to discuss how things are going and what can be improved. You should speak up about how you feel in these meetings.

Risk

The chance something may go wrong and you may get hurt. Life is full of risks and you have to take risks to know what you can and can't do.

Social stories

Often used with people on the autism spectrum to understand communication and interaction. They involve describing situations and how people are interacting.



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