

# *It's My Choice!*

A Knowledge  
Review

## It's My Choice! Toolkit

ISBN: 978-0-9922717-9-4

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(2013)

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## It's My Choice!

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**Suggested citation:** Ramcharan, P, Leighton, D, Moors, R, Laragy, C, Despott, N & Guven, N 2013, It's My Choice! Toolkit, Inclusion Melbourne/RMIT University, Melbourne.

**Funded by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs**

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Review

5



# Contents

1. Introduction	6
2. Background to the <i>It's My Choice!</i> study.	8
3. Principles of Choice	9
3.1 Some further aspects of the choice-making journey.	16
4. Principles of choice – Explanation and examples.	19
5. The <i>My NDIS Choice Pathway</i> and implications for the <i>It's My Choice! Toolkit</i>	26
5.1 What are the service options? Or my life, my experiences and who makes things happen?	29
5.1.1 What happens? Activities	29
5.1.2 Who does what? What are the issues?	32
5.2 My goals, hopes and dreams	36
5.2.1 What happens? - Activities and who is responsible for what	36
5.3 Choosing my day-to-day support	42
5.4 Implementing the plan - Who makes sure my choices happen? and living my life	45
5.5 Is it working?	54
6. Some concluding remarks	56
References for the <i>It's My Choice! Knowledge Review</i>	58
Appendices	61
Appendix 1 Methodology for the <i>It's My Choice! Knowledge Review</i>	61
Appendix 2a List of limitations to choice identified in different studies: Limitation Table A	65
Appendix 2b List of limitations to choice identified in different studies: Limitation Table B	67
Appendix 3 Considerations for Practice	70
Endnotes	74

# 1. Introduction

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*Choice* is perhaps the central concept of our time. Choice sits centrally within a number of contemporary discourses, all of which have been eagerly adopted within social policy and welfare.

In this light, consumerist theories view choice as a prerequisite to being a customer for services. It is a precursor to the expression of the consumer's rights, to the customer's participation in deciding and to redress in situations where the products they receive are not up to the standard they require. It is, too, the ultimate expression of individualism.

Where choice moves from the personal, to a group consciousness and, perhaps further, to a public consciousness, it becomes collective. From a radical perspective the expression of choice and pursuit of change make choice a concept of enlightenment, one of power and the basis for all forms of emancipation through advocacy and new social movement campaigning.

From a human rights perspective choice plays a central role as one of the primary underlying principles. In the UN Convention on the Rights of Persons with Disabilities (CRPD) choice and autonomy are the basis of the first principle and linked to the aspiration of independence:

*'Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons...'*


(Article 3a)

Not surprisingly then, *choice* plays a central role in the National Disability Insurance Scheme's future. This is clear from the work first proposed by the Productivity Commission, whose report (2011) states that the system "would shift from block funding and a service-centred model to one in which people with disabilities and their carers would wield the greatest control, whether that be to cash out their package, or to have it met in flexible ways by providers. Under any arrangement, people could choose their providers, which would have to conform to common quality standards, compete on a competitively neutral basis and be remunerated using efficient prices. Informed choice would be supported by providing nationally consistent and publicly available measures of the performance of service providers." (p15)

This sentiment is refined in the objects of the *NDIS Act (2013)*, which highlights that the National Disability Insurance Scheme is to "enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports". The rules of the National Disability Insurance Scheme give further weight to this objective by stating that "choice and control for people with disability is central to the NDIS" and further highlights that people with a disability have the right to make their own decisions about the type of supports and services they use; who provides them; how services are designed and provided; and how supports and the funding of these supports should be managed. It is at the very heart of ideas around personalised services and individualised funding.

Individual choice is therefore a comfort term. It can easily feature in company vision statements, policy documents and in practice-based resources without contention. Yet as a practical task it is far from easy to implement. It suffers a number of philosophical, theoretical, practical and organisational problems.

In looking at the disability literature (like all other literature in health and human services), there are already choices built into the knowledge which largely remain unseen. For example, the research debates around *residential options* since deinstitutionalisation began have compared institutions to other options, emphasising comparisons of group homes, campus/cluster style dwellings, and only to a lesser degree supported independent living arrangements.

There is a shaded *Considerations for Practice* area at the bottom of several pages in this *Knowledge Review*. These considerations provide a summary of the page's theoretical principles and will assist in their practical application. 

## Considerations for Practice 1

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Consider the phrase *Disability without Borders* as encapsulating the mission, policy and approaches that constitute the National Disability Insurance Scheme. It is also a reminder of the need to address barriers systematically as a part of the mission and philosophy of support provision.

In this literature the opportunity structure for choice for the person is limited to those options studied in the literature. Few questions have been asked about the queue in which people with a disability are placed, the extent to which this reflects wider expectations of the public and what sort of housing that might imply in terms of individual choice. Most people, for example, would want to be placed in a housing queue which saw them as an individual or part of a family unit and not simply as one of maybe six people who share a characteristic (such as disability) defined by others. Policy can limit the potential opportunity structure for residential choice as a result.

In relation to housing, evidence shows that as people move into group homes from institutions their skills increase for a time prior to levelling off (*Stancliffe et al., 2002*). The reason for this is that they are expected to perform tasks that were previously completed for them by institutional staff. These tasks include cleaning, cooking, tidying and washing. Limited opportunity structures limit choice and limit experience.

Similar observations can be made around literature on day opportunities, schooling and employment. The abiding sense is of the creation of a parallel and segregated system in which the opportunity structure for choice is limited by how we perceive people with disability within our society.

Individual life choices can therefore be pre-determined by an *opportunity structure* that is pre-established. Later the notion of origination and a series of such limitations upon choice will be examined. But it is important to note that there is a seeming emphasis in the National Disability Insurance Scheme on an implicit value position that might be summed as: *Disability without Borders*. This report is constructed in ways that seek to address these borders using a human rights approach, one that has been seen to be central to the National Disability Insurance Scheme.

However, whilst there should not be borders constructed *because of* disability, there are limitations in people's lives. Much of this review is about seeking to help all parties come to some agreement about what limitations on a person's experience are acceptable.

In undertaking this knowledge review, and in talking with people as part of this consultation, we have identified a number of further issues with choice. Firstly, the common sense versions used by many do not fully account for the complexity of choice and choice-making, leading to actions which may have neutral if not negative consequences for the person with a disability. Secondly, bland statements such as 'everyone has choice' or 'you have the right to choice' are simply not true in that they fail to acknowledge that the person may often not be able to pursue that choice nor to expect the outcomes. This often leads to a glossing of areas in which choice does not feature and to rationalisations for actions that deny choice. Third, a focus on mundane everyday choices (e.g. this drink or that drink) means that these stand as the surrogate for choice by excluding major issues such as where a person lives and what a person chooses to be. Related is the idea that choice represents a single action and occurs at one place and time rather than choice being seen as a long term process. Finally, and, perhaps most importantly for what follows, there is an unspoken and yet false assumption in much literature that our aim should be to dispel all limitations on choice, since any such limitation does not provide the same untrammelled and unlimited experience of choice of the population at large. This last point is often uncomfortable for those who provide services who need to deliver that message and is a potential source of conflict.

We believe it is important to try and resolve these and other issues if choice is to be successfully and honestly operationalised within the National Disability Insurance Scheme.

## Considerations for Practice 2

A literature review highlights three resounding issues with choice, both conceptually and in past practice:

- People have a right to choose but cannot necessarily pursue every choice nor expect its accomplishment.
- Choice conceived in a limited way (e.g. as small day-to-day choices) glosses over choices in vital life areas and creates a veneer of accomplishment.
- Choices can be complex and involve planned action rather than spontaneous decisions alone.



## 2. Background to the *It's My Choice!* study.

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FaCHSIA has funded this project through the Practical Design Fund initiative to support the implementation of the National Disability Insurance Scheme which rolls out from July 2013. The project is required to use literature and the collection of data (see *Methodology in Appendix 1*) from people with disability, family carers and those working in disability support providers (DSPs) as evidence to inform:

1. the development of a series of ***Principles of Choice***, from which comes
2. ***a framework for choice-making***, from which can be produced
3. ***choice-making resources*** for people with disability, family carers and DSPs

We believed that there are a number of misconceptions around choice. These misconceptions are based upon assumptions and, in turn, these assumptions guide how people will act and what they do. It was absolutely vital, therefore, to explore some of the ideas around choice in order to develop substantiated philosophical principles upon which all subsequent social action takes place. These assumptions would therefore inform the framework developed as well as the resources that are produced. What follows is a knowledge review that informed the development of the above resources and which is submitted to FaCHSIA alongside the resources to substantiate the position taken in those documents. Section 3 of this knowledge review therefore states the Principles of Choice.

We have adopted an alternative approach to referencing this knowledge review. The literature and explanations about their use that have informed the points that we make are placed in the endnotes and not the text. The reason for this approach is that we want the line of argument from principles to framework to resources to be clearly identifiable in what has been written. Too much information in-text would interrupt this flow.

In Section 4 we have tabulated the Principles; explained each principle further, and provided further examples drawn from consultations (see *Methodology in Appendix 1*)

In Section 5 we have identified how each principle is relevant to the *My NDIS Pathway* which provides a framework for implementation, and outlined what consequently appears in the choice-making resources.

Once again, the relevant literature is explained and referenced using endnotes so as not to interrupt the flow of discussion.



## 3. Principles of Choice

(All principles are derived from the data collected and literature on choice-making, see endnotes).

### Types of Choice

#### Principle 1

I have the right to make choices throughout my day.<sup>1</sup>  
These are called *mundane* or *everyday* choices.

#### Principle 2

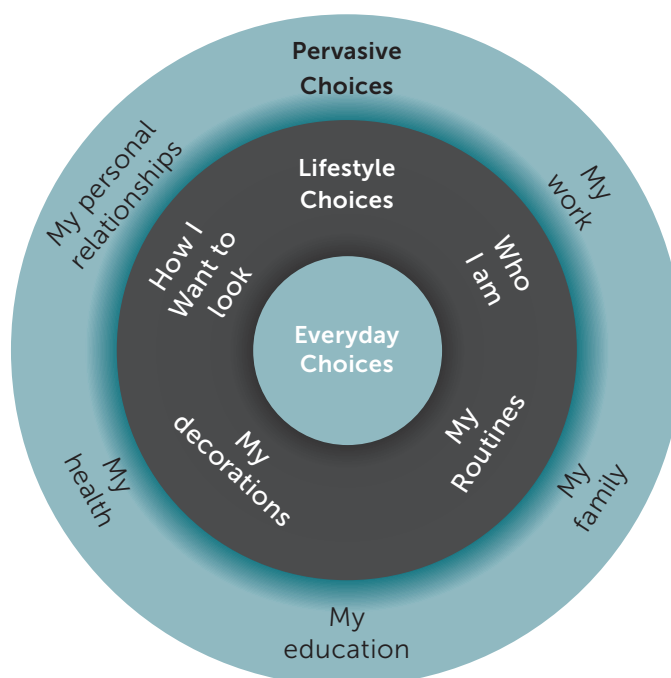
I have the right to be who I choose to be.<sup>2</sup>  
These are called *lifestyle* choices.

#### Principle 3

I can choose what I want, my hopes, dreams, and goals.<sup>3</sup>  
These are called *pervasive* choices.

Diagram 1 shows the links between the three types of choices.

Diagram 1:  
Principles 1, 2 and 3  
Types of Choices



No choices should contradict or conflict with others. *Pervasive* choice is of a higher order than *lifestyle* which is of a higher order than *everyday*.

For example, a person wants to eat more and more food (an *everyday* choice). One dream is to get fit by using a gym. Getting fit is a health need which affects the rest of their life and is therefore *pervasive*. Going to the gym is a *lifestyle* choice about getting fit. They may have chosen cycling or swimming for example.

Whilst eating more is the person's choice, it will affect their higher order choice to be fit and their lifestyle choice to go to the gym and get in shape. The discussion between friends and/or with support workers should make this contradiction clear. Just like all people, those with disability often need support, reassurance and reinforcement to accomplish their life ambitions and to see how some of their everyday choices can have a negative or positive effect on choices they make about their lifestyle and their dreams. Sometimes then, everyday choices can become a limitation on accomplishing dreams and people should be made aware of how this limits their ambitions.

## Philosophy of Choice

### Principle 4

All actions to pursue choices start with me. I am the source and *originator* of my own choices. Choice is diverse<sup>4</sup>.

Diagram 2: The importance of 'Origination'

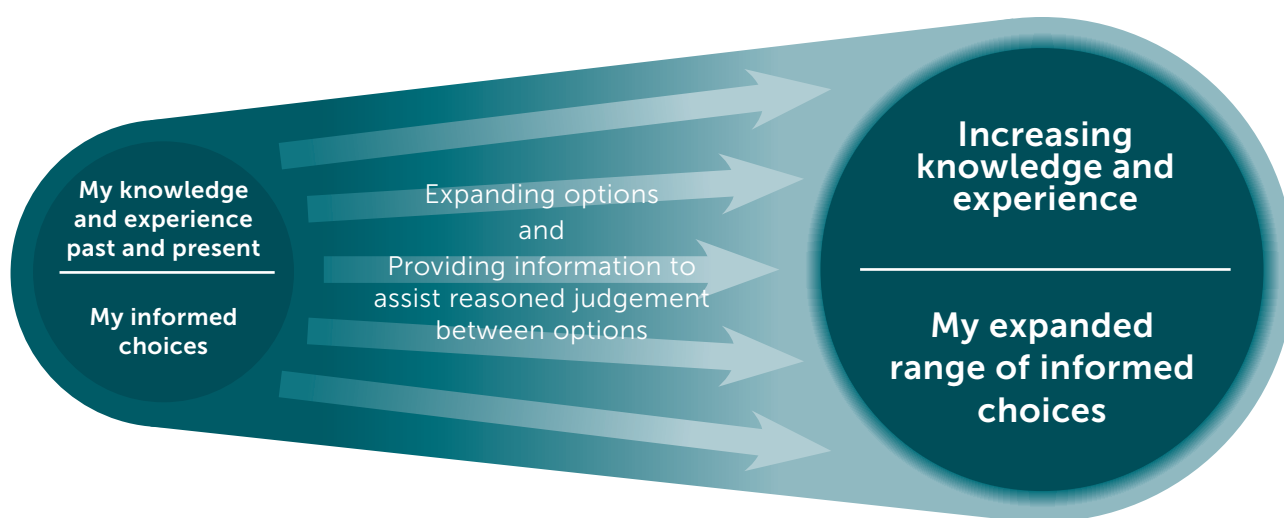


Think about how much more motivated I will be if I pursue what I want and not what you want me to want. Think of how the outcomes will be better. Think about how involving me will become easier for you. Think about the fact that I will not be as bored and that I will enjoy my choices.

## Principle 5

My choices are likely to be greater and more expansive where I have more knowledge and experience to inform them. Building knowledge and experience is important to making choices informed by past experience<sup>5</sup>.

*Diagram 3: Showing how a greater range of options leads to more informed choices.*



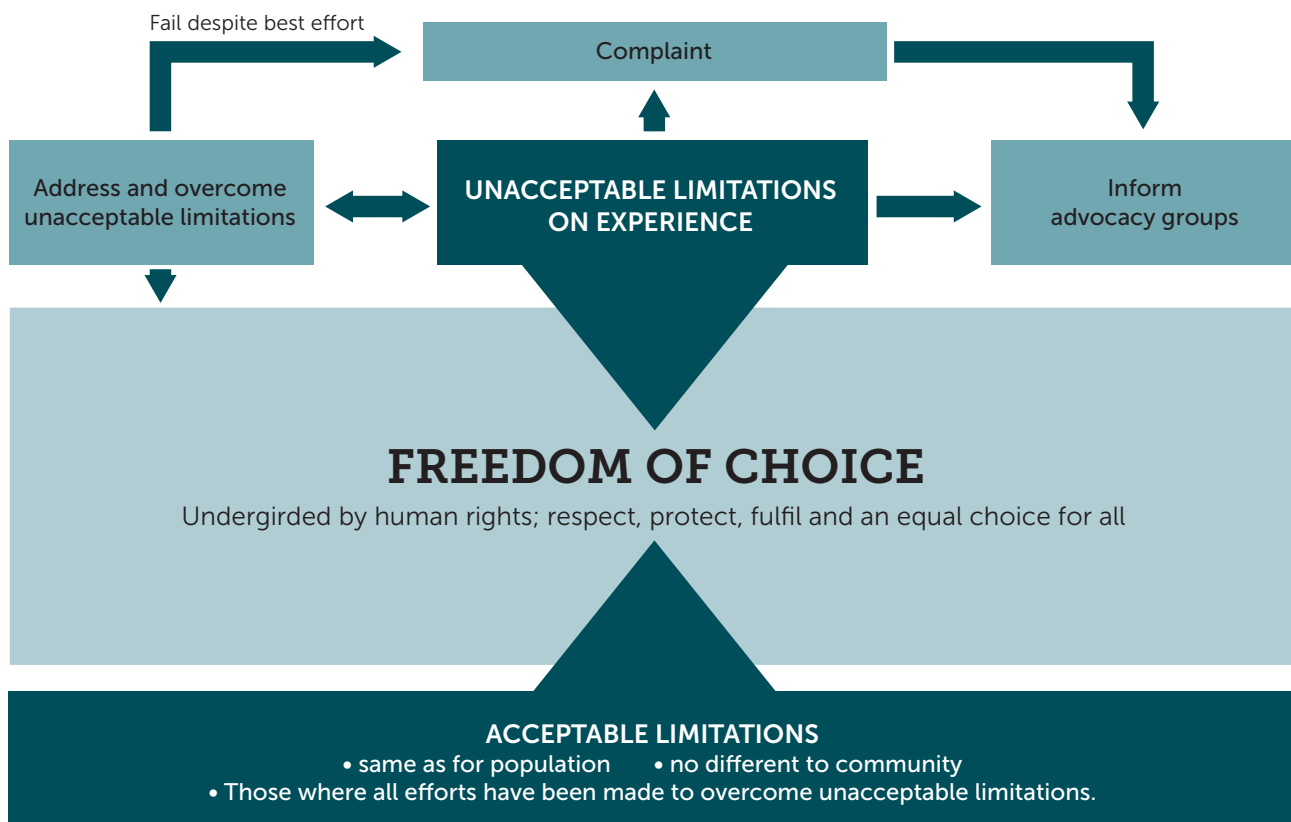
More is said about issues and problems with expansive choice in Paragraph 4 where it is argued that too much information and choice at one time can be confusing, frustrating and can limit choices. This marks up the vital importance of ongoing experiences and recording as a means of informing choice-making. However, it is also true that for some people it is consistency of experience and deep but limited relationships that furnish their lives with quality.

## Principle 6

My personal experience may be limited by money, experience or what is possible. Nobody is completely free to choose and pursue any choice they wish. What is important is whether the limitations I experience are reasonable or not.

- Based on arguments of discrimination and social justice, limitation on experiences should be no greater for me as a person with disability than it is for others
- Limitations on my experiences should be no different in form or measure to community 'norms'
- I have equal human rights to everyone else. In making my choices disability discrimination says it is an offense if these human rights are not respected, protected and fulfilled<sup>6</sup>.
- If there are reasonable limitations on my choice I have a right to try and overcome these. I cannot achieve everything I want. All people are limited by their capabilities but striving to achieve the highest level of capability is what makes life meaningful. This may only be achieved where I have dignity of risk.

Diagram 4: Showing unacceptable and acceptable limitations.



Later, consideration will be given to what is an acceptable and what is an unacceptable limitation on choice. Experiencing limitations may be about what is realistic, feasible, affordable and so forth (as discussed later). The idea that choice is always limited should NOT be a charter for those wishing to prevent or lower choice for their own reasons. This principle must therefore go hand-in-hand with a 'maximising principle', i.e. that at all times choice is maximised for the person.

## Optimising the person's right to choose

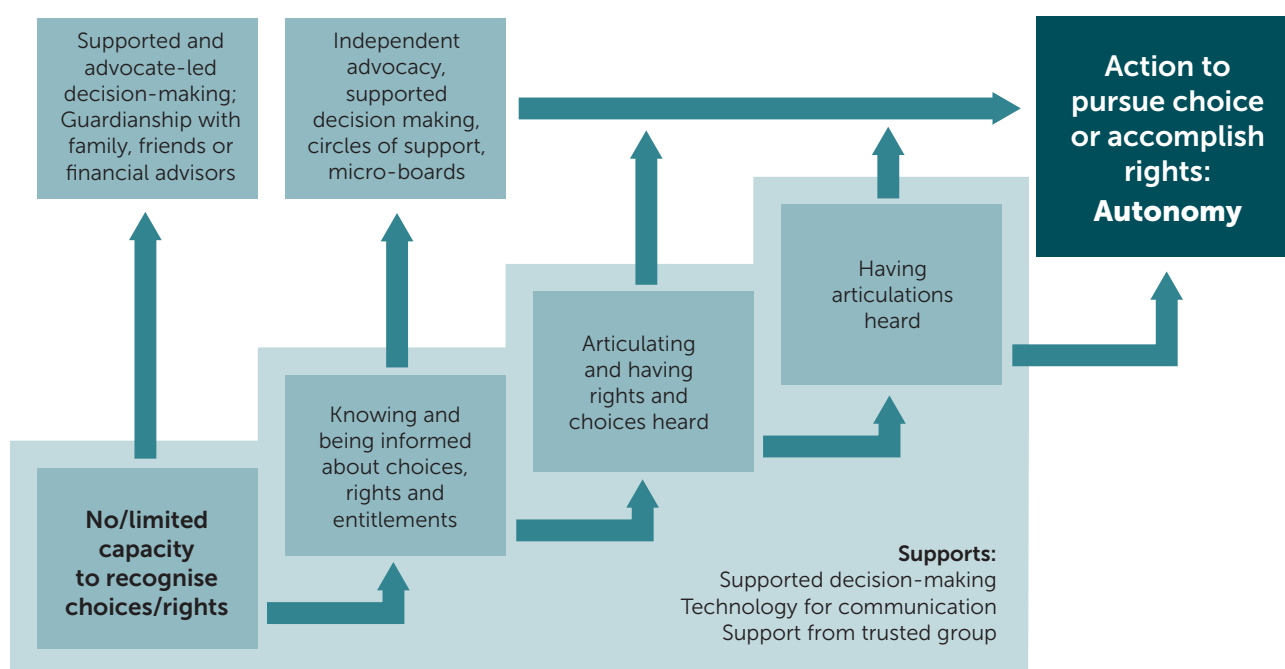
### Principle 7

Each person, including each person with disability, has the right to exercise their choice to the greatest degree possible without interference or competence-inhibiting support. All support must be competency-enhancing<sup>7</sup>.

- I am not excluded from choice if I am unable to speak for myself. I may need support (technical or personal) and/or advocacy<sup>8</sup> at different times. But that support must not stop me from making the choice myself if I can do so<sup>9</sup>.
- I do **not** need support and/or advocacy to do things I can already do for myself.
- To choose is to discern difference and favour one or more options. For choice to be experienced it should therefore be informed.
- Being informed about choices is not just about placing options in front of a person. More is required to make choices 'informed'.
- Where I choose I can make my choice with a collective<sup>10</sup> or with an advocate and/or guardian or a Plan or Correspondence Nominee<sup>11</sup>

People may need differing levels of support and advocacy. To the top left people who cannot conceptualise choice and rights are likely to need some formal advocacy or substitute decision-making arrangement. Unless the person can pursue things wholly independently they will need advocacy, supported decision-making or decision-making groups such as circles of support or micro-boards.

Diagram 5: Showing the need for advocacy and supported decision-making.



(adapted from Ramcharan, P., Nankervis, K., Strong, R. and Robertson, A. (2009) Experience of restrictive practices: A view from people with disabilities and family carers. Melbourne: Department of human Services).

## My Choice Journey

There are two features of the choice journey. First there is the nature of the choice journey itself and second is the support required during the choice journey.

### Principle 8

Support for choice-making can take place where necessary at several places in my journey.

- a. Identify what my likely choices would be if I am a person who cannot speak for myself
- b. Know more about what alternatives and options I have, so that I can select my preference,
- c. Plan with me what steps to take on the journey to achieving my choices and goals.<sup>12</sup>
- d. Plan my steps and identify what services/supports might best help me achieve my goals.
- e. Identify the limitations and how to address and overcome these.
- f. Help me to choose how best to manage my NDIS funding and payments to service and support providers so that my choices come true
- g. Support me to review where I am up to, whether things are working, and what can be done better.

### Principle 9

Choice is a continuing journey and not just a one-off action<sup>13</sup>.

- a. What I want tells others what I need to help me move towards my key life and lifestyle choices<sup>14</sup>.
- b. If I am moving towards a goal then I am growing. As I grow I fulfil my capabilities and this gives my life meaning.
- c. As my life changes, so too can my choices and pathways.
- d. The goal is not *the only option left* or *the last cab off the rank*. What I say I want tells you what I need. Choice, therefore, means planning achievable steps to get to my chosen goal. This is the standard against which formal services will be judged.

*Diagram 6* summarises just **one** choice journey, in this case relating to a wish to do paid work. It shows the nature of the supports that are required to make the journey possible and the steps along the way. These steps are not set in stone. The steps on each person's pathway will differ.

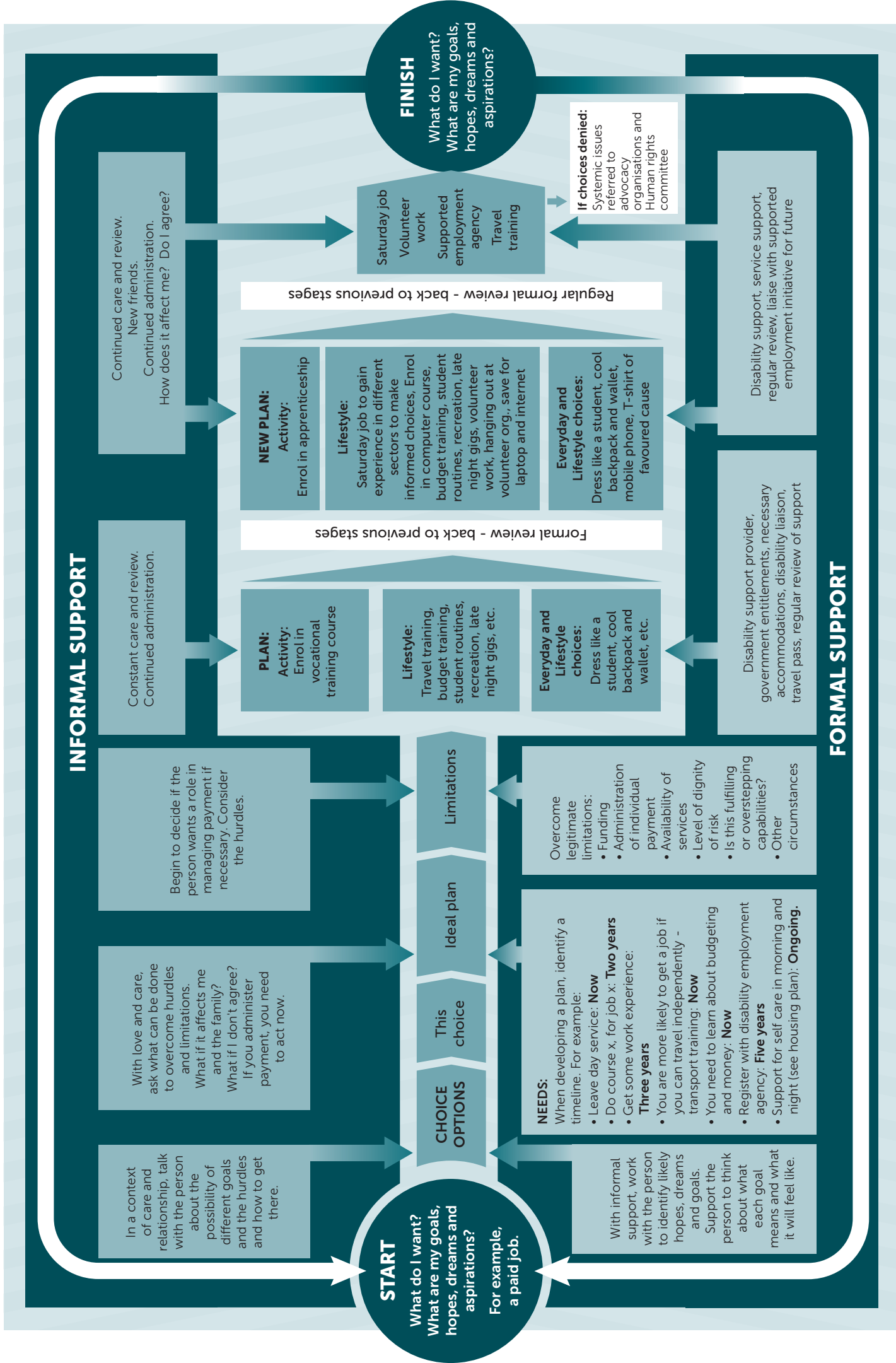


Diagram 6: Example of the choice-making journey and the supports I may need based on a life-course and a life-style.<sup>15</sup>



### 3.1 Some further aspects of the choice-making journey.

*Diagram 6* gives an example and covers just **ONE** of the person's key choices (paid work) in **ONE** area (what to do with my working days). It is vital to ensure that plans include **ALL** pervasive life choice areas in terms of a person's ultimate aims. These include what the person does each day, family, intimate relationships and friendships, health, leisure and community engagement, education and, where appropriate spirituality and culture. There are a number of other aspects that are vital in understanding *Diagram 6*:

#### Capabilities

There are some ideas and values which will help to motivate people who provide support to people with a disability. One motivating ideal is the goal of supporting people to fulfil their potential. This usually includes emphasising functional capabilities, e.g. activities that make up a person's being such as employment and working to be healthy, fulfilled, or even happy or calm. However, even the notions of *potential*, *capability* and *function* are subject to choice. People have the freedom to choose the functions that are important to them, making choice an essential dimension of capabilities. In this model the old professional emphasis within disability services on, for example, training people to develop their social skills, gives way to the recognition of what capabilities are important to, and chosen by, the person.

Supporting a person to develop capabilities tests the person to the extent that they can grow and develop to achieve the skills that will help them have fulfilled lives. It offers a variety to life, a dignity of risk and the capacity to develop both hope and resilience.

For someone who, for example, is congenitally deaf blind and has an intellectual disability, you may want to think about what their capabilities could be. What have they been interested in, excited about, stimulated by, eager to be involved with, in the past? These will give you clues. It may be that a particular level of engaging stimulation, such as patting a pet or experiencing certain sounds or textures, represents a vital element of a person's fulfilment. Relationships with family, friends and others are also important. What are the best ways of understanding communication? Can you establish some common language by a consistent input? How can you ensure that different environments they experience offer the same level of understanding, choice and comfort? What are the foods a person enjoys and how can you get them involved? Can they stay in the kitchen and experience the smells as you cook or, at a stretch, would it be appropriate, meaningful or fulfilling for them to be supported to set the table?

There are a huge number of engagement strategies that might build the person's ability to enjoy a connected life that incorporates their inherent and potential skills, capabilities and dreams. The long term goal might be achieving a routine that is stimulating; keeping meaningful contact with family; having experiences in the community which bring the community in and engage people who are not directly involved in delivering formal care; experiencing leisure in wider settings; safe engagement with animals and pets; learning to communicate essential everyday choices or learning to relax. All must be done within a human rights framework.

Fulfilling each person's capabilities will present tasks of various magnitudes. Staff must feel they have goals that are realistic and truly test and stimulate the person to extend themselves and grow through the process, *ipso facto*. There must therefore be challenges and hurdles along the way. The range of ways of engaging with a person's capabilities reflects the diversity amongst people with a disability.<sup>16</sup> Capability is therefore a concept that supports choice and diversity.

#### Considerations for Practice 3

When we work to fill our chosen capabilities we make life meaningful, we develop and we can have hope as well as build resilience.

#### Considerations for Practice 4

It is important to see the person's strengths as lying not just with them but with the wider structures of support of which they are a part. This is why people who are isolated are less likely to flourish and fulfil their human relationship needs.

## Informal help and support

This may change over time as the person makes more friends and contacts who are willing to be more involved in his/her life. If there is strength in this group it is ideal that, where the person sees it of benefit or where they cannot choose for themselves, this group has control over the *circle of support*, *microboard* or whatever vehicle is used. It is only in the absence of these people that services can take overall responsibility. Administration of payments may fall to the person, the informal group or to the support provider as a last resort. The preferred scenario should be for such payments to be held by the person or their circle.

Michael Bayley (2007) identifies a useful collection of those strategies of informal support that contribute to better lives and fulfil fundamental human needs. He identifies these to be: intimacy, nurturance, reassurance of worth, guidance, and reliable assistance. These have similarities to O'Brien's five accomplishments. What Bayley suggests is that not all of these characteristics should be invested in one person or organisation. The richness of relationships and life should furnish the person with these investments collectively and this points to a 'distributed competence' (Booth and Booth, 1994) among a number of people and inclusive of the formal service sector where necessary. Indeed Bayley suggests that where too many of the strategies for informal support are invested in one person there is potentially greater loss if that person leaves. There may also be vacuums where a person cannot fulfil some of the relationship needs, for example a parent and the need for intimate relations.

Strength does not inhere to the person as an individual but, rather, to the groups of which they are part. Strength should not therefore be simply measured against the individual but against the person's wider informal networks. Where there is a lack of strength in the person's support network, the support provider needs to establish systems of exchange and build a fabric of support, or in other words, to build social capital.

## Lifestyle choices

These are the central stepping stones moving left to right in *Diagram 6* and can be seen as a reflection of who the person is at the time. Thus, their *pervasive* life choices will affect their *lifestyle* choices. Being a student may mean new sleep patterns, new symbols that are representative of life stages (eg. music, fashion, accessories), new friendships and opportunities (going to gigs, attending particular events) and so forth. Similarly these *lifestyle* choices may affect the *everyday* choices people make. For example, a person may want to drink alcohol once their friends at college are doing so or spend a lot of time socialising or using social media. So the college life has an effect on their lifestyle and this in turn may influence their everyday choices. The richness of our lives and changes in our preferences are therefore in many ways dictated by the relationships built in our regular settings. Strip these to a minimum and growth may be stunted as a result. It may also be posited that the sense of embodiment that goes with disability pride may also feature in the domain of lifestyle choices. This reclaiming of identity can be very important to self esteem and confidence.

## Rejection of choice

Where choices have to be rejected for reasons that are *not* legitimate or due to a lack of funds or to services that are not yet available, then it is worth submitting these to systemic advocacy organisations (see *relevant box in Diagram 6*) who can use this information in their own priority setting around campaigning, lobbying or awareness-raising.

There should be nothing to fear in this mechanism!

The approach would lead to a dialogue between the systemic NGO/independent advocacy organisations and public authorities making claims about services, i.e. a human rights-based approach. It will also help government respond to the reporting requirements of the CRPD. Given the regular feedback required to the

### Considerations for Practice 5

It is possible to see lifestyle choice as including embodiment, i.e. pride in who you are, including your interests, skills, personal qualities and disability.

### Considerations for Practice 6

Operationalising the CRPD requires an ongoing dialogue between rights bearers (people with a disability and advocates) and duty holders (public authorities).

The role of advocacy in this dialogue is hugely significant.

CRPD Committee, this mechanism will be a focus for a more reasoned discussion about human rights. As well as civil and political rights, economic, social and cultural rights can be part of the debate insofar as the response of government to the advocacy organisations has the potential to systematically demonstrate *progressive realisation* of these rights over time.

The choice rejection and advocacy process will also help in relation to finding a focus for service providers (whether disability, community or private sector) to identify new niche markets into which they can develop their services based on projected demand from people with disability.

*Formal support* needs in *Diagram 6* are just examples. There may be countless such services and supports necessary. For example the person may need: speech, occupational or other therapies; health care inputs, or support with technology for communication, aids and adaptations, to name but a few. Of course, housing represents a huge area of choice and one that has been the focus of heated debate for a number of years.

## Review

Arrangements for reviewing plans are yet to be confirmed by the National Disability Insurance Scheme Launch Transition Authority. However it is expected that there will be opportunities for regular review, likely to be annual or half yearly. This will in some ways be dependent upon what changes can take place via individualised funding, independent of the statutory sector's decision-making. The capacity of people with a disability and their families, circles of support or micro-boards to choose for themselves will relieve some of the work (and control) from the statutory sector, allowing adaptations for emergencies and changes in choices and services. Formal review should be about bringing expertise to assess what is not working to accomplish the person's goals, why it is not working and to arrange replacement services and supports that keep the person moving along the choice pathway. It should not expend resources on formal assessments that are not needed.

## Adaptation and Control

Being human means that we can adapt to environments and circumstances. We often come to accept and adapt to less than ideal environments, relationships and interactions. Many people with a disability demonstrate adaptive behaviours to maladaptive environments and these environments are what need to be challenged. When the environment does not change or is not changed it is often the case that the person will make judgements about other options without knowing what the new option and experience will be like. This 'better the devil you know' attitude is not sufficient for making informed choices. Nor is the 'this is the only option left' approach suitable for the same reasons. Origination, explained earlier, is important as a starting point for establishing the nature of the choices people prefer. Testing the menu so that each person is informed about such choices is also important. It is very easy to control people who cannot do things for themselves and to impose another's will upon them without their permission. As such it is even more important to challenge the idea that adaptation and stoicism lead to better lives and better experiences. Choice therefore arbitrates the gap between resignation and hope.

In Section 4 the *Principles of Choice* (outlined above) are explored in more detail.

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## Considerations for Practice 7

It is important to ensure people do not have to demonstrate adaptive behaviours to maladaptive environments. This profound insight must be a key conceptual element of planning supports, choosing services and training support workers.

## 4. Principles of choice – Explanation and examples.

In the following section you will find tables in which each principle is stated in the left hand column followed in each row by an explanation and example taken from the data collection undertaken as part of this study. In Section 5 these principles are translated in terms of their relevance to the *My NDIS Choice Pathway*. Detailed information is provided about how the principles can be operationalised. Finally, the necessary elements of the *My NDIS Choice Pathway* project resources are set out.

TABLE 1: TYPES OF CHOICE - PRINCIPLES 1 TO 3

PRINCIPLE	WHAT IS IT?	EXAMPLES	EXAMPLES FROM THE DATA
<b>Principle 1: Everyday Choice<sup>17 18</sup></b> I have the right to make choices throughout my day. <sup>19</sup> These are called <i>mundane</i> or everyday choices.	The huge number of quick choices that are made by all people each day. They are usually simple.	I want tea not coffee; I want to go for a walk; I'd like to watch this TV program.	<i>I watch TV...I go bowling... My favourite TV show is Bargain Hunt. That's an English show.</i> (Excerpts from Focus group - people with a disability)
<b>Principle 2: Lifestyle choice<sup>20</sup></b> I have the right to be who I choose to be. These are called <i>lifestyle</i> choices.	These choices are about who a person sees themselves to be. These are about people seeing the person through their dress, cloths, hairdo, decorations and so forth.	I like my hair like this; my ritual and routine for getting up is...; I want this decoration in my room; I see myself as ...(this type of person) kind, affectionate, a do-er, a thinker etc.	<i>I wear white shirt and apron for cooking. I dress for the occasion.</i> (Focus group - self advocates).  <i>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.</i> (Focus group - self advocates).  <i>I got a cross. I'm a Christian.</i> (Focus Group - Self advocates)  <i>Moved from home to a CRU...went from tracksuit everyday to very fashionable..confidence grown... making friendships. their whole life has changed.</i> (Focus Group excerpt - Support workers)
<b>Principle 3: Pervasive choice<sup>21</sup></b> I can choose what I want, my hopes, dreams, and goals. These are called <i>pervasive</i> choices.	There are choices that, when made, will have a major effect on every other life area. When we asked about choices most people with disability with whom we spoke listed pervasive choices.	I want more time with my family; I want a personal relationship with...; I want to do this job; I would like to live in a house on my own; To be healthy I need...	<i>Housing, getting meaning out of life, who to spend time with, how you spend your money, skills.</i> (Focus group excerpt with service workers)  <i>Parents, family, friends, health, sustainability, friendship, building relationships, work as a team.</i> (Focus group excerpt - self advocates)

TABLE 2: UNDERSTANDING PRINCIPLE 4

PRINCIPLE	MEANING	EXAMPLE	EXAMPLES FROM THE DATA
<b>Principle 4:</b> All actions to pursue choices start with me. I am the source and originator of my own choices. Choice is diverse.	The starting point MUST be the person <sup>22</sup> . Each thing that happens after that must be something that happens because the person was a <i>free agent</i> to choose. So the choice must originate with the person. What the person chooses may be dependent upon advice from others and their experiences. In the past traditional methods have been to see how the person fits to already existing services. The person is therefore not the originator of the choice and what comes after. Rather they are 'owned' by the system. Because of this the choices people make under the NDIS will be hugely diverse and not limited to just a few things. Whatever services and supports follow should be pathways to the person's goals.	I want to go on holiday to the Barrier Reef. It will take two years of saving; I will have to find if the boats will take me to the reef and if I can see the fish; I will have to book a hotel. I will need support when I'm there. That's my choice, it was my idea and I will get there!  <b>or</b> My service tells me I can go to Brisbane with the other guys or they'll book me on a cabin holiday at Philip Island. I don't have an interest in Brisbane and they go every year to Philip Island. Neither is my original choice.	No origination or participation in the following example of choice-making:  <i>A lot of parents have chosen [name of day service] because it is consistent with their risk averse strategy. And [the service] has reinforced that, so if you challenge this the staff don't feel comfortable... So you have a real challenge.</i> (Interview, CEO, DSP)  <i>I want to be a traffic cop...</i> (Focus group - people with a disability).  An important aspect for the following person originates with his wish to be near to his family.  <i>I live in a supported house. It's called a CRU. I hate it...I am away from my parents'... [Would you live in a CRU nearer to your family?] I want to find some way of getting close to my family.</i>

TABLE 3: UNDERSTANDING PRINCIPLE 5

PRINCIPLE	MEANING	EXAMPLE	EXAMPLES FROM THE DATA
<b>Principle 5:</b> My choices are likely to be greater and more expansive where I have more knowledge and experience to inform my choices. Building knowledge and experience is important to making choices informed by past experience	<p>A person's choices may have been limited by experiences (e.g. in institutions) and s/he may just say "yes" to everything<sup>23</sup> ; or, the person may not have had many experiences from which to make informed choices about the future. S/he may need additional support to experience a more expansive list of options upon which more informed choices can be made. This may take time but it is very important if the person is to be the originator of their own choices.</p> <p>It should be clear that we are influenced by the experiences we have and the people in our lives. This means that increasing knowledge and experience are a product of both the people and situations that populate our experiences. These produce an 'opportunity structure' in which some choices are rejected. They should also point to what skills are relevant for a person to develop.</p> <p>However, it is not legitimate for others to be so influential in a person's life that they entirely and singularly limit choice. Moreover, it is also possible that a person can find just what makes their lives fulfilled and stick with their proven formula for life. In this case it is still healthy to have some new experiences but not to undermine what makes life worthwhile and fulfilling.</p> <p>A further issue is that all people can react to huge choice selections differently and some people with a disability can also react with frustration and sometimes even anger. At the point of making decisions about "what next?" it is often good, through conversation and knowing the person, to have limited options in front of the person. Only a continual range of rejected experiences can legitimately furnish this limited decision-making menu, prevent a person being swamped by information all at once and being disempowered by the range of choices over which they have to make a decision at one point in time. This has implications for families, for people planning choices and also for those delivering services at any point in time. Furthermore, since everyday and lifestyle choices follow on from larger choices it is both more efficient and more meaningful to maximise experiences in the pervasive choice domain.</p>	<p>I lived in an institution for twenty years. They told me what to eat, they just gave me clothes, they stopped me from having a relationship. When people ask me what I want I am afraid to say. I don't want to say the wrong thing. I'll go along with most things for an easy life. I haven't had many other experiences to help me make a choice. Staff in my new home have seen this and they've slowly helped me to trust them, to ask for things, to know I can choose for myself. They have also over time given me so many more experiences that I can now say what I want. Supporting all people to have a broad range of choices is very important.</p>	<p><i>Yes, but there are people who have started off with us as a school at 6 years old and now they are 60, and they do just sit here. So we have had to be very creative in getting them out as they are happy to sit here. We have a day where they go out into the community and meet others,</i> (Interview, Manager - day Service).  <i>Parents feel they need to protect them and they grow up with that... Sometimes our guys can't learn from lessons – to learn when they make a mistake. You have to do things in life to learn a lesson. It ties back to that control stuff...</i> (Focus Group - Support workers)  <i>Hopefully in ten or fifteen years, the kids that are in specialist education now will learn those things in a school setting which all other kids do, so when they are adults they can understand and cope a bit better</i> (Focus group - Support Workers).</p>

TABLE 4.1: UNDERSTANDING PRINCIPLE 6

PRINCIPLE	MEANING	EXAMPLE	EXAMPLES FROM THE DATA
<p><b>Principle 6:</b> Nobody is completely free to choose and pursue any choice they wish. What is important is whether the limitations placed upon a person's experiences are acceptable or not</p> <p>a. Based on arguments of discrimination and social justice, limitations should be no greater for me as a person with disability than it is for others</p> <p>b. Limitations on my experiences should be no different in form or measure to community norms.</p>	<p>Not all our dreams are possible. What gives life meaning is our struggle to achieve our goals in the face of these limitations. But the limitations should not be unfair or unjust. Appendix 2 of this document shows tabulations of limitations to choice in the literature by study and by the disability groups studied. They help us to make sense of what limitations there are and, indeed, to make decisions about what to do about them. More will be said of this later. However, some further principles apply to the limitations themselves.</p> <p>Legitimate and non-legitimate limitations will be considered in a section to follow. However, our choices and our pursuit of them should be based around arguments of human rights and social justice. I should be treated the same as others in the community and not discriminated against. This is a <i>normalisation</i> or <i>social role valorisation</i> principle and can be based in ideas such as O'Brien's five accomplishments: Taking part in community life; experiencing valued relationships with people with disabilities and others; choice; competence; taking part in activities with support that is necessary; and respect, i.e. being valued as any other citizen would be valued.</p>	<p>I might want to travel the world. But circumstances, cash and timing may mean I only go abroad twice in my life. There are limitations such as time, family commitments, cost and so forth. My journey of choice is not complete but I've got some of the way there. And it is being on the journey and doing the best I can that really counts.</p> <p>Some limitations I may overcome. I may be able to save up over time or arrange it with the family. I may be able to show my nearest and dearest that I can do it by taking smaller trips and showing them how I cope and how much I enjoy my travel. That may change their scepticism and their advice to not even think about it.</p> <p>However, if I asked to go around the world and I was told, "No way. This service cannot support you in that idea" or "we don't provide that service" then I would say that, like other members of the community, I'd just find a service that would support me in my plan.</p>	<p>A legitimate limitation?</p> <p><i>'...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 could not 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 implement the choices...'</i> (Interview, day service manager).</p> <p><i>'For us we seek their feedback about all the things they'd like to do...Out of all the five they might have three of five due to a waiting list scenario..'</i> (Manager Employment Services, DSP).</p> <p><i>'If they want to do this and that it might be a bit difficult because unit costs are this and for you and your ability you need a little bit more support and so we need to look at a group scenario.. and match up your goals [with others]...'</i> (Interview, Manager Employment service, DSP).</p>



TABLE 4.2: UNDERSTANDING PRINCIPLE 6 (CONTINUED)

PRINCIPLE	MEANING	EXAMPLE	EXAMPLES FROM THE DATA
<p><b>Principle 6:</b> Nobody is completely free to choose and pursue any choice they wish. What is important is whether the limitations placed upon a person's choices are acceptable or not</p> <p>c. I have equal human rights to everyone else. In making my choices disability discrimination says it is an offense if these human rights are not respected, protected and fulfilled<sup>24</sup>.</p>	<p>Making and pursuing choices should be characterised by protecting, defending and fulfilling human rights. These human rights are set out in the articles of the CRPD, its Optional protocol and in international covenants to which Australia is signatory.</p> <p>There are a number of principles set out in the CRPD. These can be remembered by the following mnemonic <b>I RAN FREE</b>:</p> <p><b>Individual autonomy</b> - including the freedom to make one's own choices and respect for inherent dignity</p> <p><b>Respect</b> - for difference...human diversity and humanity</p> <p><b>Accessibility</b></p> <p><b>Non-discrimination</b></p> <p><b>Full and effective</b> - participation and inclusion in society</p> <p><b>Respect</b> - for evolving capacities.</p> <p><b>Equality</b> - of opportunity</p> <p><b>Equality</b> - between men and women (Ramcharan, 2009).</p> <p>By looking at each Principle against each Article of the CRPD it is possible to assess a situation, proposed choice, an event or a person's experiences. A model for such an assessment is set out later.</p>	<p>I wanted to go to the theatre. But when I got there they could not get my wheelchair up the steps.</p> <p>Article 9 of the CRPD states that: '... States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment...'</p> <p>The area is physically inaccessible. The main CRPD principles of relevance are <b>Principle 3</b> on accessibility and <b>Principle 4</b> – that I have been discriminated against because of my disability.</p> <p>Subject to this discrimination I have been unable to exercise autonomy (<b>Principle 1</b>) and it has caused less than full and effective participation on an equal par to the rest of the community (<b>Principle 5</b>).</p>	<p><i>Sometimes people don't care about us, and they need to understand that we are the way we are. And not to discriminate against us or threaten us. I don't like it...I used to be upset on our bus but now I am not... Domination – too many people trying to control your life or control your choices or feeling. Yes I feel that way too. Because when people say 'Oh, she has a disability, stay away from her,' its very hurtful. It really gets to me.</i> (Focus Group - self advocates)</p> <p>Question: Where do you see human rights fitting in to this?</p> <p>Answer: <i>It is fundamental, those principles are fundamental. We need to have an understanding ... that it is fundamental to all of us. What do we need to support them with? We focus on support rather than care.</i> (Interview CEO, DSP)</p>



TABLE 4.3: UNDERSTANDING PRINCIPLE 6 (CONTINUED)

PRINCIPLE	MEANING	EXAMPLE	EXAMPLES FROM THE DATA
<p>Principle 6: Nobody is completely free to choose and pursue any choice they wish. What is important is whether the limitations placed upon a person's choices are acceptable or not</p> <p>d. If there are reasonable limitations on my choice I have a right to try and overcome these. I cannot achieve everything I want. All people are limited by their capabilities but striving to achieve the highest level of capability is what makes life meaningful. This may only be achieved where I have dignity of risk.</p>	<p>All too often people with disabilities are not expected to challenge themselves and to grow. Many become a 'leisured class' or are over-provided with services, becoming dependent and "learning helplessness rather than independence." (Parsons, 2008)</p> <p>There should be a 'Give it a go!' approach. For example 'try that training' or 'learn to drive'.</p> <p>All too often risk is given as a reason for people not challenging themselves and not growing. Too many services confuse a hazard with a risk. A risk assessment plans how to reduce a hazard from occurring. Secondly, services fail to balance the risk with the benefit to the person and end up with a one-sided equation. If the benefits must outweigh the risks then it is worth taking the chance in a measured and controlled way to support the person to grow.</p> <p>Taking risks produces growth and hope and equips the person with a resilience they would not otherwise have had (Ramcharan, 2009).</p>	<p>I have been living in the doldrums for quite some time. Life is boring and I play up a bit just to get some stimulation. I go for long walks. The police have brought me back on several occasions. They have locked the door and put bars on the window. That has made me mad. I am autistic and cannot communicate verbally so I just break things. They have screwed down my bed and taken loose items out of my room and that makes me more mad.</p> <p>Jack, a new support worker says the benefit of me going for walks is great. He knows I enjoy it and he knows my anger is because I can't get out. He does not see this as absconding but as "accessing the community independently." (Ramcharan, 2012)</p> <p>He has introduced me to the cycle path near my home so I don't have to go on the roads. He has got other people involved so I can go out more often.</p> <p>I hope to go walking in the mountains one day. Now I have hope and I am gaining a great deal in health as a result of my walks. I can also walk to my relatives and go into shops too. So life is much better and I am not so angry.</p>	<p><i>A third point was providing wide environments which people can feel more confident in over time and learn via experience. Creating opportunity structure, once people see opportunities they can start exploring them... putting people just outside their comfort zone is a good thing but hard to do, people grow by having this opportunity.</i> (Interview, CEO of a DSP)</p> <p><i>We had a girl coming who did not have a package – straight from school. She was going ok in the workplace for a while but became quite isolated and had no friends and she walked through the door and asked to come here. Now she comes here every day. But we worked hard with her not to do just meaningless tasks. She said she wanted to join the workforce again and is now in 3 workplaces. She volunteers now, and she has a lot of connections. As her confidence was crushed -in the first place. But now she is getting more confident and has many contacts from her different workplaces.</i> (Interview, Manager of a Day Service)</p>

TABLE 5: UNDERSTANDING PRINCIPLE 7

PRINCIPLE	MEANING	EXAMPLE	EXAMPLES FROM THE DATA
<p><b>Principle 7:</b> Each person, including each person with disability, has the right to exercise their choice to the greatest degree possible without interference or competence-inhibiting support. All support must be competency-enhancing.</p> <p>a. I am not excluded from choice if I am unable to speak for myself. I may need support (technical or personal) and/or advocacy<sup>25</sup> at different times. But that support must not stop me from making the choice myself if I can do so.<sup>26</sup></p> <p>b. I do not need support and/or advocacy to do things I can already do for myself.</p> <p>c. To choose is to discern difference and favour one or more options. For choice to be experienced it should therefore be informed.</p> <p>d. Being informed about choices is not just about placing options in front of a person. More is required to make choices 'informed'.</p> <p>Where I choose I can make my choice with a collective.<sup>27</sup> or with an advocate and/or guardian.</p>	<p>If a person cannot speak for him or herself and only present choices can be communicated, then the maximum others will understand will be the person's mundane, everyday choices (see Principle 1).</p> <p>It is vital to seek to maximise a person's communication through speech therapy, technical aids and adaptations as well as through learning.</p> <p>If communication still remains a problem then other approaches are vital. What records are there of the person's past? What do people know about the things the person has really enjoyed doing? A lot of work can be involved where this information is not systematically collected, collated and maintained. Capturing the past can therefore be as important as capturing the present and planning for the future. Indeed the present indications of happiness with experiences will never be known in the future unless committed to some form of record at the time. Having such information can maximise confidence in getting a person's choice right.</p> <p>Recapturing the past therefore extends the possibilities of choices being 'informed'. Moreover having lists of non-negotiables (Smull, 2004) and those things a person hates will also help informed choice-making. If the person cannot speak for themselves then, they may need advocacy or substitute decision-making or supported decision-making to the degree that allows them maximum independence.</p> <p>No solution to the issue of substitute decision-making will ever be perfect. The space for debate between parties is also greatest in situations where the person cannot 'arbitrate' through expression of their own preferences in any discussion and decision-making. However, by following the above pattern of decision-making, that debate is likely to be as informed as it might be. More will be said of this later.</p> <p>They may indeed also want to be part of a group, such as a self advocacy group, which makes some choices with and for them.</p>	<p>I loved to sit on my father's lap in the car and drive around the farm. I never could speak. Nobody knew about my love for cars even though I look at all the photos of new ones in the magazines.</p> <p>It was only through a chance discussion with an aunt that my advocate found out about this story about me and my dad in the car. I think she also noticed I was looking at cars too. Now I am being taken out more in cars and I can't help smiling when I am in the front seat.</p> <p>I have been given a steering wheel and computer game which I love and on my last birthday I was taken to a racing circuit. But I got a bit sick. That didn't matter. It was GREAT! I'm so glad they found out I love cars. I'm so glad someone spoke on my behalf. I'm really happy to have a go on cars on the computer. It's the best!</p>	<p><i>We sometimes need an employed advocate to advocate for the client. Clear communication that the world is their oyster helps – sometimes they think there are only 3 flavours and then find out there are a lot more.</i> (Interview - Project Worker, DSP)</p> <p><i>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.</i> (Interview, Project manager, DSP)</p> <p><i>I had a good story with communication with a house. We had an issue 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 at home in the morning...</i> (Focus group Managers, DSP)</p>

TABLE 6: UNDERSTANDING PRINCIPLE 8

PRINCIPLE	MEANING	EXAMPLE
<p><b>Principle 8:</b></p> <p>Support for choice-making can take place where necessary at several places in my journey.</p> <p>Identify what my likely choices would be if I am a person who cannot speak for myself.</p> <p>Know more about what alternatives and options I have, so that I can select my preference.</p> <p>Plan with me what steps to take on the journey to achieving my choices and goals.</p> <p>Planning my steps and identifying what services/supports might best help me achieve my goals.</p> <p>Identifying the limitations and how to address and overcome these.</p> <p>Help me to choose how best to manage my NDIS funding and payments to service and support providers so that my choices come true.</p> <p>Support me to review where I am up to, whether things are working and what can be done better.</p>	<p>See Diagram 6.</p> <p>More will be said in Section 5.</p>	<p>See Diagram 6</p> <p>More will be said in Section 5.</p>

TABLE 7: UNDERSTANDING PRINCIPLE 9

PRINCIPLE	MEANING	EXAMPLE	EXAMPLES FROM THE DATA
<p><b>Principle 9:</b></p> <p>Choice is a continuing journey and not just a one-off action.</p>	<p>It is likely that a person's dreams and goals take time to achieve, e.g. they will not get a job overnight. It needs to be carefully planned as a journey to achieve their goal. For the population as a whole there is a somewhat prescribed journey from early childhood through school to training. If the pathway deviates for a person with a disability there must still be an ultimate goal that the person aspires to accomplish</p>	<p>It's been hard but I have learned to play the piano. It has taken ten years and I'm now at Grade 3. I had to learn the notes on a page. And my fingers did not work that well so I needed lots of practice. I can play at parties and at Christmas now. I'd like to save for my own piano. That'll take time too!</p>	<p><i>So you can't get exactly what you want immediately, but you can save up or work towards it.</i> (Interview, CEO of a DSP)</p> <p><i>In the past it was all about "Here are ten options. Pick three", whereas now you have portable funding you can try other things. It's not like your traditional service...</i> (Interview - Project worker, DSP)</p>
<p>a. What I <i>want</i> tells others what I <i>need</i> to help me move towards my key life and lifestyle choices.</p>	<p>If a person <i>wants</i> something, eg. a job, then they may <i>need</i> to go on a course, get work experience, learn to complete application forms, or access a job support agency. This involves long term planning.</p>	<p>I would like to go 'retro' in my dress and surroundings. That's what I want. What I will <i>need</i> is to save for the retro clothes and the home decorations, look at magazines to see what there is to choose, to organise for my hair to be styled, and so forth.</p>	<p>[To get to your dream what do you have to do?] <i>Get training, safety training, need a passport, need money. Need training for money. I do this on Fridays... Links with the community.</i> (Focus group - self advocates)</p> <p><i>Best when it comes out of what a person really wants. Always be open to re-looking at change, it's not the only choice.</i> (Focus group excerpt - Support workers)</p>
<p>b. If I am moving towards a goal then I am growing. As I grow I fulfil my capabilities and this gives my life meaning.</p> <p>c. Since life changes and I change, so too can my choices or my pathways</p>	<p>These have been incorporated in points made earlier. To reiterate, a person must take chances to grow (see dignity of risk) and to fulfil their capabilities (see earlier). This will give them hope. It will entail 'the struggle of life' but it will make it meaningful and help them to have a more clear aim and to grow. There is always a chance that things will change and that their choices will change. But without 'testing the menu', without growth, life grinds to a halt and life's rich tapestry will elude them.</p>	<p>I cannot wait until I get a dog. It might not seem much to you but I love animals so much it makes my life really great. I have already learned about looking after a pet. I have been supported to help my neighbour. But I can't have my own dog in this house because the other residents would not like it. The staff are trying to get me a home with some like-minded people near to a park. I have been waiting a long time but it will be worth it.</p>	<p>[So the programs you do here are important?] Yes – <i>they are important, because these programs teach us how to get ready for the real world. Communication skills, money skills, people skills, how to use computers. Eventually we might leave and go to real work.</i> (Focus Group - Self advocates)</p>

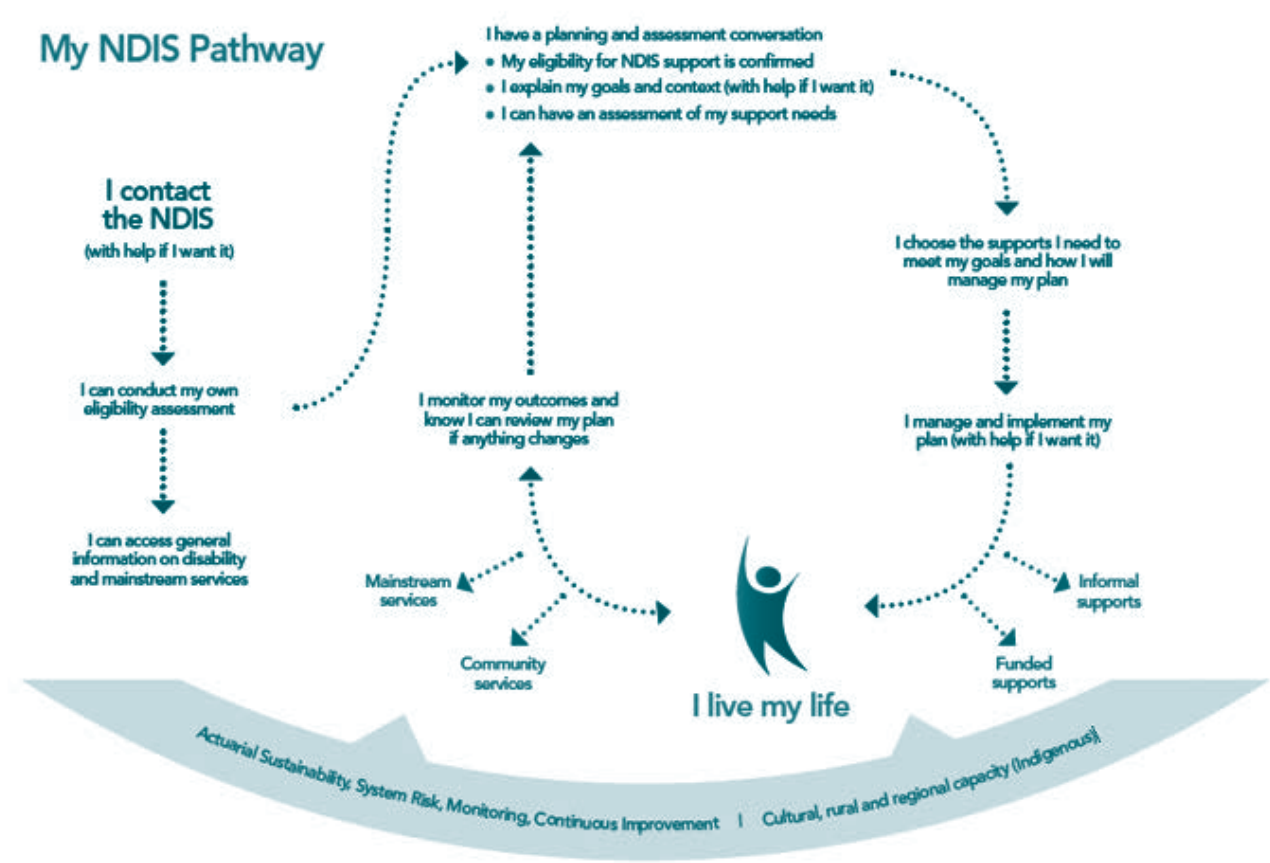
# 5. The *My NDIS Choice Pathway* and implications for the *It's My Choice! Toolkit*

Previous sections of this report have, using the literature and the data collected from people with a disability, family carers and both managers and support workers in disability support providing organisations, sought to identify, clarify and further detail the principles that underlie choice-making.

The second element of this report is the adoption of a *framework* within which choice-making takes place.

It has been decided to adopt the original *My NDIS Pathway*, shown in *Diagram 7* below. It is felt that this model is closest to that operationalised in July 2013 as part of the rollout of the National Disability Insurance Scheme.

*Diagram 7: The original My NDIS Pathway*



The aims of this section are:

- To identify choice-making activities at each point along the *My NDIS Pathway* framework
- To identify relevant principles that inform these activities
- To use these in the development of the Choosing for Yourself Project Resources that accompany this volume.

To simplify this process *Diagrams 8a and 8b* below provide two translations of the *My NDIS Pathway* diagram, one in complex form (for those people with a disability, DSP managers and workers, as well as family carers who find this 'fit for their purposes') and a second simplified form which seeks to make the model as widely accessible as possible. These translations have been called the *My NDIS Choice Pathway*

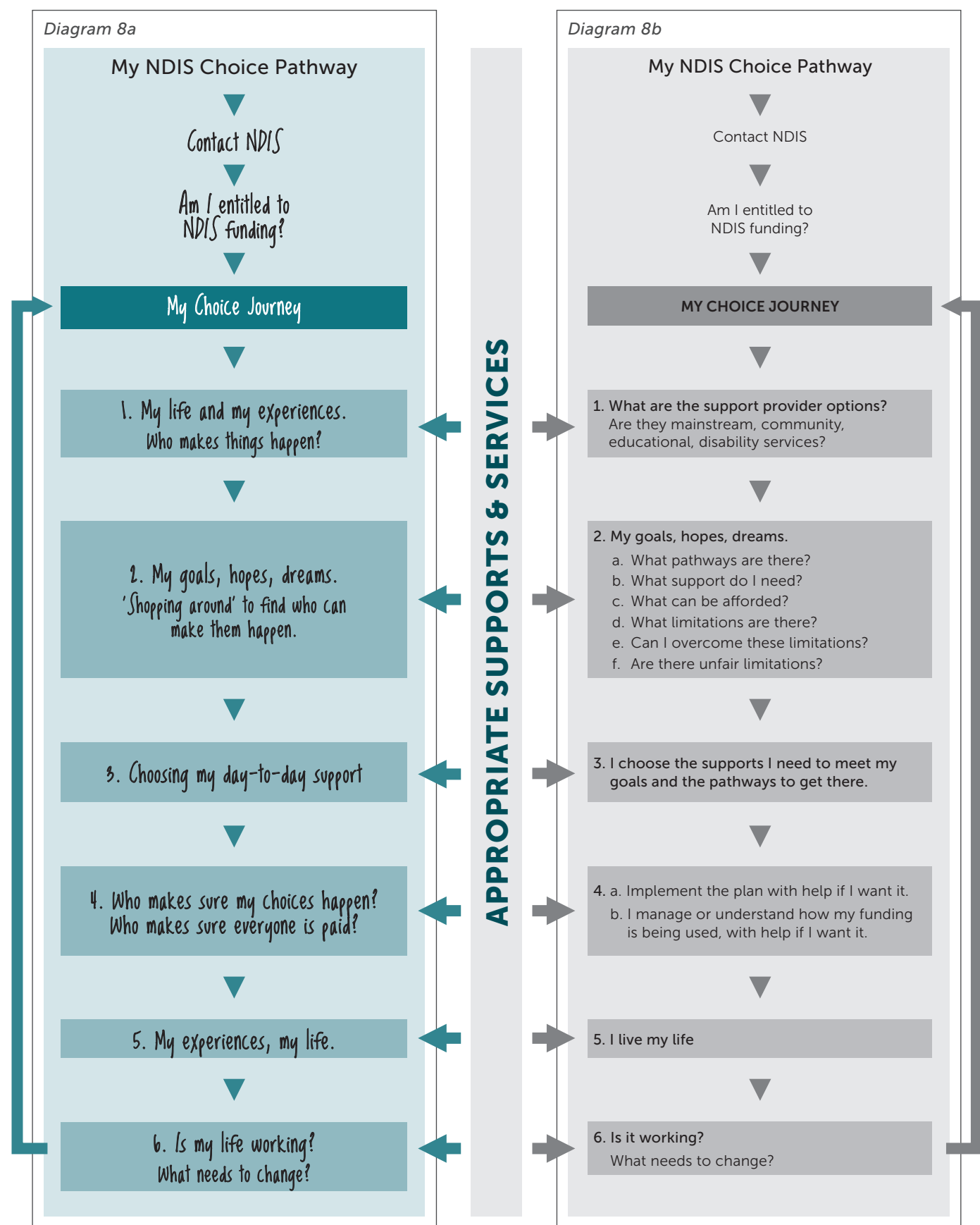
In order to develop products which are fit-for-purpose we tabulate in this section those aspects of choice which are relevant to each of the stages in the adapted *My NDIS Choice Pathway* (see *diagrams*). The diagrams show *My Circle of Choice*.

In the rest of this section of the report the cognate sections of *Diagrams 8a and 8b* are discussed in terms of the *activities* involved and 'who does what' at each stage. Reference will be made at each stage to the principles of choice that are important to good choice-making. This ties the evidence from the knowledge review and consultation directly to the best practice guides that have been produced, particularly *It's My Choice! 3: A Guide for Disability Support Providers*, which carry most of the tools that have been developed to support choice-making.

As the section unfolds the tools that can be used to support choice-making are referenced to the project's accompanying Choice-making resources. These resources are presented in five ways:

- **It's My Choice! 1: The Principles of Choice**
- **It's My Choice! 2: A Guide for People with a Disability, their Family Carers, Friends and Advocates**
- **It's My Choice! 3: A Guide for Disability Support Providers**
- **It's My Choice! 4: Film and Discussion Guide**
- **It's My Choice! 5: A Knowledge Review**

All of these resources are available on the Inclusion Melbourne website.



Considerations for Practice 8

Further considerations: Actuarial sustainability; System risk; Monitoring; Continuous Improvement; Cultural, rural, and regional capacity; Indigenous issues.



## 5.1 What are the service options? Or my life, my experiences and who makes things happen?

### 5.1.1 What happens? Activities

The MY CHOICE journey starts once entitlement to NDIS funding has been confirmed. This may be taking place for the first time. Alternatively, it may occur around the time of an (annual) review.

The National Disability Insurance Scheme system is likely to offer an annual time for 'service planning' each year and additional time for review. These will be undertaken with a local area co-ordinator (LAC). It is strongly suggested that the National Disability Insurance Scheme think about ensuring this is NOT seen as the sole space for service planning. It should be a space in which choices that have already been hatched are discussed, drawing on the LAC expertise to consider other options if necessary and agreeing costs. It is NOT POSSIBLE to undertake service planning to support a person's choices in a single meeting. Such an approach will prevent many of the principles of choice being met. (See *Choice is a journey* - Principle 9)

Choice-making is a core and continuous activity through which the person and all other people and agencies in their lives support the person to grow and to move towards their life goals so as to accomplish chosen and better lives and lifestyles.

There is therefore a huge amount of work to do prior to meeting with the LAC in phase 2.

If the person with a disability has already seen the LAC and this is not the first time through the *NDIS Pathway*, s/he will be at the end of a NDIS planning cycle and will be asking 'Is this working for me?' and 'What needs to change?' (see Section 5.5 below.) In that situation a number of documents may have been produced that will help in the discussions about moving the person toward their chosen goals. As discussed in later sections (and *It's My Choice! 3: A Guide for Disability Support Providers*, Section 3.5) these may include, inter alia:

- i. The original *NDIS Individualised Plan* agreed with the LAC
- ii. A *Statement of Goals and Pathways* to accomplishing dreams with a timescale attached
- iii. A *Statement of Roles and Responsibilities* - of the person, the service, support, family and others in accomplishing the goals (including in relation to administering the NDIS payment). This may include a 'Support for Choice' list (see Diagram 8)
- iv. *Goal Mastery Assessments* about what has been achieved, how barriers have been overcome and what barriers remain - these are a key document about the monitoring taking place by services and adjustments to their role as a result
- v. A *Statement of Choice Consistency* of how those involved have sought to ensure everyday and lifestyle choices reflect the pervasive choices the person has made at any one point in time
- vi. A *New Opportunities List* that have been tried as a means of expanding the person's choice options with commentaries on what has and has not worked
- vii. A *Statement of Capabilities and Outcomes* - what capabilities have been addressed and what outcomes there have been
- viii. A *Statement of the Limitations on Experience* and commentary on those that are not reasonable or those

#### Considerations for Practice 9

Service planning meetings and reviews are NOT the space for choice-planning. They may support choice-planning but the work around a person's choices must already be done.

#### Considerations for Practice 10

Choice-making is a core and continuous activity through which the person and all relevant people and supports in their lives assist the person to grow, to move towards their life goals so as to accomplish chosen and better lives and lifestyles. Constant work is required to move people towards achieving their pervasive life choices. Constant input is required from the person, from family and from support providers. The continuous nature of choice-making should be reflected in policies and procedures, planning methods and so forth.



in which there have been compromises

- ix. *A Personalised Human Rights Resource*
- x. *An Assessment of Human Rights Compliance* and what has been done to accomplish the person's human rights
- xi. *Dignity of Risk Assessments*
- xii. *A Statement of New Pervasive Life Choice Issues* and statement from the service about their understanding of the person's *New Hopes, Dreams and Aspirations*.
- xiii. Evidence that given any new hopes, dreams and aspirations that efforts have been made to find services or develop the present service to deliver on pathways to accomplishing this need (see *Section 5.1*), i.e. a new *Life and Service review*
- xiv. Guardian/Plan and Appointment Nominees/Advocate documentation

These documents and the levers they represent form a foundation from which the most appropriate supports for the person can be found that meet the person's choices and which will move them along the pathway to accomplishing their choices. This may be supplemented by additional work in examining the feasibility, practicability and appropriateness of any potential providers.

During each person's life, questions about happiness and their life choices may occupy that person's mind. All people reflect on the events, circumstances and progression of their lives. This is a natural experience, and on the basis of these reflections each person will think about how they, other people and services might make their lives better or move them to new experiences or towards new goals. This is an inexact science but a necessary part of life. Such reflection is also true for a person with a disability who is about to see the LAC (for the first time).

Indeed it is particularly important in this case because the ability of the system to fund and change lives will depend upon committing these very personal thoughts to some public record and finding a practical solution to accomplishing them.

It is not usually natural for public records to hold a person's most personal and treasured thoughts and wishes and so it is important that these files are kept confidential. Public records that are kept, for example, in schools and hospitals recognise the right of people to act in fairly consistent and specified ways. Such records demonstrate the movement towards positive developments in a person's life and, collectively, can work to establish requisite qualifications or document new steps towards curing identified illness. Just like health and education records, those around choice that are held by DSPs should have goals and the organisation should be judged on how well it is accomplishing such goals. However the pathways are likely to be more diverse than for pre-defined educational or health needs. They are also in an area which links a person's very personal life choices with decision-making by others. There must be an accepted ethic that, when dealing with a person's choice, these choices and dreams belong to them and that any input from professionals and support workers is designed to support their choice as far as is possible.

Once a person has identified that they are eligible for an NDIS payment they will soon meet with an LAC to talk more about hopes, dreams and wishes and to decide what services and supports will move them on the pathway to their goals (see *Diagram 8a and b*).

Just like any person who is visiting an expert such as the LAC, much more can be achieved if the person is well

### Considerations for Practice 11

Information is vital to making the right choices about support services. These choices should match the person's goals, their pervasive choices, and should move the person towards their goals.

### Considerations for Practice 12

It is natural for all people to reflect on their own lives, to dream and to think about how they can change their lives if they choose. We all do this! A person's choices and dreams are owned by them.

People may also think about what people and supports they need to try new things or pursue new choices. NDIS funds are one vital resource designed to support people to pursue these goals and choices. The extent to which these thoughts and reflections are formally documented, particularly prior to the LAC meeting, will determine how effective the NDIS system will be in helping people create pathways to accomplishing their goals.

prepared. For example before you go to the travel agent you are more likely to be happy with what you get if you have decided where you want to go, how you would like to get there (coach, car, boat, plane), when you want to go, what sort of place you would like to stay in and so forth.

This is not inconsequential because the time the person will have with the LAC will be limited.

So, the person who is eligible for NDIS funding is more likely to be satisfied after talking with the NDIS co-ordinator if that person has already thought about their ideal life, their dreams and goals, the timescale they have in mind and what steps there might be along the way.

So think big, then ask yourself 'What are the steps along the way?' (see *Diagram 6*)

At this stage the person should try thinking in terms of options – an option appraisal of what informal networks, services and supports may help achieve their goals. It should be noted that there is a potential conflict of interest at this point since it is not in the interests of present services to recommend competitor services. So if the person wants to move on, for whatever reason, they need people independent of their present service to work with and for them, around the support option appraisal.

Hence, where a person is so isolated that their dominant relationships are with the present service it is important to think about the role of an *independent advocate as bringing another voice to the decisions being made*. In some countries brokerage services have grown to fill this space. Success in producing a *mixed economy of welfare* adaptable to diverse needs and choices will be dependent upon what pressures are placed on service and support systems to adapt in a *demand*-sided economy of care, rather than a supply side.

Guardians, Appointees, advocates, families, circles/microboards should be making their own judgements about whether support providers are indeed moving a person towards their chosen goals. No person should be so isolated that their present service has the power to control decisions about their future supports. The LAC will have a key role to ensure that recommendations about how support providers reflect a person's goals do not privilege sole providers involved in the person's life.

Finally, while the person may know some service and support options and some of the limitations (e.g. the goal is beyond his/her capabilities; cost; distance of service), it will not be clear at this stage what *other limitations* might be (see *Section 5.2 below*).

### Considerations for Practice 13

*Be prepared. Think BIG.*

What are my dreams, hopes, wishes, aims, goals?

What are the steps along the way?

Who might undertake the work of planning, supporting, advocating? Who will work with me to commit these dreams, hopes and wishes to formal documentation?

- Person, their circle, family
- Advocate/Guardian/Appointee
- Support worker/service manager

### Considerations for Practice 14

Undertaking an Option Appraisal of service providers.

**Who might undertake this Activity?**

- Person, their circle, family
- Advocate/Guardian/Appointee

Where a person is so isolated that their dominant relationships are with the present service it is important to think about the role of an *independent advocate as bringing another voice to the decisions being made*. Conflicts of interest must be avoided.

### 5.1.2 Who does what? What are the issues?

It is often hard to know how to think about whether life is good and if things are going well. It can also be challenging to understand how the various components of a person's life fit together to form their life experience. However, there are ways that will help the person and others to think this through<sup>28</sup>.

The authors recommend *The Three Ways* of thinking about this:

**1) Pervasive life choice: See Principle 3 in *It's My Choice! Guides 1 and 3* and Section 3 in Guide 2. How happy is the person with their pervasive life choices?**

- Are they enjoying the best health?
- Are they happy with where they live?
- Do they have the family life and intimate relationships they choose?
- Are they doing something constructive with their days?
- Does their connection with the community reflect who they want to be?<sup>29</sup>

**2) Capabilities: See the *Philosophy of Choice (Principles 4-6)* in *It's My Choice! Guides 1 and 3* and Sections 4-6 in Guide 2. How do you help someone grow as a person?**

A criticism of using a quality of life approach to assessing long-term life experience is that the approach often measures present feelings and objective experiences in life domains but fails to be a dynamic concept that looks at pathways. Nor does it start with a person's aims. Instead, the authors of *It's My Choice!* have adopted a capability approach.

In the capability approach, all thoughts about the person should be based upon the idea of fulfilling their capabilities in life. In this view there are complex and varied functions such as employment, health, happiness and people make choices about these components of life. It is the struggle to fulfil capabilities that makes life meaningful to them. Sometimes it will be necessary to think about the person's communication and maximise this through: the introduction of communication aids; by looking at notes, or even by talking to people past and present about the person's preferences if they are unable to relate these for themselves.

Nussbaum identifies ten capabilities: Life; bodily health; bodily integrity; senses; imagination and thought; emotions; practical reason; affiliation; other species; play, and control over one's environment. Sen argues for five more metaphysical concepts: Real freedoms as an advantage to the person; transforming resources into valuable activities; multiple activities giving rise to happiness; materialistic and non-materialistic factors; and concern for the distribution of opportunities within society.

Some have overlap with pervasive life choices and so it is not necessary to repeat work relating to these areas for its own sake.

The capabilities framework offers another way of looking at possibilities and planning pathways to people's hopes, dreams, wishes and aspirations. It also helps in developing a pathway to where the person wants to go over their lives and, thus, helps in looking at services that can support personal development. This is not (social) skills training or behaviour training *for the sake of it*. No person should be expected to remain in limbo because they have not graduated from training. They should be supported to develop and try new things. The support

#### Considerations for Practice 15

*The Three Ways* constitute an effective process for answering the question "How's life for me?"

- Pervasive life choices
- Capabilities
- My Service Review

#### Considerations for Practice 16

"How's life for me?"

**Questions to consider:**

Is my life working? What needs to change?  
Do my present services need to change?

**Who might undertake this activity?**

- Person with a disability
- Family carer
- Support worker/service manager
- Circle of support

#### Considerations for Practice 17

Maximising communication is the only way to ensure as much is known about a person's choices as possible. Assessment for assistive technologies is vital but so too are constant communication and observation.

they have in everyday communities and environments will help manage behaviours and support the use of skills. But unless the wider community is tested and challenged or given the opportunity to have an input, then no community inclusion will take place<sup>30</sup>.

By the end of this phase it should be possible to have a good idea about:

1. the person's wishes and dreams.
2. the key issues around pervasive life choices.
3. what can support growth of the person's capabilities over time.
4. an appraisal of the present and other potential service and support options in terms of life goals.

The next phase is to look at whether current services and supports have been designed (and have the capability) to provide a pathway to where the person wants to go.

LIST OF ACTIVITIES	WHO DOES WHAT	CROSS REFERENCE TO RESOURCES	TOOLS
Identify the person's most important life choices (including pervasive choices and important lifestyle and everyday choices)	<ul style="list-style-type: none"> <li>• Person with disability</li> <li>• Family carer</li> <li>• Support worker/service manager</li> <li>• Circle of support</li> </ul>	Principles 1 to 3 (see tables above) and <i>It's My Choice! 2: A Guide for People with a Disability, their Family Carers, Friends and Advocates</i> , Sections 1-3.	<p>Good questions to ask might be:</p> <p>Are they enjoying the best health?</p> <p>Are they happy with where they live?</p> <p>Do they have the family life and intimate relationships they choose?</p> <p>Are they doing something constructive with their days?</p> <p>Does their connection with the community reflect who they want to be?<sup>31</sup></p>
Capabilities (Things that help a person to grow)	<ul style="list-style-type: none"> <li>• Person with disability</li> <li>• Family carer</li> <li>• Support worker/service manager</li> <li>• Circle of support</li> </ul>	<i>It's My Choice! 2: A Guide for People with a Disability, their Family Carers, Friends and Advocates</i> , Sections 4-6.	<i>A Helpful Prompt Tool - Human Capabilities</i> (see <i>It's My Choice! 3: A Guide for Disability Support Providers, Appendix 1a</i> ) shows some capabilities and describes what each one is.

### 3) My Life and Service review: See Sections 6 and 7 of *It's My Choice! 2: A Guide for People with a Disability, their Family Carers, Friends and Advocates*. How can services get me to where I want to go?

Here the person and others will assess the supports the person is presently using. The meeting with the LAC is as much about examining the success of the supports in meeting the person's goals as it is about examining the person's choices and how these can be met into the future.

In using the word *supports* it is necessary to think broadly in terms of disability support organisations, services in the community, as well as commercial and private businesses. It is also necessary to think about which informal links among family and friends can provide reliable assistance. If it is not reliable it will not work. It is possible that by using strategies of bridging, linking and bonding (*i.e. building social capital*) that some community relationships may become reliable assistance but this cannot be depended upon unless it becomes reliable and regular.

#### Considerations for Practice 18

Meaning is a key consideration in determining quality of life. Life is meaningful when, to the degree possible, a person does what they are capable of doing, when they develop what they are capable of achieving, when they are always moving forward in their life functions (eg. employment, health, social life), and when all of these are done in the context of the person's dreams, interests, values and relationships.

#### Considerations for Practice 19

All service or support inputs should pursue the person's goals or furnish them with new experiences. None should be gratuitous.

No person should be expected to remain *in limbo*. Life is about development and change.

#### Considerations for Practice 20

The planning meeting with the LAC is as much about examining the success of the supports in meeting the person's goals as it is about examining the person's choices and how these can be met into the future.

The central questions that need to be answered in relation to the services that are being used are:

- Is the person happy with these services?
- Is any dissatisfaction open to being resolved?
- Is the person growing in these services?
- Can issues of personal growth be resolved within this service?
- What other services might be used on the person's pathway to achieving their wishes?

TABLE 9: LIFE AND SERVICE REVIEW

LIST OF ACTIVITIES	WHO DOES WHAT	CROSS REFERENCE TO RESOURCES	TOOLS	EXPLANATION
Identify services (disability, community, commercial and business, leisure)	<ul style="list-style-type: none"> <li>• Person with disability</li> <li>• Family carer</li> <li>• Support worker/ service manager</li> <li>• Circle of support</li> <li>• (Beware conflict of interest)</li> </ul>	See <i>It's My Choice! 3: A Guide for Disability Support Providers</i> , Section 3.1	See <i>It's My Choice! 3: A Guide for Disability Support Providers</i> , Appendix 2b (Identifying and rating potential services). The tool was designed to rate services or service options and was designed for use by people with a disability and family carers and also appears in <i>It's My Choice! 2: A Guide for People with a Disability, their Family Carers, Friends and Advocates</i> , Section 6.  Download the scorecard in pdf format at <a href="http://www.inclusionmelbourne.org.au/resources/choice">www.inclusionmelbourne.org.au/resources/choice</a>	These will be services which may potentially deliver important life goals and capabilities.
Informal supports	<ul style="list-style-type: none"> <li>• Person with disability</li> <li>• Family carer</li> <li>• Support worker/ service manager</li> <li>• Circle of support</li> </ul>	See even numbered pages in <i>It's My Choice! 2: A Guide for People with a Disability, their Family Carers, Friends and Advocates</i> .	Add further columns to the rating tool mentioned above to cover friends, family, community contacts and rate as those with whom to link (contact and meet), bridge (to establish a sustained contact), or bond (to develop reciprocity in relationships) .	These are opportunities for social capital that might be linked, bridged, bonded, strengthened or maintained. They may include family, friends, community networks that can provide reliable assistance.

It **MUST** be possible at this stage to identify how any *short term goals* pursue a pathway to the *long term aims*. If there is no pathway there the person is on a 'voyage to nowhere'.

For each area in which there needs to be an adaptation to the present service, a commitment needs to be made by this service to make this adaptation so that they might compete with other services to provide services and supports that accomplish that person's goals.

For each area in which there is presently no service available to take the person along their pathway the next job will be to identify potential services that can do so and to find out about them.

#### Considerations for Practice 21

*Reliable assistance* can be sought from a range of services that are disability-related, community-based or in the private sector.

#### Considerations for Practice 22

There is no right to continued funding to the support provider, but continued funding to the person only.

The main support provider should make a case for how they will adapt to achieve steps along the pathway to accomplishing the person's goals.

#### Considerations for Practice 23

Maximum personal control and participation are a requirement of this system. *The individual* (when used in these Guides, particularly in relation to planning and review meetings) indicates *the best decision-making group* that does not affect the person's capacity to make their own choices and maximises the information upon which choices are made, which are to the person's satisfaction and which recognise their relationships and duties.

The person is wanting to be as informed as possible so that when they are asked to make a choice in the individualised planning meeting it is one that is informed by the available options and is expansive and not restricted (**Principle 5**). As such the choices at this stage are *open to change* and the services chosen open to change also. The person might also think about how they wish to administer their individualised payment.

'The person' in the above paragraphs is '*the best decision-making group*' which does not affect the person's capacity to make their own choices and maximises the information upon which choices are made, which are to the person's satisfaction and which recognise their relationships and 'duties'. Maximum personal control and participation are a requirement of this system. Where the person needs support the more informal and non-service orientated the group, the better they will be at supporting choices located in the person's everyday life. What the person may ask for and want from that group, may be diverse, ranging from a conversation, to asking for advice, to balancing interests that compete with others. It may involve seeking information oneself, from others who have experience or asking or relying on others to find things out for him/her<sup>32</sup>.

The group or the person will need to explore services and what they do to identify whether they might get them to their identified goals. People with disabilities and families in the consultation found it very difficult to find information about what services can offer:

*[What are main things stopping him having choices he wants?] Access to information – have to dig and dig and talk to people to find out what is going on. There is a lot on the internet, the information is very scattered. If it is out there it is not easily accessible.*

(Interview, family carer).

*'Is that information available to me...I've seen people before and they just didn't know where to go'*

(Focus group, Support Workers)

*Yes and I have done a lot of research on the internet but can't find much, if I ring organisations they say they don't do that but don't refer you on to anyone else,*

(Interview, Family Carer).

Since information about services is often difficult to find it may be important between formal reviews that opportunities to experience new services are provided. This cannot be left until the last minute. In this respect it may be that as the meeting with the LAC nears it is more a case of summarising what experiences and what appraisals the person has made of them since the previous meeting. In relation to each of these experiences they will need to discuss options and maybe even visit services or, if there is time, try them out. They will need to identify what is within travelling distance and what supports would be required to get to and to use each potential service. They may need to ask about availability and about cost.

A table, rating new services, is provided in *Appendix 1b, Resource 3* which allows comparison with potential services also.

As many people mentioned in our consultation work, there are points of transition in people's lives where the need to test new options are greater.

### Considerations for Practice 24

Information about what support providers offer needs to be more readily available and in a form that can be understood and used by people with a disability, family carers and others.

At present, people are not sufficiently well informed about what support providers do to be able to make an informed choice. This leads back to reliance on 'services they know'.

### Considerations for Practice 25

Principle 5 (expansive choice-making) makes it important that people continue experiencing new opportunities and that this is done sufficiently far in advance for the person to make a judgement about them.

Families, circles and advocates may play a role in this. At times of transition it may be useful to have a **New Opportunity Fund** available for people to try new options from which they can make better choices about their future.

### Considerations for Practice 26

Prepare all documentation to take to the meeting with the LAC. The person should decide what they would like to be taken. Support providers will have kept more formal records about their achievements for the person.



*Timing is critical – people go into panic mode at end of schooling. Should start thinking a year earlier – time to visit other places...*

(Focus Group – Support Workers)

As well as the school to adult services other transition times are when a person is expressing a wish to move into different accommodation or employment, at the age of retirement (and so forth). It is proposed that a 'New Opportunity Fund' be set up to support these additional costs in defined areas of transition.

Finally the person will need to know who will accompany them on the journey to the formal meeting with the LAC for the personalised planning process. Like all phases this is an important phase. What happens here will affect everything that comes afterwards. With the person's permission documents produced at this stage can be forwarded to the LAC prior to the meeting or taken to that meeting. These may be documents produced by the person and their family as well as those produced by the service provider. More will be said of these documents later.

## 5.2 My goals, hopes and dreams

If the stage preceding has taken place sufficiently well, the present stage will be more of a negotiation about exploring possibilities and what can be afforded rather than a process stuck with the difficult and time-consuming work of identifying hopes, dreams or goals. That task cannot easily be managed in the confines of a meeting and if that happens the meeting is likely to miss important factors and to skim areas that are of central importance to the person. As such the meeting may be preoccupied by merely getting through the process rather than thinking about how to create and accomplish the pathway to a person's goals.

The individualised or person-centred planning process is of course closely allied to choice, the focus of this document. Usually, organisations have their own expertise around this form of planning. However, they should review the available approaches to individualised planning<sup>33</sup> and ensure that the principles and methods recommended in relation to choice-making feature in the methods they adopt.

Once again though, Phases 4, 5 and 6 of the *My Choice Journey* are intimately tied to this stage. As will be seen, these stages are specifically designed to identify (changing) hopes, dreams and wishes as well as to measure progress along the pathway to accomplishing the person's choices. The following discussion takes these factors into account and saves discussion of identifying goals, hopes, and dreams until later.

### 5.2.1 What happens? – Activities and who is responsible for what

At this stage, data from *The Three Ways* (see previous section) will be made available. This will include, at the very least: the person's wishes and dreams including issues around pervasive life choices; what support has been provided around accomplishing a person's capabilities, and an appraisal of the present service and other potential providers. Table 10 lists activities which follow on from this.

#### Considerations for Practice 27

Support providers should ensure that the person centred planning process they adopt meets the *Principles of Choice* outlined in this report.

#### Considerations for Practice 28

During the planning process, support providers should seek to gauge (a) the *acceptability* of any proposed plan and (b) whether a proposed plan 'demonstrates sufficient aspirations for change' and ratifies 'the proposed pathways to accomplishing stated goals'. With the LAC, they should make judgments about whether *reasonable limitations* are being placed upon a person's experiences.



TABLE 10: MY GOALS, HOPES, DREAMS, PATHWAYS, SUPPORT AND LIMITATIONS ON MY CHOICES

LIST OF ACTIVITIES	WHO DOES WHAT	CROSS REFERENCE TO RESOURCES	TOOLS	EXPLANATION
Consideration of hopes, dreams and wishes in relation to service appraisal and identified steps to achieve goal	Documents submitted as per last section  LAC examines in terms of 'acceptability of plan, pathway and steps'; 'ratifying proposed pathway to goal' and agreeing the timeframe for change.	See previous section - <i>The Three Ways</i>	See previous section	LAC considers the link between hopes, dreams and services and the identified steps on the path to the dream
Funding level	LAC reports	Not covered in these resources.	Not covered in this resource.	NDIS assessment metric applied.
Limitations on choice experiences	Can be used by services to point to issues. LAC has decision-making authority to make judgements about acceptable limitations given funding and other issues.	See: <i>It's My Choice! 1: The Principles of Choice, Principle 6</i> <i>It's My Choice! 2: A Guide for People with a Disability, their Family Carers, Friends and Advocates, Section 8</i>	Table 11 below, copied as, <i>It's My Choice! 3: A Guide for Disability Support Providers, Appendix 1c</i>	No-one is completely free to choose. What matters is that limitations be just, legitimate, and clearly explained.
Feeding back to government to meet requirements of CRPD and to systemic advocacy groups.	LAC	See <i>Diagram 6</i> , above.	To be developed independent of this report. A computerised system would be very useful.	Not covered in this resource.

The key areas to be examined during this phase will be adopting or adapting any plan and pathway that is proposed or, if none is available, drawing up a new plan. The practical tasks will be:

- To undertake the adopted NDIS individualised planning process<sup>34</sup>
- To match services to the adopted plan or to adapt the plan
- To examine limitations - funding, dignity of risk, whether it achieves capabilities, whether the proposed services are human rights-based in their provision and to identify unacceptable limitations and inform official advocacy and government departments of such limitations
- To arrange how the individualised funding will be administered.

The individualised planning process will take place with the person at the centre and will be a central part of the decision-making process that the LAC is required to complete. In this resource we will not dwell on the individualised planning process as this is the subject of other Practical Design Projects. However, it would be fair to say that work done previously around choices and planning would be of enormous help to the LAC in making the meaningful link between dreams, pathways and appropriate services. The LAC will have a significant amount of information about available services<sup>35</sup> and about those which can be bought through NDIS funding.

It is also highly recommended that the LAC have some *advisory role* in relation to the *acceptability* of the plan as '*demonstrating sufficient aspirations for change*' and '*ratifying the proposed pathways to accomplishing goals*'. Once the long-term aims and pathways to accomplishing these aims are agreed with the LAC as part of the individualised planning process or adapted in discussion with the person and their circle, the next step will be to find the supports that will accomplish at least the first step on the pathway in a *defined timeframe*. However, they must do so in a way that recognises *legitimate limitations* on a person's experience (**Principle 6**). The LAC will therefore also have a role in making judgements and recommendations about what are and are not '*reasonable limitations on a person's experiences*'. Given this role, they should also have a role in identifying and reporting to government and the advocacy sector those limitations to experience that are not *reasonable*.<sup>36</sup>

## Considerations for Practice 29

Feeding barriers back to systemic advocacy groups systematically builds human rights compliance. Keeping records of such barriers supports government planning about how to achieve progressive realisation and the reduction of infringements to human rights.

A central question is therefore what constitutes either legitimate or non-legitimate limitations on experience (*Principle of Choice 6*).

To identify such limitations, each of the articles from the authors' referenced body of literature was examined to ascertain which forms of limitation to experience were being suggested. *Appendix 2* lists limitations to choice-making identified in the literature. Analysis of this literature indicates that these fall into a number of categories, as shown in *Table 11* below. It cannot be said that this list is exhaustive, however it can be a significant starting point for use by both LACs and support providers seeking to make some judgement about the legitimate barriers to choice. *Table 11* also proposes possible ways of minimising each limitation to experience.

Finally, it was argued earlier (and indicated in *Diagram 6*) that compliance with the UN CRPD means that where there are limitations on experience that are not legitimate, these should be recorded and submitted to both systemic advocacy groups and to government. By submitting to advocacy groups they can engage in seeking to address systemic issues and can work with people with a disability, empowering them as a collective to be part of the solution. This can lay the ground for rights bearers to make claims against the duty-holders. For Government it will mean having information which will allow reporting to the CRPD Committee that demonstrates 'progressive realisation' of economic, social and cultural rights alongside reports of rights infringements.

**TABLE 11: TYPES OF LIMITATION TO EXPERIENCE, ESTIMATION OF THEIR REASONABLENESS AND APPROACH TO RESOLVING ISSUES**

LIMITATION	REASONABLE?	APPROACH TO RESOLVING THE ISSUE
1) Funding availability	Reasonable	<ul style="list-style-type: none"> <li>- Reconsider level of assessed need against funding available</li> <li>- Consider the human rights implications, especially economic, social and cultural rights.</li> <li>- Inform systems advocacy and government departments of shortfall</li> </ul>
<b>2) CONFLICT</b>		
a) Family/ support provider disagree with person's choice	Reasonable in some circumstance. Often a process of negotiation and demonstration.	<p>Disagreement can be healthy but only if managed constructively. When people are close to each other they will have disagreements. Things that may be taken into account in negotiating an agreed position are:</p> <p>Will the choice (ultimately) undermine other choices the person makes? For example, if the choice means the family cannot work then impoverishment may follow and other opportunities will suffer.</p> <p>Is the choice the person wants to make a key choice? Is it worth demonstrating its viability and testing it in a small way?</p> <p>Does the choice test some of the family's core values? Is the person sure this is what they would pick despite knowing this difference in view? How much is the person giving up to maintain family relationships? Is it worth that sacrifice?</p> <p>Is what the support provider/family and the person wants in accordance with human rights?</p> <p>Is the objection to this choice to do with the family or support provider's view of the person's ability? Is there any harm in letting the person find that out themselves? Can the person get some way down the path (since most people do not achieve everything they would wish)?</p> <p>What are the likely consequences? How can these be managed?</p> <p>Are there other examples upon which to draw in demonstrating the feasibility of the plan?</p> <p>Is there a pathway in which smaller steps towards the goal will test its feasibility?</p>
b) A person cannot make their own choices	May be partially reasonable	<p>Very few people can indicate no emotion to stimuli. In registering such responses they register an appraisal of their situation. These appraisals should be sufficiently well known to provide some contributions to choice-making and some guesses as to potentially acceptable new pervasive life choices. Over time such resources can build significant resources. These would also significantly help Plan and Correspondence Nominees appointed under <i>Sections 86 and 87</i> of the <i>NDIS Act</i> or any other person who acts as Guardian.<sup>37</sup> The role of independent advocates may be vital where there is disagreement between parties in situations such as these. By reducing isolation it may be that a wider group of people might contribute meaningfully to the decision-making process.</p>

**TABLE 11: TYPES OF LIMITATION TO EXPERIENCE, ESTIMATION OF THEIR REASONABLENESS AND APPROACH TO RESOLVING ISSUES**

LIMITATION	REASONABLE?	APPROACH TO RESOLVING THE ISSUE
<b>3. STRUCTURAL</b>		
a) Inaccessible	Not reasonable	Disability discrimination legislation should be applied through challenge using complaints process, advocacy, human rights commission and legal challenge. In cases where it is difficult to easily resolve the issue quickly for the person concerned, notify a systems advocacy group and governmental agency.
b) Discrimination	Not reasonable	Use disability discrimination legislation
c) A relevant service	Not reasonable	Ask present provider if they can adapt for the person. If not, use brokerage agencies to search out providers that might meet the person's need or adapt to do so. Notify a systems advocacy group and governmental agency.
d) Local economy (e.g. high unemployment)	Reasonable	People with disability have an equal right to employment. Keep trying and monitor any discrimination.
e) Service does not meet NDIS criteria	Reasonable	Raise questions about how such support providers might be brought under the NDIS umbrella.
<b>4. SERVICE-RELATED</b>		
a) Risk management	Can be reasonable	Make sure risk is not <i>hazard assessment</i> . What more can be done to reduce likelihood of hazard occurring? Make sure the benefit to the person is weighed up against the risk. Make sure there is a dignity of risk. 'Benefit of the doubt' rule.
b) Lack of participation in decision-making	Not reasonable	The CRPD clearly states the importance of frameworks for individual participation and participation in decision-making by democratic organisations of people with a disability. It may be possible to move beyond <i>participation</i> to <i>co-production</i> . <sup>38</sup>
c) Home environment	Not reasonable	This is a plan for the person and not for a home. If the home is fundamentally at odds with the person's human rights or with their pervasive, lifestyle and everyday choice and comfort then a strategy needs to be put in place to change the environment or to move the person to a new home.
d) Group characteristics prevent individual choice	Not reasonable	It is not legitimate to sacrifice the person's pervasive and some lifestyle choices because they do not suit the group. Negotiations must take place around those everyday and lifestyle choices which are acceptable for the group to negotiate. Further, no human rights should be infringed (e.g. freedom of movement or privacy) in relation to everyday or lifestyle choice limitations.
e) No technology/aids/equipment	Not reasonable (except where costs are prohibitive, (see 1. above))	Hoists, wheelchairs, walking aids, eating aids, communication devices, ramps, hearing aids, etc. are vital to produce as normal and enriched a life as possible. They should be provided.
f) Low quality service or support	Not reasonable	Address with support provider and then through advocacy group or complaint or change the service.
g) Time	Can be reasonable	If the person has been unable to meet the target then reset the timeframe and adjust the service input. This is not a failure but indicates that despite best efforts the person cannot move to the next step to their goals. However, if the input of the support provider was not appropriate during the timeframe then seek new provider if desired.
h) Financial management or administration of fund	Not reasonable	Find a repair to the system of administration of finances or individual fund
i) Lack of knowledge of choice options	Not reasonable	Provide knowledge to inform decision-making and choices.

**TABLE 11: TYPES OF LIMITATION TO EXPERIENCE, ESTIMATION OF THEIR REASONABLENESS AND APPROACH TO RESOLVING ISSUES**

LIMITATION	REASONABLE?	APPROACH TO RESOLVING THE ISSUE
<b>6. PERSON'S ABILITY/CHARACTERISTICS</b>		
a) Education/IQ	Reasonable in certain circumstances only	If the 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 time-frame. Over time work with the person to adapt their end choice and what they will settle for. But always move forward.
b) Communication skills	Reasonable in some circumstances	Maximise communication using technology, therapy and practice to achieve full capability. Learn from what they are communicating everyday as a means of predicting what their lifestyle and pervasive goals may be.
c) Impairment	Reasonable in only some circumstances	Seek to optimise what the person does and take smaller steps to their achievement. Strengths-based approaches are to be used at all times and these rely on building on what a person can do. Always move forward and test boundaries.
d) Relationships	Not reasonable	Build confidence and social skills. Work with the person and their environment. However, the person excluded on these grounds has no motivation to change and will not learn new skills outside of experiencing relationships.
e) Health/mental health	Reasonable in some circumstances	Work with medical and health care professionals to maximise health and minimise ill-health.
f) Behaviour	Only if extreme	Most behaviour is a product of the person's history, present environment, interaction and circumstance. Change these prior to changing the individual and use behavioural approaches.
g) Capability and skills	Not reasonable	Break steps into smaller ones and always assume the person is able to develop no matter how slowly.
h) Psychological and emotional	Can be reasonable	Work on relationships. Build trust, deal with trauma, work on confidence, take small experiential steps towards learning to take chances and to try new things. Change the person's environment and the people with whom s/he does life, if necessary.
i) Person keeps changing their mind about choices	A concern	Continue to explore options until the person settles to particular choices. Build motivation around particular choices where preference has been expressed. Work at different choice levels to make connections between <i>everyday</i> , <i>lifestyle</i> and <i>pervasive</i> choices.
k) Lack of consistency between everyday and lifestyle or pervasive choices	A concern	Work consistently to demonstrate the links between the three levels of choice. Reinforce and encourage consistency. Think of replacement or diversionary tactics to build routine into consistency of choice-making.
l) Confusion/dislike of too much information or too many options	Not reasonable	Some people do find too much information or too many choices difficult to handle. Indeed, some people may like to stick mostly to what they know. If a person reacts in this way it is because they are being bombarded with too much information and choice at one moment. This highlights even more the importance of making sure the person gets to experience new choices over time. The role at a later date would then be to report what has or has not worked and to confirm a preference already established over time.
m) Age appropriate	A concern	Support new identity through engagement with any age appropriate choices and make links with lifestyle choices.
n) Gender appropriate	Not reasonable	Equal opportunity should be afforded to both men and women ( <i>Article 3 of the CRPD</i> )
o) Personal appearance	Not reasonable	Work on lifestyle choices with personal care, dress and behaviour. All behavioural change should take place within settings and not independent of them. Changing the environment is as important as changing the person's behaviour

Table 11 is not exhaustive. However, there are a number of working principles that underlie it:

- Build on strengths,
- Assume capabilities can change and can expand as well as contract
- Build shorter steps on the choice journey if these can be more easily accomplished but make sure that does not amount to the person being 'suspended in limbo'
- Ensure there is no disability discrimination
- Recognise that every system is limited but it must get the most for each person and must be adaptable to do so.
- No acceptance of services that are not of a high quality and that do not move a person forward in their lives
- Human rights underlie all approaches
- Accept the role of advocacy in recording limitations and addressing them individually or systemically.

As will be seen in the paragraphs to follow there are ways in which services may ensure that all their inputs are indeed based upon processes that are designed to fulfil human rights as well as to defend and to protect them.

A further element of the planning must be identifying the steps that are being taken to get the person to accomplish their chosen dreams. These steps MUST build a pathway to these goals. They MUST specify what short term targets (steps) are going to be reached in a specified time and they MUST be based on what is realistic, practical and doable. As shown in *Diagram 6* earlier, the steps may be small. But they must be realistic and take into account barriers to experience. The service should be judged against the movement the person has made towards their goals. It should not be acceptable for a person to be occupied in repeated programs over a life course. Life must develop and change to produce fulfilment of capabilities and to make the experience of life better for each person. No-one should live in 'suspended animation' or without graduation and change that builds upon life experiences and choice.

### Considerations for Practice 30

There are some working principles that may help in deducing how to reduce limitations on experience:

- Build on strengths
- Assume capabilities can expand
- Ensure there is no disability discrimination
- Ensure the service system is adaptable
- Ensure support quality is high
- Ensure human rights underlie all approaches
- Give voice to advocates and supporters in the planning review process

### Considerations for Practice 31

A plan should be realistic, practical and have steps that lead to the main life goals for the person. The steps to those goals should be laid out over the long term and the immediate goals of the support provider identified. The provider should be judged against success with these goals.

## 5.3 Choosing my day-to-day support

TABLE 12: CHOOSING DAY-TO-DAY SUPPORT

LIST OF ACTIVITIES	WHO DOES WHAT	CROSS REFERENCE TO RESOURCES	TOOLS	EXPLANATION
Involved in choosing personal support	Families, friends, advocates and DSPs to support the person to be involved in recruitment and interviewing. Families, friends, advocates and DSPs to support the person to make arrangements for new support where chosen. Managed by the agreed individualised funding administration group.	See <i>It's My Choice! 1: The Principles of Choice, Principle 7</i>	None developed in this resource.	When a person is involved in making decisions he or she: will share responsibility for them; the decisions will better reflect his/her needs and interests, and the resulting services and supports will be better rated. When a person has power to change their services and supports the services and supports will need to be responsive and of a high quality.
Identify support for choice-making	Those making decisions about the appointment of the support worker including the person themselves	See <i>It's My Choice! 1: The Principles of Choice, Principle 7</i>	Support for Choice-making tool, (see below)	Supporting diversity means supporting people diversely. You will need to think about the specific supports required by each person in achieving their choices.
Appointment of Nominee or Guardian	Responsibility for Nominee appointments held by CEO. The person should be involved to the degree they can be as well as any family, advocates, friends, circles or microboards involved.	See <i>It's My Choice! 1: The Principles of Choice, Principle 7</i>	See <i>It's My Choice! 1: The Principles of Choice, Principle 7</i> Diagram as a guide to advocacy and support.	When, despite all best efforts, a person is unable to speak for themselves and there are no de facto decision-makers acting with and for the person, Advocacy, Guardianship and appointment of a Nominee may be required to ensure the best outcome for the person.

Diagram 6, presented earlier, suggests that support needs to be provided at several points along the choice-making cycle and that the level of support will be dependent upon a number of factors. Firstly, the extent to which the person is able to pursue their own choices independently, and secondly, the number of people involved in the person's life including family, friends, advocates and, in some circumstances advocates/guardians/Appointees. The level of support required is in some ways contingent and not necessary.

*It's My Choice! 1: The Principles of Choice, Principle 7, Diagram 5*, provides one way of seeking to understand the range of personal support that may be required for choice-making. It shows that good support for a person in accomplishing their pervasive life choices can take place at a number of levels but only to the extent that the person cannot engage in the choice-making activity themselves. The default must be that the person makes and pursues their own choices to the extent that they can. There should be no learned helplessness or overbearing control by support providers nor by others.

If the support is not available where it is required then that choice cannot be accomplished. This is indicated by the Out boxes in *Diagram 9* below. What the diagram shows is that choice may require supported decision-making and other support at a number of potential junctures: with making new services available or adapting policies to make choices possible; in supporting the person to originate their own ideas or to recapture their past sufficiently to make educated guesses about their likely choices, and to support the person in making decisions, accessing resources or in pursuing choices actively. Note that where any of these are not met then the choice becomes impossible where the person is unable to undertake these activities for themselves.

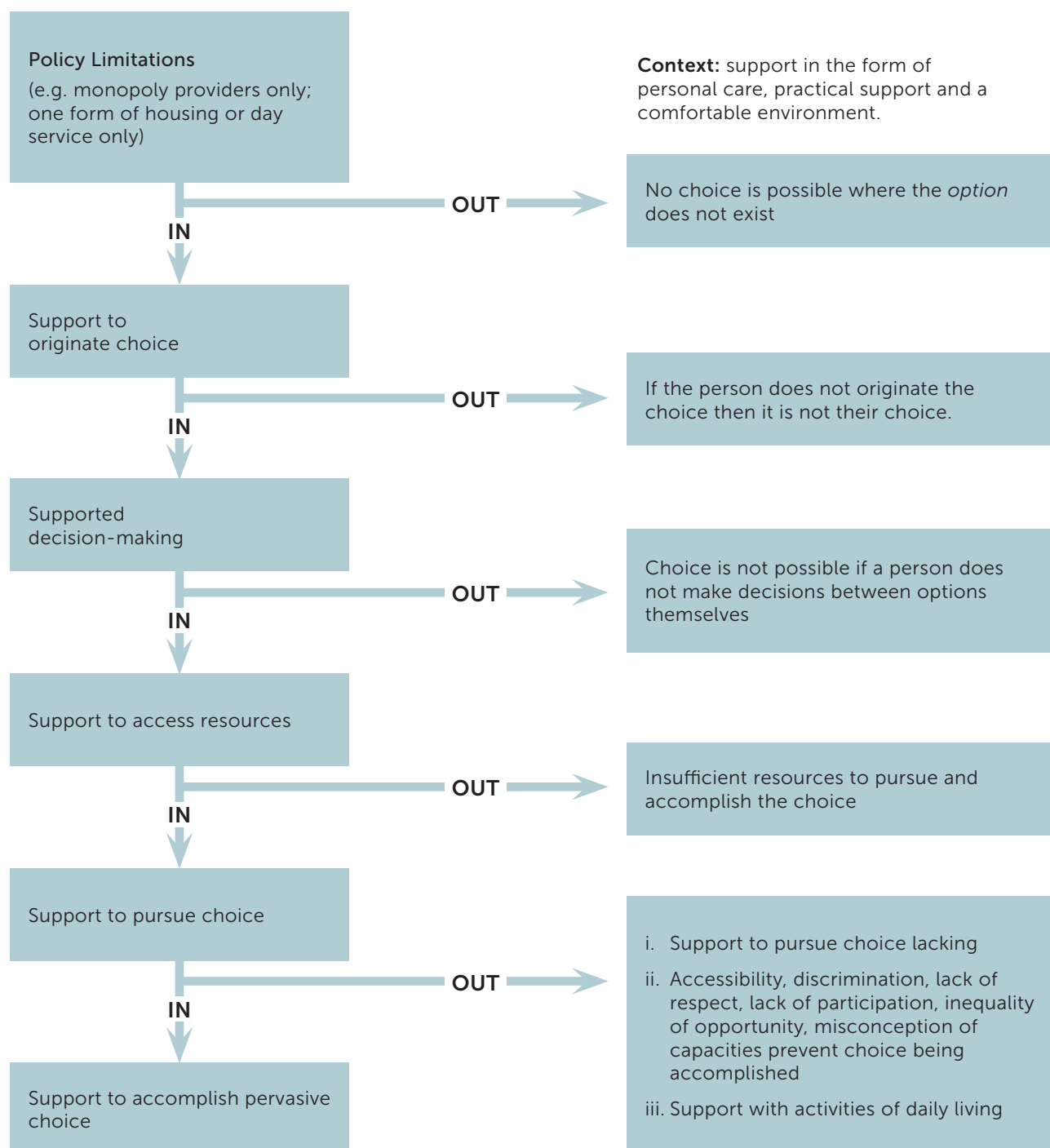
### Considerations for Practice 32

Support for choice must be exercised at a number of levels if the person's steps towards their goals are to be accomplished. If the support is not present at any of the stages then the choice will not be accomplished or it may not be the outcome for which the person had aimed.

The supports that are necessary should not just come from support providers and families. Wider *community supports* indicate a move towards community inclusion.

Diagram 9 is applicable to any of the steps required to move the person towards their goals. When a service wishes to examine its role in relation to support it might also think about how well it is faring in accomplishing what is required at each of the stages of the My Choice Journey in the NDIS Pathway (Diagrams 8a and b). Family carers too may want to use the diagram and to ask questions about the degree to which the choice affects family life as well as the roles they may play in supporting their relative. For both disability support providers and for families the support that can be provided by other organisations within the community can be helpful and indicate a move towards community inclusion. It would be useful to explore these opportunities as well as supports provided by disability-related organisations.

Diagram 9: Examining areas in which support for choice-making may take place.



Adapted from: Ramcharan, P. (2012) Roadmap for Achieving Dignity without Restraint, Unpublished Report Melbourne: DHS.



In making choices about specific support workers the involvement of the person is vital if they are able to contribute to that process. Some people in our consultation found that personal support workers were unreliable and, as one person put it, 'you would not want a stranger to come into your home to give you a shower'. There are real issues around consistency of support which remain to be resolved. The use of individualised funding can also provide a significant degree of latitude in who is hired to provide support and who is kept on. As well as characteristics which relate to how the person gets on with their support worker the above model can be used to make judgements about whether they are indeed providing support at a level which moves the person towards their goals.

The success of the National Disability Insurance Scheme will be closely related to the extent to which changes to services and supports are in the control of people with a disability and those who manage their funds. The system is likely to be *homeostatic* and *self-righting* in that funds spent which do not deliver suitable services or which turn out to be too expensive will lead to changes that represent a better balance of support over time. No person would knowingly buy the wrong services or supports if they could improve their lives by purchasing others. The system of individualised funding is therefore hugely significant in relation to the accomplishment of choice and the movement of people to better lives.

Finally, as indicated in *Diagram 6* earlier, while support involves a significant degree of advocacy on behalf of the person there may come a point at which there is a conflict of interest in this service-based advocacy. This happens largely where the choice is over the service and the supports themselves. While families have a say it may often be the case that their advocacy is limited where there are disagreements between their values and what is being chosen or in relation to the effect the choice has on family life. In situations such as these, independent advocacy should be available to ensure that there is one party available which speaks solely as if the person's view were their own. The place of, and funding for, advocacy under the National Disability Insurance Scheme needs to be further detailed.

Formal systems of Guardianship or Nominees under the National Disability Insurance Scheme also need to take into account the above issues. The *NDIS Act (sections 86 and 87)* empowers the CEO of a disability support provider to appoint Plan and Correspondence Nominees with little restriction. The CEO must, according to section 88, take 'the wishes, if any, of the participant' into account, and 'have regard to' any existing substitute decision-making appointments. After concerted effort, the draft nominee rules contain the following:

*3.1 People with disability are presumed to have capacity to make decisions that affect their own lives. However, the Act recognises that there may be circumstances where it is necessary for a person to be appointed as a nominee of a participant, and to act on behalf of, or make decisions on behalf of, a participant.*

*3.2 Appointments of nominees will be justified only when it is not possible for participants to be assisted to make decisions for themselves. It is expected that, wherever possible, participants will be supported to make decisions for themselves.*

*3.11 If the participant has requested that a particular person be appointed as nominee, the CEO is to have regard to the following:*

- (a) the principle that the person the participant has requested should ordinarily be appointed;*
- (b) whether there is any evidence to indicate that the person has unduly or improperly induced or influenced the participant to request the appointment.*

#### Considerations for Practice 33

Where possible, people should be directly involved in choosing their personal support workers

#### Considerations for Practice 34

Individualised funding provides an essential mechanism that extends control over supports and services. It therefore contributes significantly to a person's choices.

#### Considerations for Practice 35:

There are limits to advocacy where conflicts of interest arise. An independent advocacy sector is vital to ensure that the person's interests are what arbitrate decisions made around their choices.

3.12 If the participant has not requested that a nominee be appointed, when deciding whether to appoint a nominee, the CEO is to have regard to the following:

- (a) whether the participant would be able to participate effectively in the NDIS without having a nominee appointed;
- (b) the principle that a nominee should be appointed only when necessary, as a last resort, and subject to appropriate safeguards;
- (c) any formal guardianship arrangements that might be in place;
- (d) whether the participant has supportive relationships, friendships or connections with others that could be:
  - (i) relied on or strengthened to assist the participant to make their own decisions; or
  - (ii) improved by appointment of an appropriate person as a nominee.

This still leaves open possible issues around the source of the appointment and the potential conflicts of interest this may produce. Would that nominee still act for the person if s/he considered another support provider would provide better choice and outcomes, for example? Perhaps this is an important criterion for such a nominee to meet.

Support for a person in accomplishing their choices is highly significant. The support for choice-making must take place at a number of levels and it should be free from any conflicts of interest (**Principle 7** - The right to exercise choice to the greatest degree possible). Support should promote rather than inhibit competencies and capabilities.

## 5.4 Implementing the plan - Who makes sure my choices happen? and living my life

In what follows we consider both the Implementation Stage and Stage 5 (*Diagrams 8a and b*) which are about getting on with life. The two are different sides to the same coin in which 'responsibilities for executing the plan' are formal, while living one's life is the informal everyday experience.

All decisions made with the LAC will need to be implemented making this a stage of activity and engagement in a pre-designed pathway with stated aims within given time-frames. The role of services and paid disability support is to deliver agreed services and supports, to monitor regularly whether the aim is being accomplished and to keep detailed records of this and of any issues and problems as well.

At this stage, since the steps being taken are small, the pervasive life choices are unlikely to be as immediately recognisable at a day-to-day level. This is because they are long term goals and are not (usually) accomplished within a short timeframe. Because of this it is absolutely vital to do things that ensure that what a person does or chooses to do always keeps them moving towards their life goals.

From the person's point of view this means being aware of the connection between what they are doing and their chosen goals. Like everyone else they will pay attention to the advice of others they trust and if unable to do things for themselves will need to speak up for support or, indeed, for alternative services.

Like everyone else it also means that families, friends and other informal supports have a continuing interest in how things are going and a concern to encourage their relative or friend to do things that are consistent with that person's ultimate goals. Their role may also be to advocate for the person where the person cannot do so for themselves or to organise advocates or others to do so. They may all be an intrinsic part of the plan of action around moving the person forward and will need to manage change and collaborate around agreed roles.

For those who provide formal services it will entail providing support to accomplish choices as well as making regular and formal appraisals of successful moves along the pathway to accomplishing goals. It will therefore require a knowledge of when support is needed and a recording and review process. The services may also need to liaise with both family and advocates, particularly when a person cannot speak for themselves. There are a significant number of areas that will require attention in this respect:

- Support the person to make lifestyle and everyday choices that fit with the pervasive choices.
- Continue to make sure that: there are new experiences so that the person can experience options from which they can make informed choices, list any new interests, preferences, strengths, and record these as evidence that contributes to the person's future agency. If changes are required, check back with the LAC and engage the decision-making group.
- Record any unpredicted limitations - seek solutions - pursue other options where solutions cannot be found e.g. complaints, advocacy, meeting with decision-making group to access more appropriate services.
- Consider that the processes that are being used are human rights based, i.e. that means and ends are both ethical.
- Manage dignity of risk.
- Ensure supports and advocacy are in place to support the person's choices at all times
- Make sure there is movement along the chosen pathway towards goals. No movement might be a service failure.
- Ongoing review of goal mastery is needed to ensure that goals are being achieved. This may be more difficult with a new client but it should be easier once the person is known. For new clients a space to assess capabilities prior to a visit to the LAC would save time and effort.

This stage is not just one of action to achieve goals. It is also about actions that will furnish the next review or planning meeting. This means that in addition to the person's stated goals other opportunities should be afforded which expand the options from which they may later choose. It is recommended that changes in choices that do not fundamentally affect goals be notified to the LAC. However, fundamental changes because of service failure, complaints against the support provider, or a wish to change supports should trigger a mid-process review<sup>39</sup>.

The formalities of implementation from a service perspective are now considered in more detail. Earlier it was argued that the individualised or person centred planning should include a number of choice-promoting elements. These include a plan for the accomplishment of wishes and for ensuring that pervasive life choices are addressed as a matter of course. It was suggested that the steps in moving to these long term goals should be identified. More importantly it was suggested that practicable steps and a timescale for their completion should be identifiable and that these should act as a system by which the success of services and supports are judged.

The implementation of the steps in the plan will be dependent upon the skill and professionalism of services and support workers and will be diverse given the wide range of interests and dreams that are held by the person with a disability. There are some things that can be done independent of this expertise that will ensure that the means through which choices are accomplished accord with everyday human rights fulfilment and both protect and defend the person from infringements to those rights.

A human rights-based system could be supported by the use of a personalised human rights resource as well as knowledge of human rights and assessment tools (already presented) for assessing circumstances, situations and interactions. A proposed human rights resource (see *Ramcharan, 2012*) might include a number of areas (see *Appendix 1e in It's My Choice! 3: A Guide for Disability Support Providers and Table 13, below*): aspirations; non-negotiables, and choices in pervasive, lifestyle and everyday areas.

It is vitally important to ensure that at all times the approach is strengths-based and that all labels are positive. All too often negative labels have become self-fulfilling prophecies. The 'difficult resident' is treated as such and in being treated in a particular way comes to act out in that way, confirming the original label. In the words of the Nobel Laureate Amartya Sen,

### Considerations for Practice 36

One way of making sure there are links between different levels of choice-making is to develop and operationalise a *personalised human rights resource*

### Considerations for Practice 37

It is vital to pursue a strengths-based approach to planning and choice-making and that these strengths are utilised to move the person to both enhance and extend their capabilities over time.

### Considerations for Practice 38

A *personalised human rights resource* known to all those who work or live with the person can be helpful in ensuring that a person's individual rights are respected.

*The foundations of degradation include not only descriptive misrepresentation, but also the illusion of a singular identity that others must attribute to the person being demeaned’.*

(Sen, 2006: p.8)

Given this is the case, there is an urgent need to *reclaim identities*, to repair *damaged reputations*, to produce an identity more complete in its reflection of the complexity of the person and to produce *positive identities* which are owned and controlled by the person themselves. Records should be positive and celebrate the uniqueness of the person. Efforts should be made to understand the person, what motivates them, what history tells us about what they enjoy. Over time, such information can collect into quite a substantial resource.

It is possible even for those who do not communicate verbally to build up a positive plan based on identified strengths and wishes. The list of non-negotiables built up over time can represent a significant personalised human rights resource. Where support does not respect these rights, this resource will make it clear that the person’s human rights are being infringed. It therefore places the responsibility upon those who provide care and support to work in ways that recognise the person’s rights and know the person’s wishes when they work with the person or when they arrive for a shift. All support workers should be (made) aware of each person’s personalised human rights resource. This should be part of any individualised plan and should be widely known and understood among those providing care for the person.

The service may want to ensure that a link is established between the three forms of choice in a way that reflects strengths and everyday preferences. The *personalised human rights resource* (see Ramcharan, 2012) would be useful in expressing this link. This would be a positive approach that would place the person at the centre of decision-making. It would reclaim the person’s identity as their own and direct support to be delivered as the person wants it and in line with their non-negotiables. It would mean a move away from the administrative requirements for recording all the difficult things in the person’s life and the problems they cause. Instead, with a positive approach the self-fulfilling prophecies would be based on positive views and not upon negative stereotypes, stigma and prejudice.

Table 13 below provides one attempt to capture data which would be worthwhile keeping in a personalised human rights resource. It might be included as part of the person centred planning process also.

TABLE 13: PERSONALISED HUMAN RIGHTS RESOURCE	
Name	
Who are the people who are closest to this person?	
Person’s strengths	
Person’s aspirations	
Person’s pervasive life choices	
Top three most valued life choices	
Things that must be avoided	
Most important people	

NON-NEGOTIABLES (EXAMPLES)	HOW SUPPORTED TO ACCOMPLISH?	NOTES
<b>PERVASIVE LIFE CHOICES</b>		
How is [the person] best supported to make their own choices?		
Which valued relationships need to be maintained and nourished?		
What preferences does [the person] have for how they spend weekdays?		
What preferences does [the person] have for their weekends?		
What residential preference does [the person] have?		
Is [the person] living with people s/he would not choose to live with?		
Does [the person] want or have an intimate relationship that needs to be supported or established?		
What personal development aspirations does the person have?		
What personal rituals are important to [the person]?		
Does [the person] get out as much as they would like?		
How does [the person] like to relax?		
What preferences does [the person] have for contact with the community?		
What is [the person's] favoured drink and how is it made?		
What is [the person's] favourite food and do they get this often enough?		
How does [the person] like to celebrate special occasions (birthdays, religious festivals and so on)?		
Does [the person] take part in the religious and cultural life of his/her community?		
What are [the person's] favourite possessions?		
Are there other areas of everyday choice making that are considered pervasive that will fundamentally affect [the person's] life?		

NON-NEGOTIABLES (EXAMPLES)	HOW SUPPORTED TO ACCOMPLISH?	NOTES
<b>LIFESTYLE AND EVERYDAY CHOICE MAKING</b>		
Favoured personal appearance (clothes, grooming)		
Dietary choices		
How does [the person] enjoy him/ herself?		
How late does [the person] want to stay up?		
Does [the person] have the chance to manage their finances?		
How does [the person] like to spend his/her evenings?		
What media does the person enjoy (TV, books, magazines, iPod, radio, computer)?		
How does [the person] want to be treated if they're sad or angry?		
What compliments make the person feel good about themselves?		
What makes [the person] angry?		
Person's health choices		
Involvement in self advocacy		
Does [the person] want a pet?		
Choice of furnishings and decorations		
Favourite leisure pursuits		
Lively or quiet environments preferred?		
Others....		

Looking at the person's individual human rights preferences provides assurances that the actions of people who come in contact with the person will reflect the person's rights and be sufficiently informed of the person's preferences.

However, when thinking about choice it is often necessary to go beyond what is known. As pointed out in **Principle 5** (ensuring an expansive and broad range of choices), it might well be that there are opportunities and opportunity structures yet to be tried out by the person. This relates also to *Article 9* in which choice is seen to be a journey. By looking at the wider human rights picture it may be possible to explore whether the breadth of choices and options are being pursued on behalf of the person and, indeed, what barriers there are to their accomplishment.

One way of doing this is to think about the experience of the person with a disability in the light of the Principles of the CRPD and the 30 substantive Articles of which it is comprised. Ramcharan (2012) has proposed the following as a quick way of examining human rights compliance and thinking about how to expand opportunity structures. These are set out in *Diagrams 10a and b*.

Diagram 10a:  
The Human Rights Wheel

It is possible to superimpose the principles wheel on the right over the human rights articles wheel on the left. Questions can then be asked about what Articles are at issue in a person’s life and which provide grounds for additional opportunities to be discussed. The reasons why any right proves a problem can be considered by looking at which human rights principles are at play. These principles are as set out in *Diagram 11*.

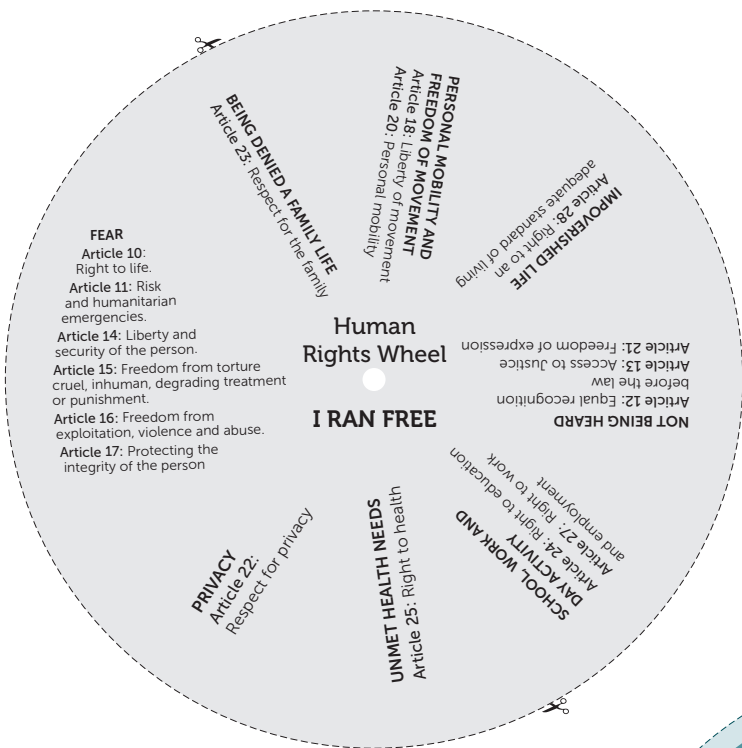
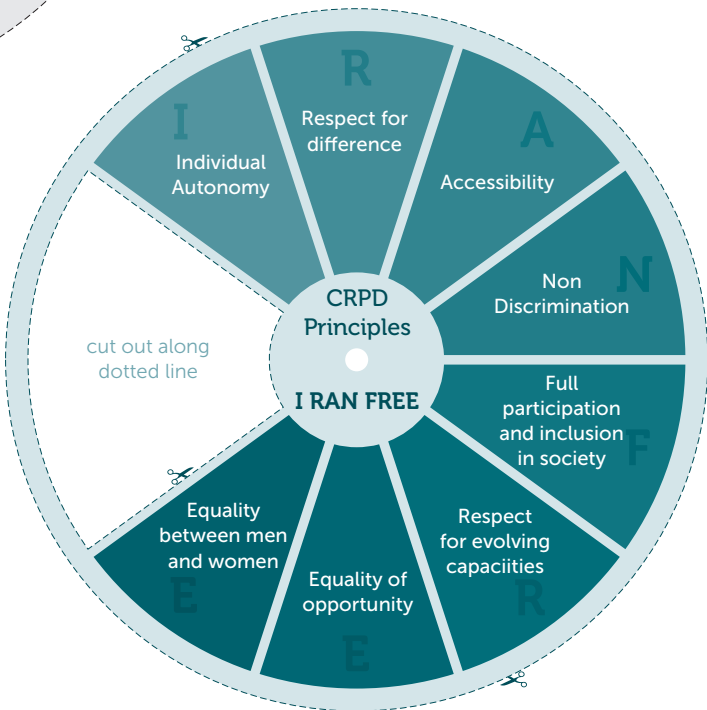


Diagram 10b: The CRPD Principles



Larger versions of these wheels can be found in *Appendix 2* of *It’s My Choice! 3: A Guide for Disability Support Providers*



## Diagram 11: Principles of the CRPD

1. *Individual autonomy - including the freedom to make one's own choices and respect for inherent dignity*
2. *Respect - for difference, entailing human diversity and humanity*
3. *Accessibility*
4. *Non-discrimination*
5. *Full and effective - participation and inclusion in society*
6. *Respect - for evolving capacities.*
7. *Equality - of opportunity*
8. *Equality - between men and women*

These Principles are set out in Article 3 of the CRPD as the General Principles.

It will not have escaped the reader's attention that the first principle of the CRPD relates directly to choice and a person's autonomy. This makes it a perfect fit for any proposed resource used to expand choice while protecting a person's human rights.

Once again, keeping notes of these assessments is important. So too are working with the person to explore what possibilities might be available given the work that has been done. There is a chance the person may not express any interest in the new opportunities and this too should be recorded, perhaps in the personalised human rights resource.

In implementing the plan the goals and associated dates (that move the person towards their goals) are essential. Support providers should have in place a method of regularly reviewing and adapting what is being delivered with the view that the outcome is what really counts. Providers need both an authorising environment capable of doing this and they also need to be adaptable. The providers best able to adapt in this market are likely to be those that ultimately gain a greater market share. CEOs and Boards need to be aware that they will for the first time be judged against their achievements for each individual.

One of the very telling issues in the *It's My Choice!* research interviews was the extent to which support providers are often risk-averse. This may have a major impact on choice. Without some new mechanisms to address this issue, a dignity of risk cannot be achieved.

Nay (2002) asks why it is for older people that formal providers seek to reduce risk as close to zero as possible, a point also made by Tom Kirkwood in his 2007 Reith Lectures. The links between risk and both resilience and the good life are well highlighted in Parsons's (2008) consideration of arguments around the dignity of risk:

### Considerations for Practice 39

It is possible to explore opportunities and barriers by employing a human rights assessment tool to a person's life. The assessment may point in directions that can be explored and will also focus on barriers that may need to be overcome.

### Considerations for Practice 40

Use the I RAN FREE mnemonic to remember the CRPD principles. The first principle relates to choice and autonomy.

### Considerations for Practice 41

Services need a mechanism to review whether the person is moving towards their goals. This is a regular task, a little like *keeping an eye on the patient or continually monitoring the student*. It is no longer acceptable for a person to simply remain in a service long term if there are no positive changes and no movement towards the goal.

### Considerations for Practice 42

Taking risks is an essential part of growth. Without acceptable risk people lose hope and learn helplessness. Dignity of risk means exploring new opportunities and extending a person's choice.

*Central to the notion of recovery is the notion of hope. Every choice involves both the possibility of failure and the possibility for success. Every choice involves hope. Overprotection by taking away people’s choices and not allowing them to take risks or try new things crushes hope. This, as can be seen in many people who have been institutionalised or hospitalised for any great length of time, can lead to learned helplessness, which is often more debilitating and disabling than any illness itself (Petersen et al., 1995). By supporting dignity of risk and encouraging people to make choices and take chances, service providers can help to combat learned helplessness and bolster self-esteem, self respect, empowerment and hope.*

(Ramcharan, 2012, p132).

Taking away risk is therefore deleterious in a multitude of ways. A few means can be conjured which will address this issue and further arguments from this publication (Ramcharan, 2012) point to additional ways in which risk acts as a form of control over people’s choices. The first is the way in which a target goal may seem hugely risky, but when broken down into smaller more manageable parts it may become less scary as a service strategy and as a way of negotiating with parents.

*A lot of parents have chosen [name of day support provider] because it is consistent with their risk averse strategy. And [the provider] has reinforced that, so if you challenge this the staff don’t feel comfortable... So you have a real challenge. Internally and externally, how do you convince parents you provide safety while stretching the boundaries?*

(Interview, CEO, DSP)

More fundamentally, there are a few further considerations. Related is the propensity of providers to make decisions on the basis of eliminating *hazards*. Yet risk is a calculation of what means can be put in place to manage that hazard to an acceptable level. It is therefore important to be able to move away from such a *hazard-elimination culture*.

Risk is sometimes applied to groups rather than in relation to an individual’s choices. A locked house may not be appropriate for all residents and yet all may suffer this sort of restriction on their freedom to move. It is therefore essential to ensure that labelling or blanket policies do not prevent those who are able from exercising choice.

Additionally many of the calculations of risk take place as a one-sided equation. It is often unclear what benefits have been considered against the level of risk. In their seminal work on biomedical ethics, Beauchamp and Childress (2008) assert that the most important factor in calculating the balance of risk against benefit is the concept of autonomy, i.e. that the person has freedom to choose whether to take the risk. This balancing of risk and benefit should meet the standards of social justice in being equally applicable to all.

Taking away people’s rights to express their choices produces resentment and breaks the trust that is so necessary between those who provide a service and the person receiving that service. Diagram 12 below outlines some positive ideas for a dignity of risk model.

Diagram 12: A Positive Model for Dignity of Risk (Adapted from CSCI, 2006)

**Good practice** - Assume capacity; Act in people’s best interests; Shift from organisational to personal risk assessment; Being safe can also mean taking risks; Whose risk is it anyway?; Managing conflicts and choices; Public expectations and the media: Creating safe environments; Balance risk to physical harm versus risk to independence and choice

**Key messages** (*passim*: para 3.1): Deliver person centred support for choice; Put services around people not people into services; Manage risk with people not for them; Learn from other people’s experiences; Learn lessons from other sources; Help people to design and create solutions that are right for them; Harness social capital and community support

Implementation of the person’s plan will take place with a model of individualised payments in which the person, their family, friends, circle or microboard manage the payment or where support providers do or do so with others.

Considerations for Practice 43

Reduce the risk into smaller parts and deal with each part in turn

Considerations for Practice 44

Don’t have blanket risk policies. People should not be prevented choice because of *blanket risk policies*.

Considerations for Practice 45

Distinguish the hazard from the risk. Risk must be set against the benefit to the person.

Considerations for Practice 46

Risk is about autonomy, about social justice and central to choice and to growth.

In considering support earlier it was indicated that the person should themselves be in control of the process of choosing the supports and directing them to the extent that they are able to do so. Families and friends also have a key role that they may play for the person in supporting their choice-making. They may be actively involved in exploring with the person their everyday responses to new experiences, keeping up-to-date with how things are going if the person wants them to. They may be involved in the administration of the budget or in collaboration around the person's *personalised human rights resource*. They may advocate for change and pressure on behalf of the person and may be involved in supporting their risk-taking.

Outside of support providers and family, it is time to start asking communities to gear up to support people with a disability to experience life with peers in the community. This moves beyond accessible environments to learning how to provide community encouragement and support when people wish to become more widely involved in the cultural, social, employment and community orientated areas that most people take for granted.

Table 14 below sets out the activities and resources that can be used at this stage:

TABLE 14: MAKING CHOICES HAPPEN AND LIVING A LIFE OF CHOICE				
LIST OF ACTIVITIES	WHO DOES WHAT	CROSS REFERENCE TO RESOURCES	TOOLS	EXPLANATION
Goal mastery	Responsibility of DSP, or other organisation providing support		None produced with this resource	The provider must accomplish the step in a specified time. Goal mastery allows constant monitoring and adaptation of inputs to achieve the desired goal (output). These notes can be important in reorganising steps at a later date.
Personalise human rights	DSP. Collaboration with family, friends, advocate, circle is advised.	Use <i>It's My Choice! 4: Film and Discussion Guide</i> .	Tool: <i>Personalised Human Rights Resource (see above)</i>	Everyday and lifestyle choices for the person and how they link to everyday practice.
Human rights assessment of person, situation, environment	DSP manager or support staff	See above	Tool: <i>I RAN FREE and Circle of Human Rights, (see above)</i>	To ensure that the delivery of services and supports are human rights-based and fulfil everyday human rights, use the resources proposed.
Dignity of risk	DSP manager or support staff	See above	Advice: - Make sure you are assessing risk and not stating a hazard - Make sure risk is set against benefits - Downsize the risk into smaller more manageable bits - No blanket policies based on varied levels of individual risk - Risk is about autonomy and choice, about social justice as well as growth.	Many services are risk averse. A new way of looking at risk is required to ensure that dignity of risk is achieved. Such dignity of risk helps people to grow. It establishes hope about life's challenges, accomplishes capabilities and develops autonomous and resilient individuals.
Positive identities	DSPs and all who write (case) notes about the person.	See above	No specific resource developed. Advice is to take a strengths-based approach and recording to create the best view of the person and not the worst view.	The history of support provision has been one of identifying and addressing problems. This means the view of the person from the notes is generally negative. A strengths-based approach can produce a more positive approach to the person.
New Experiences	DSPs, families, advocates and others	See Table 9 above	See Table 9 above	The time to try new services is during the delivery of services and, especially on the basis of growth, in relation to new and emergent needs.

## 5.5 Is it working?

For the person this is about looking back at how their life has been. It is also about how to move forward towards their goals.

For support providers there should be a number of documents already completed which can act as a way of gauging the success of different inputs and these should be put together as a review. These should include inter alia, the documents listed in *Section 5.1.1*, above. It will be possible with all these documents to start the individualised planning process discussed earlier and to once again start looking for the supports that reflect the person's goals and those capable of moving them to the next stage.

An important rule at this stage is that the contract with the support provider comes to an end at the point of review and that there is no automatic renewal. The issue around conflict of interest is again relevant here and it would be good to see some independent brokerage role in advising LACs around what options there are that could move the person further along the pathway to their goals. Perhaps a good and efficient way of managing this would be for the broker to be employed in situations where the LAC feels advice from an independent party about support provider options would be useful.

The review should ensure that a section of the work involved is set aside for addressing any limitations that can be resolved, non-legitimate limitations to experience which need to be addressed, and limitations of capability which may mean changing goals with the person's consent or adapting the number of steps towards the goal. The process should also focus on the support provider's ability to meet the person's needs. Some referral to systemic advocacy will help to ensure that recurrent problems in the lives of people with a disability are taken up by advocacy organisations and that individual or self advocacy can be offered where these are relevant and where the person wishes.

The services should have a review summary of goal mastery demonstrating the changes that have been made for the person as a result of continuing review processes. These will act as one marker of whether the service is attaining the goals set for the person on their choice journey.

For the person with a disability, key questions may relate to capabilities inter alia:

- Do I feel fulfilment in my life?
- Do I feel I have been tested to get the most out of life?
- Am I getting closer to my long term goals?
- Do I look forward to each day? What is missing?
- Am I able to remove the barriers that stop me from having a full life?
- Are there things, people, services I have learned I really do not want in my life?
- Do I have a sense of comfort in my surroundings?
- Am I happy with who I am and how people see me?
- Have I taken some chances and done some exciting things?
- Am I still trying new options and opportunities?
- Do I think I could get out more?
- Do I have all the friends I would like?
- Do I laugh enough?
- Do I have enough contact with animals and the environment?

If planned, the work done consistently over the period since the previous review should automatically feed straight back into the process where this section began. *Table 15* lays out responsibilities and activities at this point in the *My Choice* cycle.

TABLE 15: IS THE PERSON'S LIFE WORKING - WHO DOES WHAT?				
LIST OF ACTIVITIES	WHO DOES WHAT	CROSS REFERENCE TO RESOURCES	TOOLS	EXPLANATION
How is it working for the person?	Families, friends and advocates can have a really important contribution to make as well as DSPs.	See <i>It's My Choice! 2: A Guide for People with a Disability, their Family Carers, Friends and Advocates</i> .	Tools for families reproduced later.	
Collecting together all documentation for review/planning meeting with LAC	See list above - DSP should take overall responsibility. Person, family and others should be encouraged to submit their own documentation.	The collection of thoughts, activities and notes developed around the person's choices and preferences and recommended in this resource.	All those mentioned in <i>It's My Choice! 2: A Guide for People with a Disability, their Family Carers, Friends and Advocates</i> Appendices can contribute relevant information.	This stage is similar to the first stage considered earlier in that it brings the person back to preparing for a review or meeting with an LAC. While choice-making is ongoing this step provides an opportunity to take stock and make adjustments and changes to improve the person's life, outcomes and achieve their goals and choices.

## 6. Some concluding remarks

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In this Knowledge Review, arguments have been proposed to populate resources that are:

- Based upon the choices of people with a disability
- Based on the evidence of previous research and practice
- Based on human rights
- Practical
- Representative of the main aims of the National Disability Insurance Scheme

What has been proposed seeks to draw on the accrued knowledge around disability and choice. It has drawn upon people's current experiences of choice. It has also been conjured from some of the latest theoretical ideas associated with the personalisation of services, self management of funding, person centred approaches and a Disability without Barriers perspective that moulds aspects of a social model of disability with pre-existing paradigms. In short this review has been brave and aspirational. But such aspiration is never completely free of problems.

The area of making and pursuing choices can be affected by the ways people look at things and, as a result, what they value. For example some choices are made about what is 'said on the brochure'. And yet many of those things that are claimed are not necessarily accomplished. Without personalising choice the person's life will not develop.

*...Some parents just want what is on the brochure, but it may not fit. There is a responsibility for the person to work towards the ideal... see it as a destination. To get there is hard but to stay is hard too.*

(Focus Group - Support workers)

There can be a similar reticence about trying something new either in terms of the person or their parents and friends,

*...Parents [are] often afraid of new choices. [A] big challenge [is] with the parents, educating them and making them feel safe.*

(Interview, Manager of Day Service)

Some of these attitudes will not change by themselves. It is often the case that it takes time to *work together* in relation to an individual with a disability. Experience also seems to show that as people's lives begin to transform in a new system parents, friends and others also begin to ask questions about why the person's life is not changing for the better. Improved outcomes and ostensibly better lives can be their own advertisement for change and significantly affect expectation.

Levels of support and appropriate support can often be a problem. The first, mentioned already, is the conflict of interest support providers have in recommending other services or options. Another is simply the level of support that can be afforded.

*We're big...on encouraging choices outside of here. [It's] Important to encourage things outside of this service, so we started up a work experience program where people work in local business. 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. [Question: Do you have an 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 could not 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 the choices being implemented.*

(Interview, Day Service Manager)

In adopting the new the National Disability Insurance Scheme legislation, much has been made of the potential increase in funding that will accrue to people with disabilities. However, it really is vital to ensure that this is funding that is not spent on professional groups or administration to the exclusion of those in receipt of services and supports. Recognition is essential that a *demand-led* assessment and delivery structure is better than one in which data and information are gratuitously collected.

A related issue in support organisations is that some people and programs receive more attention than others and for the wrong reasons.

*Often resources have gone to the squeaky wheel and quiet ones missed out.*

(Interview, CEO, DSP).

The move towards individualised services is not going to be easy. In a low paid sector support work is also going to remain a major issue where the expectations about the support worker's role are transforming and where more may be asked of them. Services too will find it challenging to individualise their care any further without being afforded the time to do it properly and to step outside of planned programs that prove efficient. However, the congregation of funds around programs is always likely to favour some over others, and to oil 'the squeaky wheel' also, as noted in the comment above. It is absolutely vital, therefore, that the choice journey, goal mastery and the achievement of stated goals in stated time-frames are the key criteria against which any service is judged.

Another issue that is of importance is the context in which choices are made and the relationships in which such choices are best expressed.

*[It can be] so difficult to get them to articulate their choices. [The] challenge is to create an environment where the person is able to express themselves and make a time where we can specifically talk with them about them, as most activities here are group focused.*

(Interview with CEO of a DSP)

However, there are also issues with choices that do not reflect best evidence about their outcomes. For example, one person expressed a preference to move back into a group living situation.

*Yes, I had a house recently on my own and I found it very difficult. It was very lonely. So better to have a house with friends or a partner.*

(Focus Group - people with a disability)

In some cases there are strong lobbies, for example, to keep old institutions open or, indeed, to build new institutions. Some standards need to be established around human rights, discrimination and outcomes which preclude some options on the grounds that they are discriminatory and that they cause harm to those receiving such services. There needs to be work to ensure that policy bans options that are dangerous or discriminatory while supporting choice to the greatest degree possible.

As has been the case for far too long, there remain key issues about the extent to which the society will welcome and support people with a disability to take part actively in these communities.

*Sometimes, people don't care about us, and they need to understand that we are the way we are...and not to discriminate against us or threaten us. I don't like it...I used to be upset on our bus but now I am not...Domination – too many people trying to control your life or control your choices or feelings. Yes, I feel that way too...because when people say 'Oh, she has a disability. Stay away from her,' it's very hurtful. It really gets to me.*

(Focus Group - people with a disability)

Many people with a disability interviewed as part of the *It's My Choice!* project were unlikely to complain or speak up about their experiences in the community. Once again, the solution is sometimes not clear and straight forward but may depend upon people simply being in their communities, finding advocates within the community and, with case support, using disability discrimination legislation. But unless these expectations of the community begin to be actively claimed they are unlikely over time to become any more real than they already are. Toxic spaces do not build human social capital and they certainly do not support the unencumbered freedom to choose due to the limitations of prejudice. Ultimately, it is with these basic human rights and rights to citizenship that the future of people with a disability rest.



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# Appendices

## Appendix 1: Methodology for the *It's My Choice! Knowledge Review*

This project was designed to produce a Toolkit of resources for people with a disability, family carers and disability support providers that would incorporate the best evidence around choice-making, in multiple media formats using fit-for-purpose images and language for each group.

This project has employed a qualitative methodology based on the gathering of empirical data, a literature review and the testing of tools by a reference group.

The project undertook a category analysis of best practice in choice-making, self-determination and autonomy among three groups (people with a disability, family carers and disability support professionals) to identify how they construct, accomplish and pursue outcomes through choice-making. We anticipate from this that a number of academic articles will also be produced from the systematic analysis of focus group and interview data.

The project was originally designed to be Australia-wide. However, given the limits of time most data collection was conducted in metropolitan and regional Victoria. This project underwent scrutiny and received ethics approval by the RMIT University Ethics Committee. A Reference Group was drawn from industry leaders and appointed to oversee the project and offer expert advice on the development of the resources. This reference group was selected to include people with a disability, family carers, academics and experts from the service and advocacy sectors. The Reference Group met twice. In the first meeting comments were made around the emergent literature review, recommendations were made about what should appear in the framework, principles and content of the resources, and support with accessing participants for the interviews and focus groups was provided. In the second meeting the group advised on the content and quality of the nearly complete resources and provided advice about their veracity, practicability and usefulness.

### Data gathering

There were two major data gathering exercises in this project, the compilation of a literature review and the conducting of focus groups and interviews.

The literature review involved two strategies. Firstly a Cross Search of databases was undertaken using key words: Choice, self-determination, autonomy and disab\*, disability, learning disability, intellectual disability, mental retardation. The documents were examined for relevance and then the second strategy was used by hand searching through relevant references in each of the articles. The literature was read to provide information for developing the principles and framework for choice-making and later, once these principles had been identified, to explore the limitations on choice they were implying or indicating.

With regards to the data collection, the research team originally proposed to conduct a total of eight focus groups of leaders from self-advocacy groups, family carer groups and DSPs and 40 interviews with people with a disability, family carers who have moved to individualised funding packages as well as support workers, to identify better practice in choice-making.

We found that it was better to run focus groups with people with a disability than to offer individual interviews. We also found that many of the family carers who applied to take part were caring for children. A day set aside for two arranged focus groups attracted just two people, one for each group leading to two interviews instead of two focus groups. We collected data from 71 people. Given focus groups with around eight people the total number of research contacts proposed was 98 so the research team fell a little short in that respect. More details of the data collection are shown over:



- 8 focus groups (59 people altogether) with the following populations:
  - a. 2 focus groups with Support Workers
  - b. 4 focus groups with people with a disability
  - c. 2 focus groups with service managers
- 12 interviews were conducted:
  - a. 3 interviews with managers of services
  - b. 3 interviews with service support workers
  - c. 6 interviews with family carers

## Gathering the participants for interviews and focus groups

To reach the target populations the following approaches were used:

- The existing networks of the three chief investigators and reference group members
- Advertisements were placed for carers in the online newsletters of Carers Victoria and AMAZE, advertising the study and asking interested carers to contact us. Although there was a substantial response to this, many carers were not interviewed as they cared for children or did not have an ISP.

## Procedure

An innovative aspect of the second part of the data gathering (focus group and interviews) was the employment of a co-researcher with a disability. This co-researcher associated with Inclusion Melbourne was interviewed, briefed and trained by Dr Paul Ramcharan in: What the *It's My Choice! Toolkit* project was about (aims and products); the ethics of research (especially confidentiality and consent); how to ask questions; how to recognise when people are becoming upset or agitated, and what happens to the data and how it is stored. The co-researcher was mentored by Dr Paul Ramcharan which involved regular meetings and briefings and reflection on the work and experiences designed to support the person to build skills and confidence in their work and to address any issues.

The co-researcher was keen to participate and contribute to discussions and we found that often the sharing of his own experiences as a young man with an intellectual disability put the interview subjects at ease and encouraged them to reflect on their own situation and provide examples of their day-to-day challenges with choice-making. The co-researcher with a disability brought this *expertise by experience*. He brought with him experience that allowed him to empathise with other people with a disability, to ask questions during the semi-structured interviews which reflected his own history and experience (perhaps not in the repertoire afforded through reading academic books) and to translate issues that may be difficult into concepts that the respondents could understand. His specialist skills and contributions do not warrant academic expertise in the same form as would ordinarily be expected in traditional research forms. Rather his everyday experience was invaluable and he was a contributing member of a team, each member of which brought their own strengths.

The interviews and focus groups lasted approximately one hour each. All those participating in interviews and focus groups were provided with a plain language statement and a consent form to sign in accordance with RMIT University ethics requirements. The interview schedules and focus group questions were semi-structured and are summarised below. We also used the *NDIS Pathway* to explore with managers and DSPs issues around the current model proposed by the National Disability Insurance Scheme.

## Focus group questions

People with a disability:

- What are the most important choices that are made by people with a disability?
- What good practice examples have you got about supporting choice-making? (Specify issues around choice-making for those unable to communicate for themselves and how these issues have been addressed as well as for those who are able to speak for themselves).
- What good examples have you got about pursuing choices?

- How do you make sure the day to day choices people have are their own?
- How can you make sure that people's lifestyle choices are respected and pursued?
- How can you make sure people's pervasive life choices are accomplished (i.e. those that affect every other area of their lives such as where they live and work, what friends they have, etc).

## Family carers

- What choices are most important to your relative?
- How do you know when your relative has expressed a choice?
- What additional choice-making tools (technology and communication aides for example) have worked for people with a disability whom you know? (Specify issues around choice-making for those unable to communicate for themselves and how these issues have been addressed as well as for those who are able to speak for themselves).
- Are there any choice-making packages that you know of that have been used and that work well? What are they?
- What do you see as best choice-making practice among co-ordinators (case managers) and support workers?
- What are the best ways to deal with conflicts between family carers and the choices being made by their relatives or by the services that act on behalf of their relatives?

## Disability support providers

- How do you organise your assessments to maximise choice?
- How do you organise your individualised budgeting arrangements to maximise choice?
- What limitations have there been in the service system?
- Can you give us any good examples of where choice-making has worked well? What have been the key features of this choice-making?
- Do you use technology such as communication aides to support communication and choice-making. If so, which ones have proved most useful? (Specify issues around choice-making for those unable to communicate for themselves and how these issues have been addressed as well as for those who are able to speak for themselves).
- Do you have any supported decision-making practices in place? How are these organised?
- Do you use any choice-making tools? What are these and how useful are they?

## Interview questions

People with a disability:

- What are the most important things in your life?
- What are important life choices for you?
- If you had three wishes about things you think could come true, what would these be? (How might you make these wishes come true? Would you need help and if so, from whom?)
- What are the personal things you would like that you have not got? How would you get these? (Prompt - pet, camera, clothes, decorations, DVD collection, haircut, etc.)
- What routines do you value? Are there things you would change about your routines? How might these change? Who would you ask?
- Do you have examples of people who have helped you to make a choice?
- Have you got any good examples of people who have helped you make a choice come true? How did this happen?

- What things have you not chosen but which you have to do?
- Are there people who have stopped you from doing what you want to do?
- You have an individualised funding arrangement. Has this been better and, if so, how? Has it improved your choices? What advice would you give to others about how they spend their money?

## Family carers

- What do you think are the key choices for your relative?
- Who should be involved in supporting your relative to make their own choices?
- Do you have any good examples of where choice has made a real difference? Who has been involved and why have these differences been made?
- Has the individualised budget/ISP arrangement made a difference? How has it affected choices and accomplishments of those choices? Can you give some good examples?
- How do you manage conflicts between your own choices and those of your relative?

## Service personnel

- How do you organise your service to maximise choice?
- Are there things that get in the way of supporting people to make choices and to pursue those choices? How might these be changed?
- Do you have any good examples of how choices can best be made with people with a disability?
- How do you make sure the person's everyday choices are recognised and pursued (prompt with examples)?
- How do you make sure the person's lifestyle choices are recognised and pursued? (prompt with examples)?
- How can you make sure the person's pervasive choices are recognised and pursued (prompt in relation to family, intimacy, work/education and living arrangements)?

## Analysis of focus group and interview data

The original aim of the analysis was to analyse the data from focus groups alone, interview data alone and both together so as to afford the potential for triangulation. Each transcript was to have been analysed using a five stage process: familiarisation; identification of key themes; indexing of themes in the transcribed text; changing the data headings and sub-headings using a constant comparative approach, and interpretation and explanation (*Charmaz 2006*).

However, time for this work was not available though it will continue after project completion for the purposes of academic publication. Instead the research team progressively transcribed major portions and themes, listening to tapes and also extracting useful quotations. The themes were those of which the team was already aware given the knowledge it had gleaned from the interviews and the literature. In many cases the analysis was less systematic than the team had wanted, though the analysis that was performed did clearly confirm the major themes. The analysis allowed the team to test its 'hypotheses' about the data and to refine the concepts which came to populate this review and the project resources.



## Appendix 2a - List of limitations to choice identified in different studies: Limitation Table A

AUTHOR / DATE	GROUP CHARACTERISTICS	TIME	LOCAL ECONOMIC CONDITIONS	FUNDING	RESOURCES	PERSONAL APPEARANCE	RELATIONSHIPS WITH OTHERS	HOME ENVIRONMENT	DISCRIMINATION	ACCESS	PSYCHOLOGICAL & EMOTIONAL ATTITUDINAL	BEHAVIOURAL	SERVICE-RELATED SUPPORT
Achterberg 2009	Youth - all disability										✓		
Aldridge, 2010	Intellectual disability				✓	✓		✓					
Antaki, 2008	Intellectual disability												✓
Azaiza, 2011	Intellectual disability												
Barton, 2012	ID Complex needs and challenging behaviour						✓ (Case Study 1)	✓ (Case Study 3)			✓ (Case study 6 & 7)	✓ (Case study 2 & 5)	
Bent, 2001[1]													
Black 2002	Participation of people with disability		✓	✓									
Botticello, 2012	Spinal cord injury employment	✓	✓										
Bowey, 2005	ID and housing												
Brill, 1994	Adolescents with a disability, participation					✓				✓	✓		✓
Browne, 2012													
Cameron, 2002	Young people at transition												
Cardol, 2002	Adults with chronic disability/ participation										✓		
Clarke, 2011	Community participation, adults with a disability												
Cullen, 1999	Choice-making[1]						✓						✓
Dalton, 2010	ID, Communication				✓			✓					
Degura, 2012	ID, consultative committee, housing and living arrangements												
Duffin, 20[1]10	Moderate severe ID												✓
Edwards, 2012[2]	Disabled people and Housing choice												
Egilson, 2009[3]	School participation												
Espiner[4]	ID, individual planning												
Finlay, 2008	ID, residential						✓ Dependency						✓ Off the shelf risk averse
Fisher, 2011	Mild intellectual disability												
Fyson, 2012	Human rights and ID[1]												✓ Human rights
Gibson-Mee, 2012	ID in hospitals and communication skills												
Glendinning, 2008[2]	Aged/disability/ policy												✓ Market style mechanics

[illegible]

[illegible]

## Appendix 2b - List of limitations to choice identified in different studies: Limitation Table B

[illegible]

AUTHOR / DATE	CAPABILITY / SKILLS	CHOICE-MAKING/ LACK OF PARTICIPATION	HEALTH MEDICAL (INCLUDING COMORBIDITY)	IMPAIRMENT	EDUCATION /IQ	GENDER	UNEMPLOYMENT	KNOWLEDGE OF CHOICE OPTIONS	TECHNOLOGY	RISK MANGMT VS BENEFIT	FINANCIAL MANAGEMENT	PREVIOUS CHOICE MAKING EXPERIENCE	COMMUNICATION SKILLS	AGE
Clarke, 2011														
Cullen, 1999														
Dalton, 2010	✓	✓												
Degura, 2012			✓											
Duffin, 2011														
Edwards, 2012[2]														
Egilson, 2009[3]														
Espiner[4]		✓												
Finlay, 2008	Assume no skills													
Fisher, 2011									✓ Visual calculator					
Fyson, 2012														
Hatton 2004	✓													
Heller 2012														
Herps 2012		✓			✓			✓						
Hillman 2012										✓				
Hu 2011														
Isler 2009					✓ education of family members									
Jenkinson 1992	✓	✓			✓									
Jenkinson 1998					✓									
Jukes														
King 2010														
Kirkpatrick 2011											✓			
Lovell 1998		✓												
Macer 2010									✓					
Marsden														
Mansell 2003														
Mansell 2012														
Martin 2009														
McClimens		✓	✓											
McGuire			✓											
Mitchell 2012	✓	✓							✓ Talking mats					

[illegible]

## Appendix 3 - Considerations for Practice

### 1: Page 6

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Consider the phrase *Disability without Borders* as encapsulating the mission, policy and approaches that constitute the National Disability Insurance Scheme. It is also a reminder of the need to address barriers systematically as a part of the mission and philosophy of support provision.

### 2: Page 7

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A literature review highlights three resounding issues with choice, both conceptually and in past practice:

- People have a right to choose but cannot necessarily pursue every choice nor expect its accomplishment.
- Choice conceived in a limited way (e.g. as small day-to-day choices) glosses over choices in vital life areas and creates a veneer of accomplishment.
- Choices can be complex and involve planned action rather than spontaneous decisions alone.

### 3: Page 16

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When we work to fill our chosen capabilities we make life meaningful, we develop and we can have hope as well as build resilience.

### 4: Page 16

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It is important to see the person's strengths as lying not just with them but with the wider structures of support of which they are a part. This is why people who are isolated are less likely to flourish and fulfil their human relationship needs.

### 5: Page 17

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It is possible to see lifestyle choice as including embodiment, i.e. pride in who you are, including your interests, skills, personal qualities and disability.

### 6: Page 17

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Operationalising the CRPD requires an ongoing dialogue between rights bearers (people with a disability and advocates) and duty holders (public authorities).

The role of advocacy in this dialogue is hugely significant.

### 7: Page 18

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It is important to ensure people do not have to demonstrate adaptive behaviours to maladaptive environments. This profound insight must be a key conceptual element of planning supports, choosing services and training support workers.

### 8: Page 28

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Further considerations: Actuarial sustainability; System risk; Monitoring; Continuous Improvement; Cultural, rural, and regional capacity; Indigenous issues.

### 9: Page 29

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Service planning meetings and reviews are NOT the space for choice-planning. They may support choice-planning but the work around a person's choices must already be done.

### 10: Page 29

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Choice-making is a core and continuous activity through which the person and all relevant people and supports in their lives assist the person to grow, to move towards their life goals so as to accomplish chosen and better lives and lifestyles. Constant work is required to move people towards achieving their pervasive life choices. Constant input is required from the person, from family and from support providers. The continuous nature of choice-making should be reflected in policies and procedures, planning methods and so forth.

### 11: Page 30

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**Information** is vital to making the right choices about support services. These choices should match the person's goals, their pervasive choices, and should move the person towards their goals.

### 12: Page 30

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It is natural for all people to reflect on their own lives, to dream and to think about how they can change their lives if they choose. We all do this! A person's choices and dreams are owned by them.

People may also think about what people and supports they need to try new things or pursue new choices. The National Disability Insurance Scheme funds are one vital resource designed to support people to pursue these goals and choices. The extent to which these thoughts and reflections are formally documented, particularly prior to the LAC meeting, will determine how effective the National Disability Insurance Scheme system will be in helping people create pathways to accomplishing their goals.

### 13: Page 31

*Be prepared. Think BIG.*

What are my dreams, hopes, wishes, aims, goals?  
What are the steps along the way?

Who might undertake the work of planning, supporting, advocating? Who will work with me to commit these dreams, hopes and wishes to formal documentation?

- Person, their circle, family
- Advocate/Guardian/Appointee
- Support worker/service manager

### 14: Page 31

Undertaking an Option Appraisal of service providers.

**Who might undertake this Activity?**

- Person, their circle, family
- Advocate/Guardian/Appointee

Where a person is so isolated that their dominant relationships are with the present service it is important to think about the role of an *independent advocate as bringing another voice to the decisions being made*. Conflicts of interest must be avoided.

### 15: Page 32

*The Three Ways* constitute an effective process for answering the question "How's life for me?"

- Pervasive life choices
- Capabilities
- My Service Review

### 16: Page 32

"How's life for me?"

**Questions to consider:**

Is my life working? What needs to change?

Do my present services need to change?

**Who might undertake this activity?**

- Person with a disability
- Family carer
- Support worker/service manager
- Circle of support

### 17: Page 32

Maximising communication is the only way to ensure as much is known about a person's choices as possible.

Assessment for assistive technologies is vital but so too are constant communication and observation.

### 18: Page 33

**Meaning** is a key consideration in determining quality of life. Life is meaningful when, to the degree possible, a person does what they are capable of doing, when they develop what they are capable of achieving, when they are always moving forward in their life functions (eg. employment, health, social life), and when all of these are done in the context of the person's dreams, interests, values and relationships.

### 19: Page 33

All service or support inputs should pursue the person's goals or furnish them with new experiences. None should be gratuitous.

No person should be expected to remain *in limbo*. Life is about development and change.

### 20: Page 33

The planning meeting with the LAC is as much about examining the success of the supports in meeting the person's goals as it is about examining the person's choices and how these can be met into the future.

### 21: Page 34

*Reliable assistance* can be sought from a range of services that are disability-related, community-based or in the private sector.

### 22: Page 34

There is no right to continued funding to the support provider, but continued funding to the person only.

The main support provider should make a case for how they will adapt to achieve steps along the pathway to accomplishing the person's goals.

### 23: Page 34

Maximum personal control and participation are a requirement of this system. *The individual* (when used in these Guides, particularly in relation to planning and review meetings) indicates *the best decision-making group* that does not affect the person's capacity to make their own choices and maximises the information upon which choices are made, which are to the person's satisfaction and which recognise their relationships and duties.



**24: Page 35**

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Information about what support providers offer needs to be more readily available and in a form that can be understood and used by people with a disability, family carers and others.

At present, people are not sufficiently well informed about what support providers do to be able to make an informed choice. This leads back to reliance on 'services they know'.

**25: Page 35**

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Principle 5 (expansive choice-making) makes it important that people continue experiencing new opportunities and that this is done sufficiently far in advance for the person to make a judgement about them.

Families, circles and advocates may play a role in this. At times of transition it may be useful to have a **New Opportunity Fund** available for people to try new options from which they can make better choices about their future.

**26: Page 35**

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Prepare all documentation to take to the meeting with the LAC. The person should decide what they would like to be taken. Support providers will have kept more formal records about their achievements for the person.

**27: Page 36**

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Support providers should ensure that the person centred planning process they adopt meets the *Principles of Choice* outlined in this report.

**28: Page 36**

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During the planning process, support providers should seek to gauge (a) the *acceptability* of any proposed plan and (b) whether a proposed plan 'demonstrates sufficient aspirations for change' and ratifies 'the proposed pathways to accomplishing stated goals'. With the LAC, they should make judgments about whether *reasonable limitations* are being placed upon a person's experiences.

**29: Page 37**

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Feeding barriers back to systemic advocacy groups systematically builds human rights compliance. Keeping records of such barriers supports government planning about how to achieve progressive realisation and the reduction of infringements to human rights.

**30: Page 41**

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There are some working principles that may help in deducing how to reduce limitations on experience:

- Build on strengths
- Assume capabilities can expand
- Ensure there is no disability discrimination
- Ensure the service system is adaptable
- Ensure support quality is high
- Ensure human rights underlie all approaches
- Give voice to advocates and supporters in the planning review process

**31: Page 41**

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A plan should be realistic, practical and have steps that lead to the main life goals for the person. The steps to those goals should be laid out over the long term and the immediate goals of the support provider identified. The provider should be judged against success with these goals.

**32: Page 42**

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Support for choice must be exercised at a number of levels if the person's steps towards their goals are to be accomplished.

If the support is not present at any of the stages then the choice will not be accomplished or it may not be the outcome for which the person had aimed.

The supports that are necessary should not just come from support providers and families. Wider **community supports** indicate a move towards community inclusion.

**33: Page 44**

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Where possible, people should be directly involved in choosing their personal support workers

**34: Page 44**

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Individualised funding provides an essential mechanism that extends control over supports and services. It therefore contributes significantly to a person's choices.

**35: Page 44**

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There are limits to advocacy where conflicts of interest arise. An independent advocacy sector is vital to ensure that the person's interests are what arbitrate decisions made around their choices.

### 36: Page 46

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One way of making sure there are links between different levels of choice-making is to develop and operationalise a *personalised human rights resource*

### 37: Page 46

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It is vital to pursue a strengths-based approach to planning and choice-making and that these strengths are utilised to move the person to both enhance and extend their capabilities over time.

### 38: Page 46

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A *personalised human rights resource* known to all those who work or live with the person can be helpful in ensuring that a person's individual rights are respected.

### 39: Page 51

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It is possible to explore opportunities and barriers by employing a human rights assessment tool to a person's life. The assessment may point in directions that can be explored and will also focus on barriers that may need to be overcome.

### 40: Page 51

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Use the I RAN FREE mnemonic to remember the CRPD principles.

The first principle relates to choice and autonomy.

### 41: Page 51

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Services need a mechanism to review whether the person is moving towards their goals. This is a regular task, a little like *keeping an eye on the patient or continually monitoring the student*. It is no longer acceptable for a person to simply remain in a service long term if there are no positive changes and no movement towards the goal.

### 42: Page 51

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Taking risks is an essential part of growth. Without acceptable risk people lose hope and learn helplessness. Dignity of risk means exploring new opportunities and extending a person's choice.

### 43: Page 52

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Reduce the risk into smaller parts and deal with each part in turn

### 44: Page 52

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Don't have blanket risk policies. People should not be prevented choice because of *blanket risk policies*.

### 45: Page 52

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Distinguish the hazard from the risk. Risk must be set against the benefit to the person.

### 46: Page 52

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Risk is about autonomy, about social justice and central to choice and to growth.

## Endnotes

- 1 The distinction between everyday, lifestyle and pervasive choices was first proposed in: *Ramcharan, P. (2012) Roadmap for Achieving Dignity without Restraint. Melbourne: Department of Human Services* and relates to the first three principles of choice. This categorisation came from an examination of studies in which choice featured as an outcome (e.g. *Stancliffe et al, 2011; Robertson et al, 2007*). It was clear that the authors were examining different levels of choice. Whilst day to day choices and some lifestyle choices were clear improvements given new residential options, little had actually changed for people with disabilities in major areas of their lives such as schooling, employment and intimacy. This distinction is designed to establish a clear distinction and, as such to develop relevant practices for each. In terms of other literature *Heller (2012)* found that the daily decision making of adults with disability differed significantly by type of personal support worker hired. Agency staff was more likely to encourage choice making in the adult with intellectual and developmental disabilities than family members operating as support workers (p472).
- 2 The idea of lifestyle choice is alluded to in the work of Aldridge (2010) who found that independence is an essential part of 'becoming a person'. In that sense the links with external networks defines who the person is and how they choose to express their identity. Much of this is the subject of Goffman's (1959) seminal work on *The Presentation of Self in Everyday Life*. In the work by Raibee (2010) interviewees said having choice made them feel healthier and more independent (p830) once again indicating the part expansive choices of new interactions and environments can play on independence, autonomy, self-image.
- 3 Raibee (2010, p830) found that having authentic choices made people feel healthier and more independent it also helped them reinforce their chosen identities enable them to practice their chosen lifestyle and maintain family relationships. This is confirmed in the systematic study of the outcomes of person centred planning undertaken by Robertson et al (2006) as part of the Learning Disability Research Initiative (*Grant and Ramcharan, 2007*) in the UK which was designed to support the implementation of Valuing People, their first national intellectual disability policy for forty years. As this research showed, the link between one area of life and others is very close making it difficult to separate 'a choice' from others.
- 4 This is termed 'origination' an idea that is taken from the philosopher Ted Honderich (2008). Origination is an old philosophical idea but in relation to choice it has been used by this author to explain how it is that so many people who receive services do not get what they want. They do not do so because the services limit the choices of what people want in the first place. since they are nor the originators of the choice the outcomes can never be what they want. In the wider literature Schelly (2008) suggests that origination is particularly pertinent for those who are unable to either conceptualise or express their own choices for example many people with intellectual disability or acquired brain injury for example.
- 5 A person's history affects how they perceive choice and choice-making. their history can lead to low expectations, acquiescence or, in worst cases, having handed over their identity wholly to others (what Goffman terms disacculturation in his seminal work *Asylums, 1959*) are simply not in a position to see themselves as a person who has choice and agency. Shah (2008) - the author highlights how families, schools and other services can reinforce low expectations in young disabled people who then have a limited landscape of choices. For example in being excluded from work or work-experience, and other structural and attitudinal barriers that construct their image of their future selves. We can see potential extensions to this argument in the segregated and parallel lives many people with disabilities lead once they enter the formal institutions of state such as separate schools and day services instead of jobs.
- 6 Respected, protected and fulfilled come from the CRPD. Rights must be respected, i.e. organisations must ensure they are working to recognise and deliver human rights. Rights must be protected in that they should not be infringed and organisations must take steps to ensure that this does not happen; Rights must be fulfilled as an everyday experience in the work of those involved in any public authority or organisation that does the work of government, such as a DSP.
- 7 The notions of competency-inhibiting support and competency-enhancing support is taken from Booth and Booth's work *Parenting Under Pressure (1994)* in which parents with disability found much support inhibited their capacity to cope and provide for their own children. The Booth's recommend that support needs to promote competence. They posit that competence does not have to be individual but can be a 'distributed competence'. This is a bit like saying that grandparents, friends and others can provide wider support and help for families with children (with disability or not!!) and that this is positive just so long as they do not take over or create dependency.
- 8 The primary principle of advocacy is that there is no conflict of interest. Often people working for services have conflicts between the needs of their organisation, practical circumstances, their profession, or just through inertia which mean they cannot advocate for the person as if that person's voice and choice were their own. A secondary principle of advocacy is that when such conflicts arise the worker recognises that someone independent needs to speak for and with the person.
- 9 Dalton (2010) outlines organisational factors that support and promote (p16) communication – such as the principle that everyone can communicate, that the staff role is as communication partners, and providing opportunities to develop communication skills using technology, knowledge of non-verbal communication and so forth. Cascella (1999) also points out that the organisational environment can support or inhibit the individual's ability to communicate needs /wants too, making this context important. There is also evidence from studies of the outcomes of varying residential options that 'opportunity structure' plays a key role. For example in the old institutions cooking and cleaning were undertaken centrally. In group homes these were jobs passed on to residents and accordingly their skills increased to fill the new 'opportunity structure', reaching a plateau thereafter (*Stancliffe, 2002*). So, in making choice the opportunity structure within the environment is also vital especially where people can only communicate what they choose through what is available in their immediate surroundings.
- 10 Choice-making is not something that occurs wholly independent of others. I cannot choose to do things that will upset those who are closest to me without that having an effect on my relationship with them. So, sometimes I must make compromises to sustain my relationships with others. Muir 2011 also argues that a 'whole family' approach to disability is needed so that family's needs are met. Where such close family and friendship networks do not exist I can involve others. However, the sense of control is not then defined by my longer term relationship with them. Some microboards, circles may be of this nature and may not involve family and friends but they may represent the best way to get things in motion and get me to where I want to go. Finally, I may share my views or interests with self advocates, with leisure groups with community groups and may decide to express my choices within these groups. It is MY WISH TO STAY PART OF THE GROUP that sustains me in perhaps sacrificing some of my choices to the wider view of the group.
- 11 See Sections 86 and 87 of the *NDIS Act*
- 12 Barton (2012) Gives case studies of how disabled peoples goals can be achieved by nursing/ case staff when they are listened effectively. During the assessment 'essential lifestyle plans', MAPS and PATHS are drawn up with the client and their support team (p12). The Essential Lifestyle Plan (ELP) describes the decisions that people with intellectual disability make during their lives e.g. including where to live and with whom, what to do, what routines to follow, preferred characteristics of carers. It also covers mundane choices – visiting cinema, to more lifestyle choices – holidays etc, to pervasive choices e.g where to live. Martin (2009) takes us through setting an essential lifestyle planning

tool. Conversely Mansell 2003 conducted a literature review of individual plans. He found that often individual plans are not translated into daily practice, often administrative interests predominate. Individual plans are not well associated with the people they are meant to be for (p8). Moreover, often clients, relatives are not present when plan is made.

- 13 We believe that choice-making for all of us is dependent upon planning. For some people with a disability undertaking that planning to accomplish goals means time and effort are required. Choice cannot therefore be a one-off event in these circumstances but, rather a process. All forms of individualised or person centred planning demonstrate this principles of choice being a movement and not something that is static (see, *Essential Lifestyle Planning*, Smull et al., n.d.; MAPS, Forrest and Lusthaus, 1989; *Personal Futures Planning*, Mount and Zwernik, 1988; *PATH*, O'Brien et al, 1993 for example). Muir 2010 looks at choice making as a continuum and recognises the need for education in making choices. Helping people develop social skills and community activities (p383). Social and recreational activities were found to be key (p384) to interaction with the community (385) exposing clients to different activities and contacts (p. 385). In addition, in taking part in such organised community-based activities it is '... important for policy-makers to recognise that the purpose and opportunities activities afford – such as skill development, socialisation, Interaction in the community and working towards goal achievement – can be more important than the activity per se', (Muir, 2010, p386).
  - 14 The distinction between 'needs' and 'wants' has been taken from the seminal work of Steve Dowson in his volumes *Moving to the Dance* (1991) and *Who Does What?* (1990). Making a choice requires identifying what one wants, which in turn generates what one needs to get there. The fact that choices create needs is demonstrated by Espiner 2011 in discussion with an intellectually disabled young person who wished to go on a fishing holiday 'I have to get a fishing rod, I will go and buy one, it might be cheaper to hire one...' and another example 'I have to open a savings account' (Espiner p68). To realise those needs, people need to be empowered with the skills to achieve them (i.e. to understand what a savings account is and how to open one). To realise those needs, people therefore need prerequisite skills to achieve them (i.e. to understand what a savings account is and how to open one).
  - 15 This is an example and covers just one of the person's key choice in ONE area. It is vital to ensure that plans include all pervasive life choice areas in terms of a person's ultimate aims. These include what the person does each day, family, intimate relationships and friendships, health, leisure and community engagement, education and, where appropriate spirituality and culture.
  - 16 The following list, taken from Wikipaedia, is a good list of Nussbaum's key capability areas:
    - a. *Life*. Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.
    - d. *Bodily Health*. Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.
    - e. *Bodily Integrity*. Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.
    - f. *Senses, Imagination, and Thought*. Being able to use the senses, to imagine, think, and reason—and to do these things in a "truly human" way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing works and events of one's own choice, religious, literary, musical, and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid non-beneficial pain.
    - g. *Emotions*. Being able to have attachments to things and
- people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)
- h. *Practical Reason*. Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience and religious observance.)
  - i. *Affiliation*.
    - i. *Being able to live with and toward others, to recognize and show concern for other humans, to engage in various forms of social interaction; to be able to imagine the situation of another.* (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.)
    - ii. *Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others.* This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin and species.
  - j. *Other Species*. Being able to live with concern for and in relation to animals, plants, and the world of nature.
  - k. *Play*. Being able to laugh, to play, to enjoy recreational activities.
  - l. *Control over one's Environment*.
    - i. *Political*. Being able to participate effectively in political choices that govern one's life; having the right of political participation, protections of free speech and association.
    - ii. *Material*. Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.
- 17 See note 1.
- 18 Everyday or mundane choice - Both Aldridge (2010) and Antaki (2008) discuss mundane choices such as choice of food to eat, personal grooming and appearance and look at how choices are actually offered to people with intellectually disability in everyday situations. Antaki (2008) takes us through the actual process of choice making as directed by nursing staff in a residential home. Using conversational analysis to analyse staff client interactions for residents with intellectual disabilities, he concludes that the pressure to elicit clear choices from residents may often motivate the staff to be overly directive in their interactions. Indeed Antaki concludes that the 'institutional imperative is that the resident must be seen to make his choice accountable' (2008, p.x) even if the resident may not be fully cognisant of what choice he/she is actually making.
- 19 The distinction between everyday, lifestyle and pervasive choices was first proposed in: Ramcharan, P. (2012) *Roadmap for Achieving Dignity without Restraint*. Melbourne: Department of Human Services and relates to the first three principles of choice. This categorisation came from an examination of studies in which choice featured as an outcome (e.g. Stancliffe et al, 2011; Hatton et al, 2004). It was clear that the authors were examining different levels of choice and observations from this study nd over many years of data collection from people with intellectual disabilities, family carers and others.. In the research day to day choices and some lifestyle choices were clear improvements given new residential options. However, very little had changed for people with disabilities in major areas of their lives such as schooling, employment and intimacy. As such there is a need to establish a clear distinction between levels of choice and, as such to develop relevant practices for each. In terms of other literature Heller (2012) found that the daily decision making of adults with disability differed significantly by type of personal support worker

hired. Agency staff was more likely to encourage choice making in the adult with intellectual and developmental disabilities than family members operating as support workers.

- 20 *Lifestyle Choices* - Schelly (2008) gives a personal account of trying to provide lifestyle choices for a client with intellectual disability who could not conceptualise such choices, and finally concludes that people with ID 'cannot think in ways to make choices which would improve their quality of life' (p. 719) perhaps confusing the act of communicating choice with giving people sufficient experiences to respond to over time and upon which their reactions might indicate a preference. Aldridge 2010 also discusses *Lifestyle* choices such as appearance, attending social events, managing money on a day to day basis, and lifestyle choices <<.....say more about this.....>>

- 21 Pervasive choices are discussed by a significant number (over 20) authors and the topic focused on the most is housing. Stancliffe (2011) establishes the lack of real housing choice available. His research found that most adults with intellectual disability did not choose where or with whom they lived. Exercising pervasive choices such as moves to more independent living situations requires appropriate supports. Managing the home and managing a tenancy are discussed by Aldridge (2010) and Kirkpatrick (2011). Kirkpatrick views this from the provider perspective advocating activities such as an analysis of supply and demand for housing by local authorities and that they develop a wide range of housing options. There are major challenges going on around Australia in this respect in which some states have clearly identified clients on the basis of their support needs as requiring particular accommodation types. Needless to say these have moved much closer to congregate facilities (the modern-day equivalent of the old institutions). The Shut In campaign being run through People with Disability Australia and VALID seeks to use Article 19 of the CRPD around the right to community inclusion to challenge these new congregate care facilities on the basis that they have been shown to systematically provide worse outcomes for community inclusion. There are ways then in which policy can prevent choices which have been shown to systematically produce worse outcomes and, indeed, sometimes brutalised experiences.

Other main topics discussed under pervasive choices are employment (Aldridge, Black 2002, Botticello 2012, Duffin 2010 and Van Campen 2009) including transition from school to work (Cameron 2002, Jenkinson 1998). Fewer authors focused on the issue of health as a matter of choice which is interesting in that the fall back position is only ever addressing health where it falls into ill-health. Indeed, Raibee (2010) found that not all those interviewed believed choice in healthcare was a good thing, for example those with a recent, sudden disabling condition preferred to defer to medical experts, whereas those with ongoing, fluctuating conditions felt more assured at making treatment choices. The choices in healthcare usually centred on where to have treatment and what treatment to have. A subset of health is participation in leisure activities (Dattilo & Schleen, 1994 from Azaiza 2011, p100). Azaiza (2011) found that participation in leisure activities was significantly lower for those with cognitive impairment than with physical physical impairment (Azaiza p. 101) and, for those with intellectual disabilities, financial concerns were the main barrier to leisure activities, especially outdoor activities.

In short there are a multitude of limitations around pervasive choice many of which it is very difficult to address from the perspective of an individual choice-making model. The vital need for such limitations to be moved into a systemic advocacy arena is highlighted in this regard. Here collective choice and campaigning would play a role of identifying and addressing recurrent issues in a time in which individualisation challenges the grounds upon which collective action recruits its members and operates.

- 22 See Note 6.
- 23 One of the key ways of identifying relationships in which there is a significant power differential is the deference with which some people show to others. Acquiescence shows that the person has given up having a sense of self and of autonomy (Ramcharan et al., 2009). They remain a 'slave' to the requests of others.
- 24 Respected, protected and ensured (fulfilled) come from the CRPD. Rights must be respected, i.e. organisations must

ensure they are working to recognise and deliver human rights. Rights must be protected in that they should not be infringed and organisations must take steps to ensure that this does not happen; Rights must be ensured (fulfilled) as an everyday experience in the work of those involved in any public authority or organisation that does the work of government, such as a DSP.

- 25 The primary principle of advocacy is that there is no conflict of interest. Often people working for services have conflicts between the needs of their organisation, practical circumstances, their profession, or just through inertia which mean they cannot advocate for the person as if that person's voice and choice were their own. A secondary principle of advocacy is that when such conflicts arise the worker recognises that someone independent needs to speak for and with the person.
- 26 Dalton 2010 outlines organisational factors that support and promote communication – such as the principles that all behaviour is communicating something, that everyone can therefore communicate, that the staff role is as communication partners, and providing opportunities to develop communication skills using technology, knowledge of non-verbal communication and so forth. Cascella (1999) also points out that the organisational environment can support or inhibit the individual's ability to communicate needs /wants too, making this context important. There is also evidence from studies of the outcomes of varying residential options that 'opportunity structure' plays a key role. For example in the old institutions cooking and cleaning were undertaken centrally. In group homes these were jobs passed on to residents and accordingly their skills increased to fill the new 'opportunity structure', reaching a plateau thereafter. So, in making choice the opportunity structure within the environment is also vital especially where people can only communicate what they choose through what is available in their immediate surroundings.
- 27 Choice-making is not something that occurs wholly independent of others. I cannot choose to do things that will upset those who are closest to me without that having an effect on my relationship with them. So, sometimes I must make compromises to sustain my relationships with others. Muir 2011 also argues that a 'whole family' approach to disability is needed so that family's needs are met. Where such close family and friendship networks do not exist I can involve others. However, the sense of control is not then defined by my longer term relationship with them. Some microboards, circles may be of this nature and may not involve family and friends but they may represent the best way to get things in motion and get me to where I want to go. Finally, I may share my views or interests with self advocates, with leisure groups with community groups and may decide to express my choices within these groups. It is MY WISH TO STAY PART OF THE GROUP that sustains me even if I have to sacrifice some of my choices to the wider view of the group.
- 28 The dominant models of 'quality of life', generally speaking, split life into a number of domains (Schalock, and Verdugo, 2002; Cummins, 2005). Formal assessments take place objectively in relation to these areas and subjective appraisals in relation to the person's experiences. The quality of life approach suffers, however, because it does not establish 'pathways' to anything better. This is left to those with power and to those services that are readily available. The great leap forward for the NDIS must be that it introduces pathways and that the services are found to match the steps to the person's goals. There are a number of person centred planning mechanisms which do this. Some of these are mentioned later. Our belief is that it is time to operationalise the 'capabilities' perspective. This asks no more and no less than the person grows to fulfil their capabilities. It is a dynamic concept which seeks to support the person's growth.
- 29 There are real issues for community involvement for some people with a disability. If, despite all best efforts, a person does not like, for example, loud noises, crowds or prefers company with a select few very close people then this will limit the broad community involvement one naturally imagines when community inclusion is mentioned. But as well as the number of links with the community, equally as important is the depth of these links. Meaningful links in just a few places can be as good as superficial links in many. We know that many people on the autism spectrum for example will find expanding relationships difficult



but may find deepening relationship more pleasing. It may take time but it can be done.

- 30 As discussed by Ramcharan (2009) it is vital to avoid adaptive behaviours to maladaptive environments. Such behaviours are avoidable by making environment and interactions as supportive and enjoyable as possible as a means of reducing the occurrence of behaviours others see as a challenge.
- 32 The circle of support (Mansell and Beadle-Brown, 2003) is one way of thinking about this. However, all too often such circles are led by professionals and this was not what was originally intended in the theory. The problem seems to have been that what is necessary informally does not meet the contractual and actuarial responsibilities of services. However, once the group begins to act in this contractual and actuarial way it increases the workload on families and others and turns the group into a bureaucratised and 'cold' phenomenon rather than a 'warm' and informal experience. One resolution to this is that services use collect information from the group and keep their contractual and actuarial records whilst allowing the group to act as it chooses.

The second issue is that many people with disabilities are so isolated that bringing together any group is a problem. These people are likely to sit between formal Guardianship and informal support with neither being either available or appropriate. In this case efforts should be made over time to extend the membership and always to involve people independent of the services the person uses. Where a person is solely defined by their service the chances of institutionalisation increase.
- 33 The individualised planning framework may rely on any number of person centred planning (PCP) tools. Presently, recommendations about this framework are being pursued by Melba Support Services as part of their PDF funded work. If the previous stage has been completed, it will aid in several of the PCP frameworks. For example, telling the person's story is the focus of the Essential Lifestyle Planning (ELP) (Smull et al., undated). In this it is important to learn the person's unique skills and qualities, how they communicate, what supports they require. With MAPS (Forest and Lusthaus, 1989) the idea is to 'find a way together' by exploring the person's story and what the 'best life' would be. Personal Futures Planning (Mount and Zwernick 1988, Mount, 2000) maps a person's life around community, health, choices and addresses areas of concern. It can be used well to create pathways in areas where development is needed. PATH (O'Brien et al., 1993) develops a plan for action and change and so fits well with the idea of the choice being a journey in which there are stepping stones to the person's ideal outcome.
- 34 Again, this process is yet to be adopted but projects are funded as part of FaCHSIA's Practical Design Fund.
- 35 In the UK many disability led organisations, especially the Centres for Independent Living, supported the introduction of Direct Payments (Ramcharan, 2008). It was found that when these organisations were involved in local areas, those areas were more likely to develop Direct Payments and to do so innovatively (Glasby and Littlechild, 2009). Moreover many such organisations have begun to act in roles as service brokers and in supported decision-making. In their service broker role they have managed and administered budgets, provided salary services, and arranged interviews where the person and their family have been unable to do so. This means that much decision-making is taking place outside of formal support providers and it resolves some of the issues with a conflict of interest in known providers simply choosing themselves as the best for the person. Importantly too, since individualised funding should represent a demand for service approach (as opposed to a supply of service approach) they have, together with advocacy organisations, been instrumental in stimulating the provider sector to develop new and required niche services not already available.
- 36 In a consumerist model the consumer is seen as having the right to be informed, to choose, to participate in making choices and to have access to redress. By adopting the model suggested the issue of redress can be formalised in a role for the independent advocacy sector. This allows pressure to be placed on the system which is constantly reflecting the experiences of people with a disability. In doing so it allows the production of a

dialogue between the rights bearer and the duty holder (a human rights-based approach) and allows both government (and any NGOs creating shadow reports) to better identify progressive realisation of positive rights under the CRPD. These should not exist independent of the individual's right to make a complaint where they feel their individual civil and political rights have been infringed.

- 37 The present situation is dictated by the following draft rules:
  - 3.1 People with disability are presumed to have capacity to make decisions that affect their own lives. However, the Act recognises that there may be circumstances where it is necessary for a person to be appointed as a nominee of a participant, and to act on behalf of, or make decisions on behalf of, a participant.
  - 3.2 Appointments of nominees will be justified only when it is not possible for participants to be assisted to make decisions for themselves. It is expected that, wherever possible, participants will be supported to make decisions for themselves.
  - 3.11 If the participant has requested that a particular person be appointed as nominee, the CEO is to have regard to the following:
    - (a) the principle that the person the participant has requested should ordinarily be appointed;
    - (b) whether there is any evidence to indicate that the person has unduly or improperly induced or influenced the participant to request the appointment.
  - 3.12 If the participant has not requested that a nominee be appointed, when deciding whether to appoint a nominee, the CEO is to have regard to the following:
    - (a) whether the participant would be able to participate effectively in the NDIS without having a nominee appointed;
    - (b) the principle that a nominee should be appointed only when necessary, as a last resort, and subject to appropriate safeguards;
    - (c) any formal guardianship arrangements that might be in place;
    - (d) whether the participant has supportive relationships, friendships or connections with others that could be:
      - (i) relied on or strengthened to assist the participant to make their own decisions; or
      - (ii) improved by appointment of an appropriate person as a nominee.

It is important in these rules that the interests of the nominee sit external to those of the support provider that has appointed them. The danger is that there will be a significant conflict of interest in their recommendations and plans for the person.

- 38 Co-production - is a means of ensuring that people are involved in the planning and delivery of their own care and the decision-making that goes hand-in-hand with that (Needham, 2007). As the person is actively involved, the outcomes are likely to be more satisfactory to them. They will have a stake in the solutions as well as the issues at hand and there will be fewer complaints and a greater level of dialogue and co-operation.
- 39 In some circumstances that would need further elaboration it is conceivable that where a person's situation is stable, where the services are not changing and where the next steps are committed to paper and a clear plan submitted alongside evidence of successful achievement of previous goals, a paper review may be undertaken by the LAC.









Volume 5 of 5

ISBN 978-0-9922717-9-4



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Produced  
with the  
support and  
assistance of  
the Gawith  
Foundation.