

It's My Choice!

A Guide
for Disability
Support Providers

**It's My Choice!
Toolkit**

ISBN: 978-0-9922717-9-4

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(2013)

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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.

The authors have used pictures from CHANGE Picture Banks to make information accessible and easy to understand. CHANGE Picture Banks are accessible via www.changepeople.co.uk

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

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Providers

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1. Introduction

This guide is designed for Disability Service Providers (DSPs) and support workers to support people with disabilities to make their own choices and to develop service and choice planning frameworks that deliver better lives.

This is the *third of five* resources in the *It's My Choice!* toolkit. The resources are:

- **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**

These resources have been designed to address some of the issues encountered with choice-making in the past. Some of these issues are:

- the idea that people having total freedom of choice does not represent reality
- that there are different levels of choice-making that are seldom taken into account in developing choice-making models
- that the levels and types of support required to make the outcome successful in terms of a person's expressed wishes, dreams and preferences have not been addressed sufficiently
- that making choices is not a single action but an ongoing activity - for many people with disability making choices means being able to encounter or experience options first
- that there are often conflicts between people who care about and for the person which affect their choice-making
- that power is an important part of the relationship equation
- the potential conflicts of interest between what services want and can deliver, and what the person would really like and benefit from
- the place of human rights in choice-making and how these are an important way of ensuring both means and ends are human rights-based
- The way in which choice links into the individualised planning process

In *A Guide for Disability Support Providers*, you will be using all of the resources as a toolkit to support choice and choice-making by the people who use your service, for whom you provide support and for whom you will often advocate in individualised planning and review meetings. We recommend you encourage the person, family carers, friends and advocates to use the other resources, guides and films and to be aware that choice is a continuing journey.

In thinking about your role in choice-making for people with a disability we have designed this toolkit around the *My DisabilityCare Choice Pathway* model which is described and addressed in section three of this guide.

However it is vital first that as a professional you understand the principles that underlie choice. These are set out and described in this guide and also in *It's My Choice! 1: The Principles of Choice*. What differs in this guide is that we include an explanation of each principle and examples. Choice is often about negotiation. By having one set of principles upon which all stakeholders might rely we hope to provide a common space for this negotiation, recognising that the power you have as a professional may significantly affect how you support people in making choices designed to improve their lives.

As you move through the next section you will find exercises that may support you to think through and to apply the choice-making principles to those for whom you presently provide services or for whom you provide support.










Please note that the references for the *It's My Choice! Toolkit* can be found at the end of *It's My Choice! 5: A Knowledge Review*.

Enjoy this guide and the other resources in the *It's My Choice! Toolkit*.

Exercise

There is a shaded Exercise area at the bottom of several pages in this Guide. You can use the exercises to stimulate discussion in a group context, for personal reflection, or as an aid to engaging in the supported decision-making process. The exercises also appear together in *Appendix 3* at the back of this Guide.

2. The Principles

PRINCIPLES OF CHOICE		
1	I have the right to make choices throughout my day.	
2	I have the right to be who I choose to be.	
3	I choose my hopes, dreams, and goals.	
4	All my choices start with my ideas.	
5	I make better choices if I have had a chance to try lots of options.	
6	My experiences may be limited by money, experience or what is possible – but they should not be more limited than others just because I have a disability.	
7	Let me make my own choices as far as I can.	
8	Support me if I need help making my choices or making my choices real.	
9	Choice is a journey. It never stops.	

Above is a summary of the principles that undergird choice-making. To make the most of this section you will need to have *It's My Choice! 1: The Principles of Choice* handy so that you can examine the diagrams and explore the principles in more detail.

Refer to Principles 1, 2 and 3 in *The Principles of Choice*. Look at the diagram relating to these three principles. Now look at *Explanatory Table 1* below. This table describes the principle and provides examples of each.

EXPLANATORY TABLE 1: UNDERSTANDING THE PRINCIPLES OF CHOICE – PRINCIPLES 1 TO 3			
PRINCIPLE	WHAT IS IT?	EXAMPLES	EXAMPLES FROM THE DATA
<p>Principle 1: Everyday Choice I have the right to make choices throughout my day. These are called <i>mundane</i> or <i>everyday</i> choices.</p>	<p>The huge number of quick choices that are made by all people each day. They are usually simple.</p>	<p>I want tea not coffee; I want to go for a walk; I'd like to watch this TV programme</p>	<p><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)</p>
<p>Principle 2: Lifestyle choice I have the right to be who I choose to be. These are called <i>lifestyle</i> choices.</p>	<p>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.</p>	<p>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</p>	<p><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)</p>
<p>Principle 3: Pervasive choice I can choose what I want, my hopes, dreams, and goals. These are called <i>pervasive</i> choices.</p>	<p>There are choices that, when made, will have a major effect on every other life area. When we asked about choices, most people with whom we spoke listed <i>pervasive</i> choices.</p>	<p>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...</p>	<p><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)</p>

Linking the three levels of choice

So, for example, choice of food may reflect a healthy lifestyle or identity and a pervasive choice about being healthy. These linked choices should not contradict or conflict with others. Pervasive choice is of a higher order than lifestyle which is of a higher order than everyday choice. Yet a lot of disagreements are about everyday choices. Even though you cannot tell a person what to choose, you can point to the contradictions between their choices on the basis of what they *really* want at a pervasive choice level and the everyday choice they are making at the time.

For example, if a person consistently wants biscuits and soft drink but is also aiming to be in a cycle team (pervasive choice around health), it is possible to ask them to consider if they will accomplish their goal if they continue to choose to eat biscuits and soft drink. One relies on the other, so having aims and goals is vital.

Exercise

Can you think about how *everyday*, *lifestyle* and *pervasive* choices may apply to the persons for whom you provide services or support? Are there any inconsistencies between the areas of choice in their lives? How can these be resolved?

Refer to Principle 4 in *It's My Choice! 1: The Principles of Choice* guide. Look at the diagram relating to this principle. Now look at *Explanatory Table 2* below. This table describes the principle and provides explanations and examples of the principle.

EXPLANATORY TABLE 2: UNDERSTANDING THE PRINCIPLES OF CHOICE – PRINCIPLES 4			
PRINCIPLE	MEANING	EXAMPLE	EXAMPLES FROM THE DATA
<p>Principle 4: All actions to pursue choices start with me. I am the source and originator of my own choices. Choice is diverse.</p>	<p>The starting point MUST be the person. 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. In the past traditional methods have been to see how the person fits into 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 DisabilityCare 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.</p>	<p>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!</p> <p>Or</p> <p>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.</p>	<p>No origination or participation in the following example of choice-making:</p> <p><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></p> <p>(Interview, CEO, DSP).</p> <p><i>I want to be a traffic cop...</i> (Focus group - people with disability).</p> <p>An important aspect for this person originates with his wish to be near to his family.</p> <p><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></p>

Think about how much more motivated a person will be if pursuing what they want and not what you or others state to be the person's wants. Think of how the outcomes will be better. Think about how involving the person will become easier for you in providing your service or your support. Think about the fact the person will not be bored and that she or he will enjoy experiencing her or his choices.

When a person's choice originates with them they are a free agent, the prime mover, the first cause of everything that follows as a result. All people are influenced in their choice by their history and particularly by family; this is no different for people with or without a disability. What is important is that we create diverse histories through expanding experiences so that the repertoire for origination is as large as possible. Too many choices have in the past been limited to the 'last available option' or the 'only option this service will deliver'. Under DisabilityCare individualised funding will free people to choose and change services to those that do meet their choices. So it is in the interest of DSPs to be developing strategies to support such choice-making.

Exercise

Choose a person for whom you provide services or support:

Is the person showing different reactions to different environments? Are some reactions negative? What is the person communicating to you?

What can you do to reflect ideas that have originated with him/her?

Think of situations in which a person has become enthused about something they have chosen to do.

What examples can you point to?

Have you introduced a new experience for which a person has demonstrated enthusiasm and a desire for further engagement? Could this be accomplished?

Refer to **Principle 5** in *It's My Choice! 1: The Principles of Choice*. Look at the diagram relating to this principle. Now look at *Explanatory Table 3* below. This table describes the principle and provides explanations and examples of the principle.

EXPLANATORY TABLE 3: UNDERSTANDING THE PRINCIPLES OF CHOICE – PRINCIPLE 5			
PRINCIPLE	MEANING	EXAMPLE	EXAMPLES FROM THE DATA
<p>Principle 5: 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>	<p>A person's choices may have been limited by experiences (e.g. in institutions) and s/he may just say "yes" to everything ; 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 be expansive in experiencing options upon which more informed choices are made about what s/he wants. 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 the 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 another's 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 disabilities can also react with frustration and sometimes even anger. At the point of making decisions about 'What next?' it is often good to have, through conversation and knowing the person, 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 those 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 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 choose expansively 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).</p> <p><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 do things in life to learn lessons... it ties back to that control stuff...</i> (Focus Group - Support workers)</p> <p><i>Hopefully in ten/fifteen years, the kids that are in specialist education will learn those things in a school setting which normal kids do, so when they are adults they can understand and cope a bit better.</i> (Focus group - Support Workers).</p>

Exercise

Think of a person for whom you provide services or support. Answer the following questions in relation to one of their **pervasive** rights (e.g. where they live, education, employment, health).

If this person were to be asked to make a choice for the future in relation to this pervasive choice would they be able to do so *based upon their past experiences*?

How might you plan for the choice to be more informed? What sort of plan would help in supporting the person to make their choice informed? How much time would it take to expand their experiences?

This principle recognises that many people with a disability have histories that are sparsely populated with different experiences. Institutionalisation can result in acquiescence; histories of abuse can reduce trust in others and risk-taking; lack of skills may reduce the 'opportunity structure' for making choices. Tradition tends to place people in repeat programmes with no prospect of 'graduation' to anything new. As professionals it is beneficial to support *choice for diversity* and to respond to a person's interests, affiliations, character and life histories. Whilst there are some people who prefer structure and routine, for the majority having choice means providing *ongoing experiences* and recording these over time so that the approach is measured and not imposed at the last minute.

Refer to **Principle 6** in *It's My Choice! 1: The Principles of Choice*. Look at the diagram relating to this principle. Now look at *Explanatory Tables 4.1, 4.2 and 4.3, below*. These tables describe the principle and provide explanations and examples. This is a complex principle covering a number of areas.

EXPLANATORY TABLE 4.1: UNDERSTANDING THE PRINCIPLES OF CHOICE – PRINCIPLE 6			
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>a. Based on arguments of discrimination and social justice, limitation should be no greater for me as a person with a 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. Later, limitations to choice in the literature are turned into a table for your use. The chart helps 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 later. 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 'normalisation' or social role valorisation 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 advice not to 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? <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 with the choices being implemented...</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 [such that] 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>

This principle is an important break from the past ideas about choice-making. Sometimes it is claimed a person can have complete freedom of choice. This is not true. No person with or without disability has such freedom. Recognising that all choices are in some way limited means that disagreements around choice-making are more likely to be about whether the reasons for the limitation are legitimate. *Table 4.1* shows how experiences and choice might be limited.

EXPLANATORY TABLE 4.2: UNDERSTANDING THE PRINCIPLES OF CHOICE - 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>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.</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 I RAN FREE:</p> <ol style="list-style-type: none"> 1. Individual autonomy - including the freedom to make one's own choices and respect for inherent dignity 2. Respect - for difference...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 <p>(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 in <i>Appendix 3</i>.</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 Principle 3 on accessibility and Principle 4 – that I have been discriminated against because of my disability.</p> <p>Subject to this discrimination I have been unable to exercise autonomy (Principle 1) and it has caused less than full and effective participation on an equal par to the rest of the community (Principle 5).</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 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.</i></p> <p>(Focus Group - self advocates)</p> <p>Question: Where do you see human rights fitting into this? 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></p> <p>(Interview CEO, DSP)</p>

It is important that any limitations on experience do not infringe social justice, i.e. that similar limitations would be placed on others in similar circumstances and that no person is being discriminated against because of their disability or difference. *Explanatory Table 4.2* also highlights the importance of building human rights into the framework for decision-making around choice. DisabilityCare sees human rights as a central and important aspect of the new era in lives of people with disabilities and the new services they use. Look at the *I RAN FREE* principles in *Explanatory Table 4.2*. These are principles taken from the Convention on the Rights of Persons with Disabilities (CRPD). By applying these principles to a person's life it is possible to think about what limitations are taking place and whether they are infringing human rights.

Exercise

Think about a person for whom you provide services or support.

What do you see as the main limitations on this person's choices and experiences?

Use the I RAN FREE principles to consider whether the limitations are legitimate or not. How would you address these limitations?

If you cannot overcome these, then what recommendations would you be making for this person in terms of new services, new life experiences, new opportunities?

EXPLANATORY TABLE 4.3: UNDERSTANDING THE PRINCIPLES OF CHOICE - 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 a disability 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'.</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 everyday. But we worked hard with her not to do just meaningless tasks. She said she wanted to join the workforce again. She 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>

The list of limitations is also very important in relation to advocacy and in measuring compliance with the CRPD. Where there are limitations it is recommended that systematic communication with advocacy organisations occurs to allow these to be categorised and added to a database. It is suggested that the recurrence, the intensity and span of these issues should become a focus for advocacy and for submission to the CRPD Committee around the progressive realisation of human rights. More will be discussed in relation to human rights assessment later.

Explanatory Table 4.3 also points to the *risk appetite* within services. The more risks a person is supported to take, the more they will grow and the fewer limitations they will have placed upon them by a powerful service system. It is vital to extend dignity of risk to people's lives and this too has the potential to break down long-standing service limitations.

Refer to **Principle 7** in *It's My Choice! 1: The Principles of Choice*. Look at the diagram relating to this principle. Now look at *Explanatory Table 5* below, which describes the principle and provides an explanation and examples.

EXPLANATORY TABLE 5: UNDERSTANDING THE PRINCIPLES OF CHOICE – PRINCIPLE 7			
PRINCIPLE	MEANING	EXAMPLE	EXAMPLES FROM THE DATA
<p>Principle 7: Each person, including each person with a 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 at different times. But that support must not stop me from making the choice myself if I can do so.</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 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 most 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>

Principle 8, your role in supporting the person in their choice-making, appears throughout this guide and as such will not be discussed explicitly at this point. Refer to Principle 9 in *It's My Choice! 1: The Principles of Choice*. Look at the diagram relating to this principle. Now look at *Explanatory Table 6* below which describes the principle and provides an explanation and examples.

Exercise

Think of a person for whom you provide services or support who does not communicate verbally.

Is there anything more you can do to support communication with this person?

If not, how much do you know about this person, their indicated preferences, their history and experiences?

How would you advocate for this person given what you know about them? What more would you need to know to advocate more confidently? How might you involve others in supporting decision-making, choices and plans?

Is any of your support competency-inhibiting? In what way? How might this be addressed?

EXPLANATORY TABLE 6: UNDERSTANDING THE PRINCIPLES OF CHOICE - PRINCIPLE 9

PRINCIPLE	MEANING	EXAMPLE	EXAMPLES FROM THE DATA
Principle 9: Choice is a continuing journey and not just a one-off action.	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	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!	<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) <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)
a. What I <i>want</i> tells others what I <i>need</i> to help me move towards my key life and lifestyle choices.	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.	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.	[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) <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)
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.	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.	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.	[So the programs you do here are important?] <i>Yes – 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)
c. Since life changes and I change, so too can my choices or my pathways			

Diagram 1 summarises a choice journey, in this case a wish to do paid work. It shows the nature of the supports that are required to make the journey possible and the steps that need to be taken along the way. These steps are not fixed and will differ depending on each person's pathway. Note how this takes planning and a pathway. Note too how *pervasive* life choices and *lifestyle* and *everyday* choices may be linked.

Exercise

Think of a person for whom you provide services or support.

Can you think of something that this person has expressed a desire to do? If they cannot speak for themselves have you discovered something from their life that will give you a clue about the things they might enjoy or grow from? Can you identify a potential area of growth from the capabilities framework?

You know the person's wants or have made an educated guess. Now explain what the person needs in order for them to achieve these.

How will you break this down into smaller steps? How long do you estimate the process will take? How will the person grow after taking each of the smaller steps?

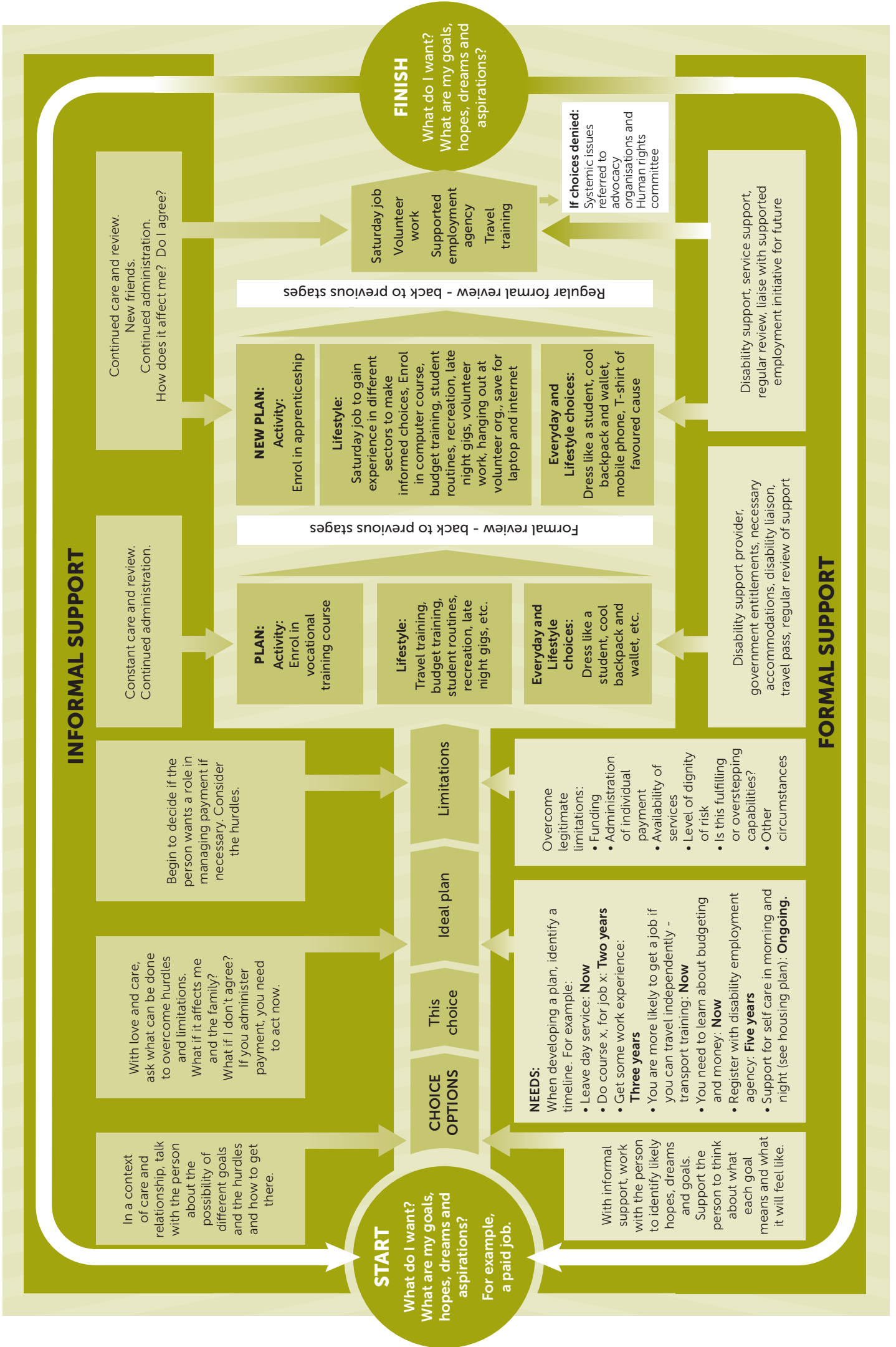


Diagram 1: Example of the choice-making journey and the supports I may need based on a life-course and a life-style

3. The My DisabilityCare Choice Pathway and the role of services and supports

This section provides the tools and concepts about how to support the choice-making of people for whom you provide a service or support. This section provides a framework for completing particular activities to maximise the chances that a person’s choice journey will work, and to ensure that the pathway is constructed in an informed way that is based in a human rights approach and which reflects the person’s self-determination and autonomy. This pathway is based upon the original National Disability Insurance Scheme (NDIS) My Choice Pathway which we have termed the *My DisabilityCare Choice Pathway*. *Diagram 2a* uses simplified language so that you can support and enable people with a disability, family, friends and advocates to participate in this process. Each numbered point in the diagram will focus on the sections to follow.

Diagram 2a

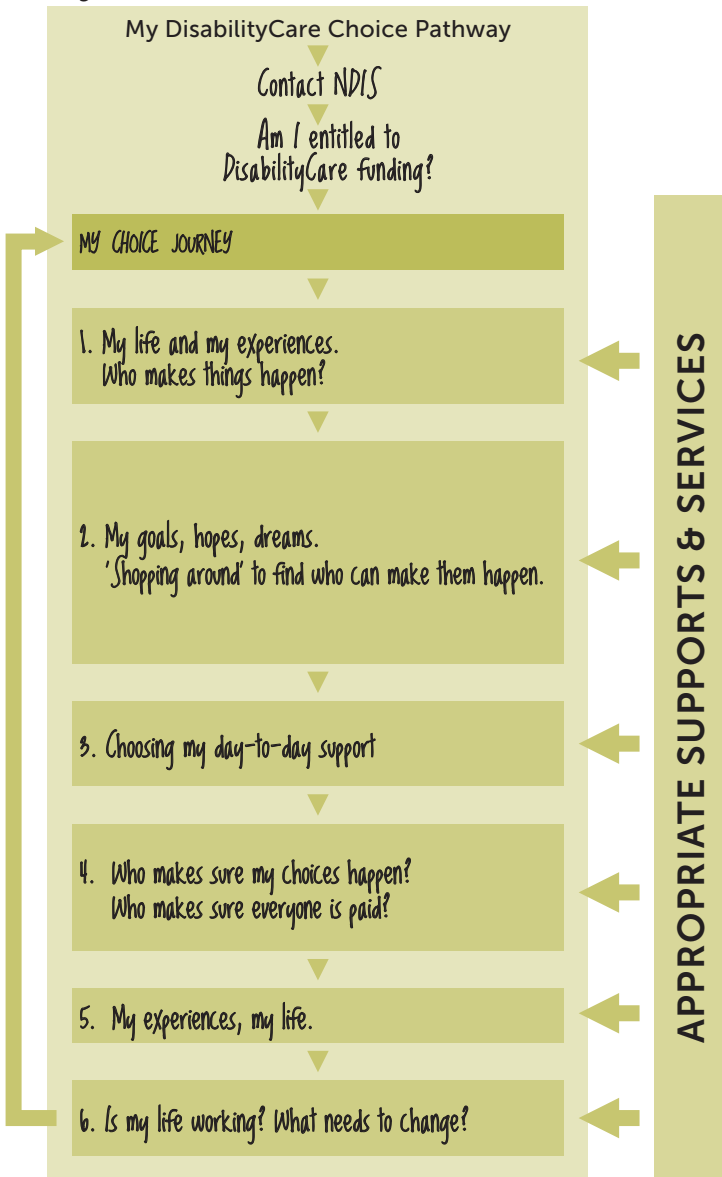
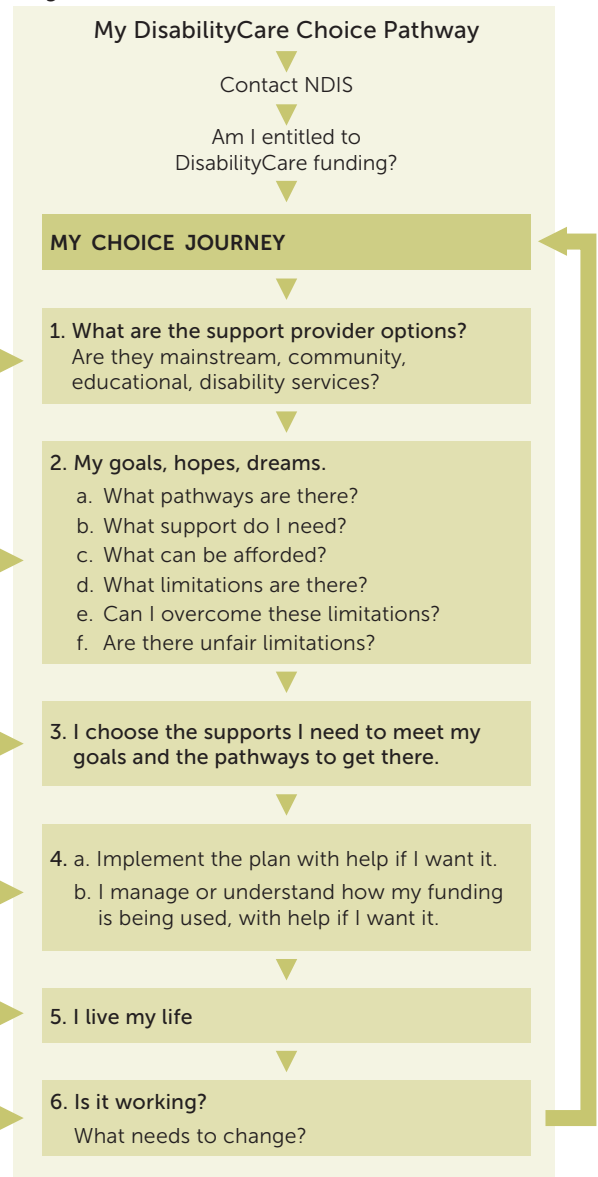


Diagram 2b



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

As this section of Choice for Disability Service Providers continues, tools that can be used to support choice-making will be referenced in connection with the project's accompanying choice-making resources. However, these tools are not prescribed. They are here to help you. Your organisation may use its own tools providing they reflect the principles of choice-making set out in this guide.

3.1 Stage 1 - What are the support provider options? Or my life, my experiences and who makes things happen?

Introduction:

This stage will culminate in an individualised planning meeting with the Local Area Coordinator (LAC) employed by DisabilityCare.

It is important to be well prepared when visiting the LAC.

The following chart sets out things that might be done prior to seeing the LAC for the *first* time.

As will be seen by the end of this resource, the next time and subsequent times a person sees the LAC there should be a significant amount of documentation which has been created since the last meeting. These will include, *inter alia*:

- The original DisabilityCare Individualised Plan agreed with the LAC
- A *Statement of Goals and Pathways* to accomplishing dreams with a timescale attached
- A *Statement of Roles and Responsibilities* - of the person, supports, the support provider, family and others in accomplishing the goals (including in relation to administering the DisabilityCare payment). This may include a *Support for Choice* list
- *Goal Mastery Assessments* about what has been achieved, how barriers have been overcome and what barriers remain - these are key documents about the monitoring taking place by support providers and consequent adjustments
- 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
- A *New Opportunities List* that shows what has been tried as a means of expanding the person's choice options with commentaries on what has and has not worked
- A *Statement of Capabilities and Outcomes* - what capabilities have been addressed and what outcomes there have been
- A *Statement of the Limitations on Experience* and commentary on limitations that are not reasonable or situations in which there have been compromises
- A *Personalised Human Rights Resource*
- An *Assessment of Human Rights Compliance* and what has been done to accomplish the person's human rights
- *Dignity of Risk Assessments*

Exercise

How would you presently advise a person with a disability about their service options if they inquired?

What is the difference under DisabilityCare?

How can your organisation prepare for this?

- A *Statement of New Pervasive Life Choice Issues* and statement from the support provider about their understanding of the person's *New Hopes, Dreams and Aspirations*.
- Evidence that efforts have been made to find support or develop the present support provider to deliver on pathways to accomplishing any new hopes, dreams and aspirations (see *Section 5.1*), i.e. a new *Life and Service review*
- Documentation relating to appointment of Guardian/Appointed Nominee/Advocate

However, the first time a person has an individualised planning meeting, a number of activities should have taken place.

Be prepared!

If you went into a travel agent not knowing where you wanted to go, how you wanted to travel, or where you wanted to stay the outcome would be more difficult to reach and may not reflect your wishes. The same is true when a person with a disability meets an LAC. The more clarity the person with a disability has, the better the outcome will reflect what the person chooses in their lives. You may have a role and duty to support that process.

It is proposed that a good starting point may be to adopt *The Three Ways*, these are to:

1. Identify Choices
2. Explore Capabilities
3. Undertake an Option Appraisal - My life and Service review.

Table 7 below sets out responsibilities, as well as activities and tools that may help.

TABLE 7			
LIST OF ACTIVITIES	WHO DOES WHAT	CROSS REFERENCE TO RESOURCES	TOOLS
Identify the <i>person's most important life choices</i> (including pervasive choices and <i>important</i> lifestyle and everyday choices)	Person with disability Family carer Support worker/ service manager Circle of support	Principle 1 - 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.	Good questions to ask might be: 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?
Capabilities (Things that help a person grow)	Person with disability Family carer Support worker/ service manager Circle of support	Knowledge Review - Section 5.1.2 <i>It's My Choice! 2: A Guide for People with a Disability, their Family Carers, Friends and Advocates</i> , Sections 4-6	<i>Appendix 1a - A Helpful Prompt Tool - Human Capabilities</i> shows some capabilities and describe what each one is.

Exercise

Think of a person for whom you provide services or support.

Write notes on their *pervasive* and important *lifestyle* and *everyday* choices.

List capabilities for that person using the capabilities tool.

Do you know this person well enough to support their choices? What more can you do to identify these choices?

By the end of the phase shown in *Table 7* it should be possible to have a good idea about:

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

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 of support 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 so that they can try new options. These new experiences will contribute to helping them make better choices about their future.

The next phase is to look at whether current services and supports are designed to provide a *pathway* to where the person wants to go. This is summarised in *Table 8* below.

TABLE 8: LIFE AND SERVICE REVIEW				
LIST OF ACTIVITIES	WHO DOES WHAT	CROSS REFERENCE TO RESOURCES	TOOLS	EXPLANATION
Identify services (disability, community, commercial and business, leisure)	Person with disability Family carer Support worker/ service manager Circle of support (Beware conflict of interest)	See <i>Knowledge Review 5.1.2</i>	See <i>Appendix 2b</i> (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 appears in <i>It's My Choice 2: A Guide for People with a Disability, their Family Carers, Friends and Advocates</i> , Section 6 Also download the <i>scorecard.pdf</i> at www.inclusionmelbourne.org.au/resources/choice	These will be services which may potentially deliver important life goals and capabilities.
Informal supports	Person with disability Family carer Support worker/ service manager Circle of support	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 above <i>It's My Choice!</i> tool to cover friends, family, community contacts and to rate as: - those with whom to Link (contact and meet) - Bridge (to establish a sustained contact) - Bond (to develop reciprocity in relationships) .	These are opportunities that might be linked, bridged, bonded, strengthened or maintained. They may include family, friends, community networks that can provide 'reliable assistance'

There are further issues that arise at this stage.

People with a disability and family carers who participated in our consultation were perplexed by the range of services and found it difficult to know how to get information about alternative services and their appropriateness, accessibility, acceptability and comprehensiveness. There were difficulties in finding information and discerning the supports that each service provided.

Exercise

Think of a person for whom you provide services or support.

How well do you know the disability, community, commercial, business, and leisure services that have been called upon to meet the client's chosen pathway?

How familiar are you with the informal supports provided by people such as family, friends, and circles of support? How far have you sought to tap into natural supports that reflect the pathways and choice of the person?

[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 is it 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)

This is an important area that needs to be developed and those services involved with a person should seek to support them to find and try other support providers that better meet their needs. The problem in these situations is the *conflict of interest* that arises. In other countries brokerage agencies have had a major part to play in matching services to people's stated goals.

The idea that people try new support providers is really important otherwise they will not be able to make informed choices between the support options. This is why the process described above must be *ongoing*. Choices are not singular and one-off. As argued in **Principle 9**, choice is a journey and not simply a one off expression of preference.

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

Timing is critical – people go into panic mode at end of schooling. [They should] start thinking a year earlier - [when there is] time to visit other places...

(Focus Group - Support Workers)

As well as the school-to-adult transition, 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.

Recommendation to DisabilityCare

A *New Opportunity Fund* should be set up to support people at times of transition so that they can plan and can make informed choices about their future services and supports.

Families, circles of support or microboards, advocates, Guardians and Plan Nominees should be making their own judgements about whether services are indeed moving a person towards their chosen goals and capabilities.

No person should be so isolated that their present support provider has the power to control all decisions about their future supports. The LAC will have a key role to ensure that recommendations about how services reflect a person's goals do not privilege sole providers who act as monopoly providers over a person's life. It may also be useful to involve independent advocates in such situations of monopoly.

A decision should be made in consultation with the person about who should attend any meeting with the LAC. 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.

There may also be documents produced by the person and their family and friends as well as those produced by the service provider. More will be said of these documents later.

Exercise

Considering the information found in Section 1-3.1 of this Guide, how can your organisation adapt its policies to reflect the requirements set out in this material?

How might you prepare for the meeting with the LAC? Who would you involve?

3.2 Stage 2 - My goals, hopes and dreams

Introduction

As seen in *Diagram 2a*, this stage is one in which the work of the LAC links hopes and dreams to services that aim to fulfil these dreams in a planned step-by-step way. This part of the cycle includes consideration of:

- a. What are the person's hopes, dreams and goals?
- b. What are the pathways and steps to goals?
- c. What support does the person need?
- d. What can be afforded?
- e. What limitations on experience are there?
- f. Are these limitations on experience fair and legitimate?

Individualised planning

The centre-piece of identifying goals, hopes and dreams is the person centred and individualised planning process which is covered in other DisabilityCare resources. The individualised or person-centred planning process is of course closely allied to choice, the focus of this document. Organisations will have their own expertise around this form of planning, however they should review the available approaches to individualised planning and ensure that the principles and methods recommended in relation to choice-making feature in the methods they adopt.

It would be fair to say that work that the person, their family and friends or that you yourself have previously undertaken 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 and about those which can be bought through DisabilityCare funding. The LAC should also have been given the information from *The Three Ways* which was covered in the previous section.

It is recommended that the LAC have an advisory role in relation to the 'acceptability' of any proposed plan, that they assess that a proposed plan 'demonstrates sufficient aspirations for change' and ratifies 'the proposed pathways to accomplishing stated goals'

Exercise

What system of individualised planning does your organisation use?

How does the system find out about a person's hopes, dreams and wishes?

Has your organisation undertaken a recent review of individualised planning resources and approaches?

However, there are a number of working principles that underlie this part of the DisabilityCare pathway:

- 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 this 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 supports 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 systematically.

As will be seen in the sections to follow, there are ways in which support providers 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 individualised planning must be identifying the steps that are being taken to get the person to accomplish their chosen dreams.

Taken together, these steps **MUST** make a pathway to their chosen goals. They **MUST** specify what targets are going to be reached *in a specified time* and they **MUST** be based on what is *realistic, practicable and achievable*.

As shown in *Diagram 1* earlier the steps may be small. But they must be realistic and take into account barriers to experience. The support provider *should be judged* against the *movement the person has made towards his/her goals*.

It should not be acceptable for a person to be occupied in the same 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.

It is also 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 services which 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*. 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 the LAC should also have a role in identifying and reporting to government and the advocacy sector those limitations to experience that are not 'reasonable'.

Exercise

Think of a person with a disability for whom you provide services or support.

Use the bullet point list to the left to build a strengths-based description of the person, recognising that some strengths will be hidden if a person is not in their optimal environment. How does your list differ from what is presently in the person's case notes?

How might you use the new information on page 24 of this Guide to support a better pathway to the person's chosen goals?

Exercise

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 should be identified. The supports provided should be judged against these goals.

How well are these ideas reflected in your organisation?

Earlier, the limitations on choice experiences were discussed (*refer to Principle 6*). We undertook a review of literature around choice-making and lists were made of the identified limitations on choice and the approaches used to address these limitations.

The resultant tool (*Appendix 1c*) that may help you and your organisation think through what limitations on a person's experience are indeed relevant and, additionally, some strategies that can be used to address these limitations. The list is not exhaustive but it can be built upon and added to over time as you experience more issues that challenge a person's choice making.

A central question is therefore what constitutes either legitimate or non-legitimate limitations on experience (*Choice Principle 6*). *Table 9* below lists the activities, responsibilities and tools that may be used at this stage of the process.

TABLE 9: 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 achieving 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 - The Three ways	See previous section	LAC considers the link between hopes, dreams and services and the identified steps on the path to dreams
Funding level	LAC reports	Not covered in these resources	Not covered in this resource	DisabilityCare 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: 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</i>	<i>Appendix 1c</i>	No one is completely free to choose. However, it is important that any limitations are explainable, just and legitimate.
Feeding back to government to meet requirements of CRPD and to systemic advocacy groups.	LAC	Not covered in this resource	To be developed. A computerised system would be very useful	Not covered in this resource

Exercise

Think of a person for whom you provide services or support.

Use Appendix 1c to explore the limitations on this person's life experience.

What can be done to address these identified limitations?

How might you overcome long held beliefs about a person's capabilities? Use your list of strengths developed in the previous exercise.

Who should be involved? How can these people and organisations be mobilised?

3.3 Stage 3 - Choosing my day-to-day supports to meet goals and pathways

Introduction

The success of DisabilityCare will be closely related to the extent to which changes to supports are in the control of people with a disability and those who manage their funds.

The system is likely to be homeostatic, that is, *self-righting*. This is so because funds spent which do not deliver suitable services or which turn out to be too expensive, will lead to changes to supports that have better outcomes for the person. 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.

It is therefore in the interests of services to ensure appropriate and high quality support. Another DisabilityCare resource called *Making it Work: A workforce guide for disability service providers (2013: Laragy (RMIT University), Ramcharan, Fisher, McCraw, Williams)* is available that discusses these issues further. Where possible the person should be actively involved in the recruitment of their personal support and should have power through the individualised funding arrangement to make changes when they see a need to do so. This begs questions about how to choose that support and, additionally, what categories of supports are identifiably necessary – this area is not covered in this resource.

The type and level of support will be dependent upon a number of factors: the extent to which the person is able to pursue their own choices independently; the number of people involved in the person's life including family, friends, advocates and, in some circumstances Guardians and Plan/Correspondence Nominees. The level of support required is in some way contingent and not necessary. Finding the right support may therefore take some trial and error.

Support for choice-making can take place in a number of ways as shown in *Appendix 1d*. This guide is meant only to explore support around the choice-making process, and not the other aspects of support.

Appendix 1d shows that the role of support may be:

- in making sure the person's choices originate from them (*see next section*);
- in applying supported decision-making (supporting access to various supports, services and experiences and hence supporting informed choice-making);
- in accessing resources (funds, transport and so forth);
- in the actual accomplishment of the choice (e.g. supported employment, support with a sport).

On the basis of the identified choice-based support needs, the support worker may need to train others (or be trained) in areas in which they require expertise, for example with communication devices. All of this may take place in a context of personal care and practical support or other areas in which choice-making takes place in a comfortable backdrop.

Exercise

Think of a person for whom you provide services or support.

Use *Appendix 1d* as a tool to explore who is involved in supporting the person's choice-making. Are family, friends, advocates or others involved? Could they do with any further support in their role?

Think back to the pathway that may achieve this person's goals. What are the specific tasks, roles and processes with which you might be involved in supporting this person's choice-making?

In making your decisions have you made sure that the person is as autonomous and self-determined as possible?

Is there a conflict of interest in any decision-making? Does the person need an independent advocate?

Principle 7 says that support should be used to the lowest degree necessary to allow the person autonomy and self-determination. However the principle also points to the need for advocacy and for forms of substitute decision-making at times. In making a decision to appoint a Nominee or a Guardian the NDIS Act (*Sections 86 and 87*) empowers the CEO to appoint Plan or Correspondence Nominees. A series of rules is proposed in the appointment of such nominees which reflects **Principle 7**. More is said of these rules in *It's My Choice! 5: A Knowledge Review*. However it is vital that such nominees pay close attention to the person and their family and friends.

Table 10 below lists the activities, responsibilities and tools that might be used at this stage.

TABLE 10: CHOOSING DAY-TO-DAY SUPPORT				
LIST OF ACTIVITIES	WHO DOES WHAT	CROSS REFERENCE TO RESOURCES	TOOLS	EXPLANATION
Involvement 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: Principles of Choice, Principle 7</i> <i>It's My Choice! 5: A Knowledge Review, Section 5.3</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; the resultant services and supports will be better rated. When a person has power to change their supports, the support provider 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: Principles of Choice, Principle 7</i> <i>It's My Choice! 5: A Knowledge Review, Section 5.3</i>	Support for Choice-making tool, <i>Appendix 1d</i>	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: Principles of Choice, Principle 7</i> <i>It's My Choice! 5: A Knowledge Review, Section 5.3</i>	See Diagram in <i>It's My Choice! 1: Principles of Choice, Principle 7</i> as a guide to advocacy and support.	When, despite all best efforts a person is unable to speak for themselves and there are no <i>de facto</i> 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.

3.4 Stages 4 and 5 – Implementing the plan and living my life

Introduction

Once decisions have been made by the LAC the work begins of implementing the plan. This will initially be a stage of high activity and engagement putting in place those programs, people and services that will deliver the desired outcomes on the pathway to a person's goal in an agreed time-frame.

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 time frame. Because of this it is absolutely vital to do things which 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 regularly made aware of the connection between the ordinary things they may be doing every day 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 the right 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 to do things that are consistent with their ultimate goals. Their role may also be to advocate for the person where the person cannot speak for themselves or to organise independent advocates or others to do so in some circumstances.

Plans will not move forward as well as they might if the skills of all relevant people in a person's life are not being accessed and used in a team effort around agreed roles.

For those who provide formal services this stage will entail *providing support to accomplish choices* as well as making *regular and formal appraisals of successful moves along the pathway to accomplishing goals*.

This stage will therefore require knowledge of when a supports are needed and a recording and review process to monitor the effects of the support provider. 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 their *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, and strengths and ensure that these are recorded 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 - goal mastery - the need to review regularly 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 *one of action to achieve goals*. The activity in this stage will also 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.

Responsibilities of services

The formalities of implementation from a service perspective are now considered in more detail.

Earlier it was suggested 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 which 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 is shown in *Appendix 1e* (see *Ramcharan, 2012*).

First, it is vitally important to ensure that at all times the approach is strengths-based and that all labels are positive as described earlier. All too often negative labels have become self-fulfilling prophecies. The 'difficult client' is treated as such and in being treated in a particular way comes to act out in that way confirming the original label.

As well as building a strengths-based approach in the present it may also be important to *reclaim identities*, to repair *damaged reputations*, to produce an identity more complete in its reflection of the complexity of the person and their unique history. Records should be positive and celebrate the uniqueness of the person. Efforts should be made to understand the person; what motivates them, and what history tells us about what they enjoy. Over time such information can collect into quite a substantial resource. And this resource can provide important clues about what the person's preferences might be.

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 (things that the person wants or does not want that are not open to negotiation) developed over time can represent a significant *personalised human rights resource*. Having such information can tell you where support itself does not respect these. It therefore places the responsibility upon those who provide support to work in ways that recognise the person's rights. All support workers should be (made) aware of each person's *personalised human rights resource* (*Appendix 1e*). This should be part of any individualised plan and should be widely known and understood amongst those providing care for the person.

Exercise

Think of a person for whom you provide services or support and who has a behavioural support plan.

What reputation does the person have?

Have you explored the person's life history? Do you know the important and positive people and things in their lives over the years?

How can you explore this more without invading the person's privacy?

Use the Personalised Human Rights Resource (*Appendix 1e*) to examine the person's own chosen rights.

Has this changed the service and supports you deliver? Has it helped share information with others who are important in the person's life?

How can you construct a more strengths-based and positive identity in your notes about this person?

As well as individual rights it is also vital to ensure the wider human rights set out in the CRPD are being fulfilled. By looking at the wider human rights picture it may be possible to explore more choices and options on behalf of the person and, indeed, to explore what barriers there are to their accomplishment (**Principle 5**).

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. A tool to help with this is presented in *Appendix 2, (Ramcharan, 2012)*. It is possible to superimpose the principles wheel over the human rights articles wheel. Questions can then be asked about which articles are at issue, which principles are at issue and what can be addressed to fulfil, protect and defend the person's human rights.

The first principle of the CRPD relates directly to choice and a person's autonomy. So, from a choice-making perspective, keeping notes of these human rights assessments can be important. It might help a person explore new possibilities or new ways of achieving the goals. 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 associated *goals and dates* that move the person towards *defined outcomes* 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*.

Services need both an authorising environment capable of doing this and they also need to be adaptable. Those services best able to adapt in the DisabilityCare market are likely to be the services which ultimately gain a greater market share. CEOs and Boards need to be aware that they will be judged against their achievements for each individual.

One of the very telling issues in our interviews was the extent to which services 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 formal services seek to reduce risk for older people to 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*.

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.
(From Ramcharan 2012, p132)

Taking away risk is therefore deleterious in a multitude of ways.

Exercise

Are you a human rights-based service?

Think of a person for whom you provide services or support.

Use Appendix 1f to examine whether the CRPD Articles are being fulfilled.

When you identify areas that need improvement, take note of the CRPD articles and Principles of Choice that are involved then formulate a plan for making sure these rights are fulfilled as part of the process of delivering support.

How will this approach benefit the person? How might using this approach benefit the provider for which you work?

Ramcharan (2012) points to some approaches to risk that may help:

The first problem is that a target goal may seem hugely risky. However, when broken down into smaller more manageable steps it may become less scary as a service strategy. More fundamentally, there are a few further possibilities.

Related to the first problem above is the propensity of services 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 an elimination of hazard culture.

Another issue is that risk is sometimes applied to groups rather than in relation to an individual's choices. A locked house may not be appropriate to all residents and yet all may suffer this sort of restriction of their freedom to move. It is therefore essential to ensure that labelling and 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 not very often clear what benefits have been considered against the level of risk. The balance of risk against benefit is mediated in large part by a service's concept of autonomy, i.e. that the person has freedom to choose whether to take the risk as a reflection of social justice, i.e. in being equally applicable to all in similar circumstances.

(Beauchamp and Childress, 2008)

Taking away people's rights to express their choices produces resentment and breaks the *trust* that is so necessary between those who provide supports and the person receiving those supports.

Table 11 sets out the activities and resources that can be used at this stage:

Exercise

Think of a person for whom you provide services or support.

Is there any hazard avoidance that challenges a person's right to choice in your organisation?

Are there any risk assessments in place for the person?

Is the person experiencing any *blanket policies* that affect their choices?

Can you think of a client who has a dream for which the risk is considered too high?

Have you thought of whether the benefits outweigh the risks?

Have you thought of ways of breaking the risk into smaller parts and dealing with each part in turn?

How can you produce growth for this person without taking risks?

TABLE 11: 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 a service	See <i>It's My Choice! 5: A Knowledge Review</i> , Section 5.4	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> See <i>It's My Choice! 5: A Knowledge Review</i> , Section 5.4	Tool: Personalised Human Rights Resource, <i>Appendix 1e</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 <i>It's My Choice! 5: A Knowledge Review</i> Section 5.4	Tool: I RAN FREE and Circle of Human rights, <i>Appendix 2</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 <i>It's My Choice! 5: A Knowledge Review</i> , Section 5.4	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 or collective risk - Risk is about autonomy and choice, about social justice as well as growth.	Many support providers are risk averse. A new way of looking at risk is ensuring 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 <i>It's My Choice! 5: A Knowledge Review</i> , Section 5.4	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 traditional disability services 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 <i>Table 9</i> above <i>It's My Choice! 5: A Knowledge Review</i> , Section 5.4	See <i>Table 9</i> 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.

3.5 Is it working?

For the person this is about looking back at how their life has been. It is also about how to continue towards achieving their goals. Reflecting like this is part of life. But sometimes it is important to take stock; it is important to talk with trusted friends and relatives; it is important to once again start confirming how well life has treated you, to celebrate successes and to think about how to push on towards long term goals and dreams.

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 the documents listed on pages 19-20 of this Guide.

It will be possible with all these documents for you as a service to start the individualised planning process discussed earlier and to once again start looking for support providers that reflect the person's goals and the support providers capable of *moving them to the next stage*. *Table 12* summarises the activities that might take place at this stage.

TABLE 12: 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 in <i>Appendix 1f</i>	
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 and activities and notes developed around the person's choices and preferences and recommended in this resource.	All those mentioned in 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. Whilst choice-making is ongoing this step provides an opportunity to take stock and make adjustments and changes to improve the person's life and outcomes and achieve their goals and choices.

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 any report to the LAC is set aside for any limitations that cannot be resolved and non-legitimate limitations to experience which need to be addressed. This may mean changing goals with the person's consent or adapting the number of steps towards the goal. The report should also focus on the service'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 systemic advocacy organisations and that individual or self advocacy can be offered where these are relevant and where the person wishes.

The support providers 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. One such chart designed for people with a disability and family carers is set out in *Appendix 1f. Table 12* also highlights who does what at this stage and points to tools and resources which may be useful. If planned, the work done consistently over the period since the previous individualised planning meeting or review should automatically feed straight back into the next meeting with the LAC.

Exercise

Think of a client for whom you provide services or support. Imagine you are nearing a review or another planning meeting with the LAC.

Who have you involved in discussions that take stock of the person's life?

What documentation have you put together to reflect the part you have played in this person's life?

Go back to Exercise 1 and work your way through this resource again, exercise by exercise. This will provide substantial input into the task of ensuring that the people you support achieve their dreams.

4. Conclusions

It is hoped that this guide has provided some useful tools and ideas that will support you to focus on a person's choices at varying stages of the DisabilityCare Service Pathway.

The tools are meant to be instructive and not prescriptive. You may have different tools that you are more used to.

However, it is advised you do look to see whether your work does fit with the Principles of Choice detailed in this guide and in *It's My Choice! 1: The Principles of Choice*.

We hope in some small way to have made your role as support providers or support workers easier and more fulfilling.

Most of all, we hope that by using this guide you will have improved the lives of people with a disability whose personal choices are so vital.

Appendices

Appendix 1a

A Helpful Prompt Tool - Human Capabilities

Each person is different and each person has different potential. To achieve these capabilities is what makes the journey of life interesting, liveable and meaningful. The capabilities below have some overlap with human rights and with *pervasive* and *lifestyle* choices also. But it is worth thinking about whether each person is moving forward in each of these capability areas. Those identified and used below have been taken from Martha Nussbaum's work (see *It's My Choice! 5: A Knowledge Review*) and described from Wikipedia.

CAPABILITY	EXPLANATION
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
Bodily health	Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter
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.
Senses, Imagination and thought	Being able to use the senses, to imagine, think, and reason; 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.
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.
Practical reason	Being able to form a conception of the good and to engage in critical reflection about the planning of one's life.
Affiliation	Being able to live with and toward others, to recognize and show concern for other humans, to engage in various forms of social interaction; 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.
Other species	Being able to live with concern for and in relation to animals, plants, and the world of nature.
Play	Being able to laugh, to play, to enjoy recreational activities.
Control over one's environment	Being able to participate effectively in political choices that govern one's life; work, property and with physical surroundings.

Appendix 1b

Identifying and rating potential services

RATING SERVICES	PRESENT SERVICE	SERVICE B	SERVICE C
What need will this service fill on the pathway to goals?			
Has this service delivered or failed to deliver in the past?			
What is the cost?			
Is it accessible?			
Are additional supports required?			
Is the service available?			
What is the cost of the service?			
What cost are any additional supports?			
Will this service treat me with dignity and respect. Do I trust this service?			
Is additional training required (e.g. travelling, budgeting)			
Who will administer the budget?			
What sort of service is this? (government, NGO, commercial)			
Is it likely to fit with DisabilityCare service criteria?			
How will this choice affect the family?			
Is the person happy in the present service(s) they use? (present service(s) only).			
Is any dissatisfaction open to being resolved? (present service(s) only).			
Is the person growing in this service? (present service(s) only).			
Can the issues about personal growth be resolved within this service? (present service(s) only).			

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

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



Appendix 1c

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"> - Reconsider level of assessed need against funding available - Consider the human rights implications, especially economic, social and cultural rights - Inform systems advocacy and government department of shortfall
2. CONFLICT		
a) Family/service disagree with person's choice	Reasonable in some circumstances - 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 service/family and the person wants in accordance with human rights?</p> <p>Is the objection to this choice to do with the family's or service'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 records can build significant resources. These would also significantly help Plan and Correspondence Nominees appointed under Sections 86 and 87 of the NDIS Act or any other person who acts as Guardian. 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>

Lack of resources – It's no good having a great vision but no support.

(Focus Group - Support workers)

You need to also get to know the families.

(Focus Group - Support workers)

[One] difficulty [is the] language barrier. It was difficult to communicate with [the] family so we got other services involved that [the] family trusts.

(Focus Group - Support workers)

LIMITATION	REASONABLE?	APPROACH TO RESOLVING THE ISSUE
3. STRUCTURAL		
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) No relevant service	Not reasonable	Ask present services if they can adapt for the person. If not, use brokerage agencies to search out services that might provide or develop to meet the person's need. 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 DisabilityCare criteria	Reasonable	Raise questions about how such services might be brought under the DisabilityCare umbrella.
4. SERVICE-RELATED		
a) Risk management	Can be reasonable	Make sure risk is not 'hazard assessment'. 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 disability. It may be possible to move beyond participation to co-production.
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 choices 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, 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 are vital to produce as normal and enriched life as possible. They should be provided.
f) Low quality service or support	Not reasonable	Address with service 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, 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 service was not appropriate during the timeframe then seek new service 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.

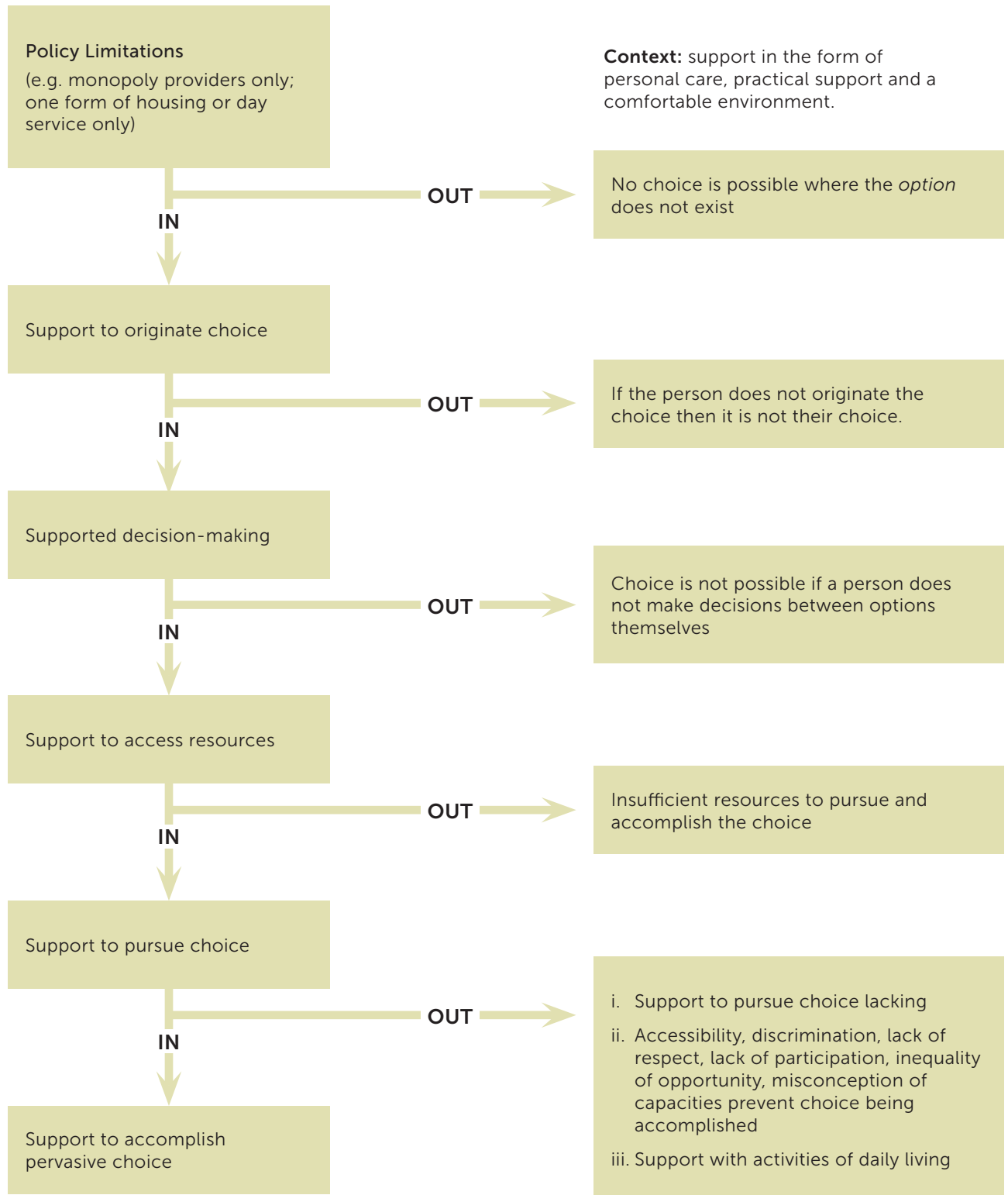
LIMITATION	REASONABLE?	APPROACH TO RESOLVING THE ISSUE
6. PERSON'S ABILITY/CHARACTERISTICS		
a) Education/ Intellectual ability	Reasonable in certain circumstances only	If education and intellectual ability are seen as preventions to moving forward then break the steps on the pathway down into smaller parts so there is movement to the goal or adapt the 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 using 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.
j) 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.
k) 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.
l) Age appropriate	A concern	Support new identity through engagement with any age appropriate choices and make links with <i>lifestyle</i> choices
m) Gender appropriate	Not reasonable	Equal opportunity should be afforded to both men and women (<i>Article 3 of the CRPD</i>)
n) 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

There is no use having rhetoric of choice if still constrained by same systems.

(Focus group - Support workers)

Appendix 1d

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



Appendix 1e

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
PERVASIVE LIFE CHOICES		
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?		

NON-NEGOTIABLES (EXAMPLES)	HOW SUPPORTED TO ACCOMPLISH?	NOTES
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?		
LIFESTYLE AND EVERYDAY CHOICE MAKING		
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....		

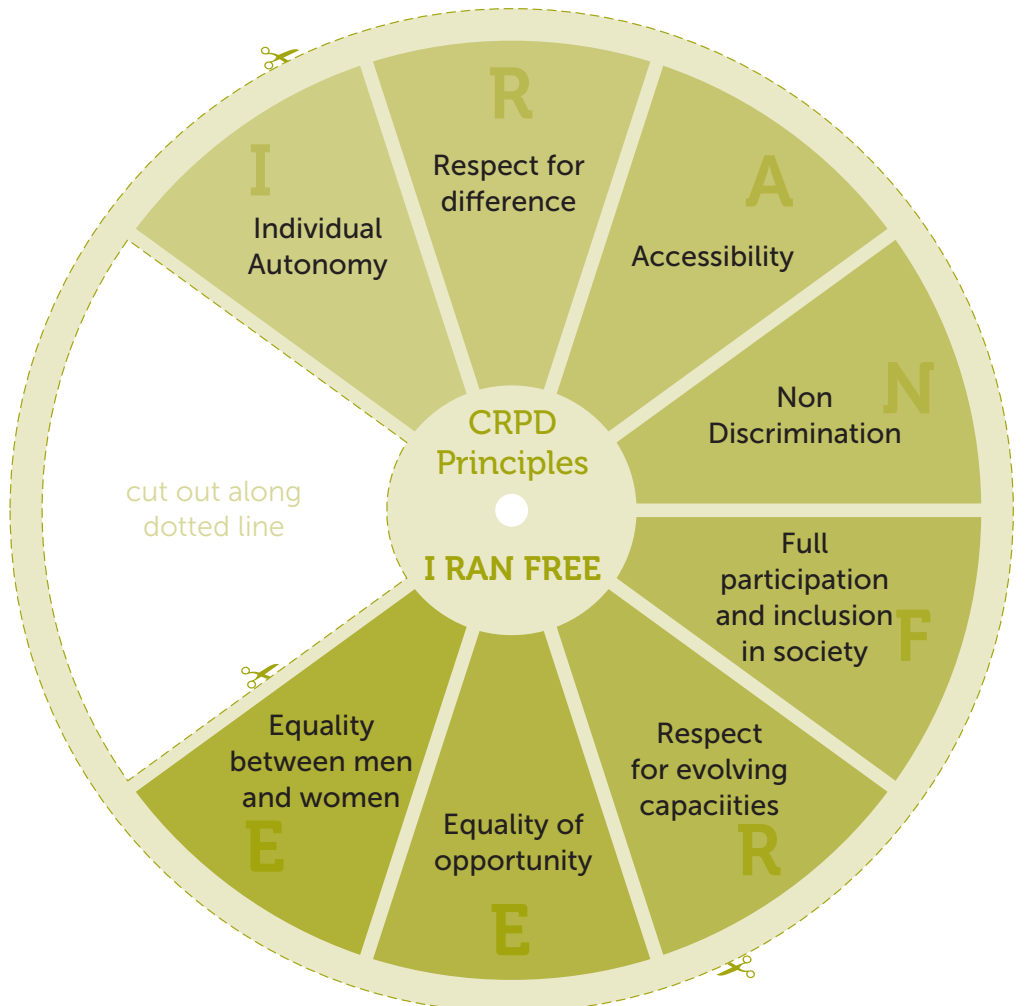
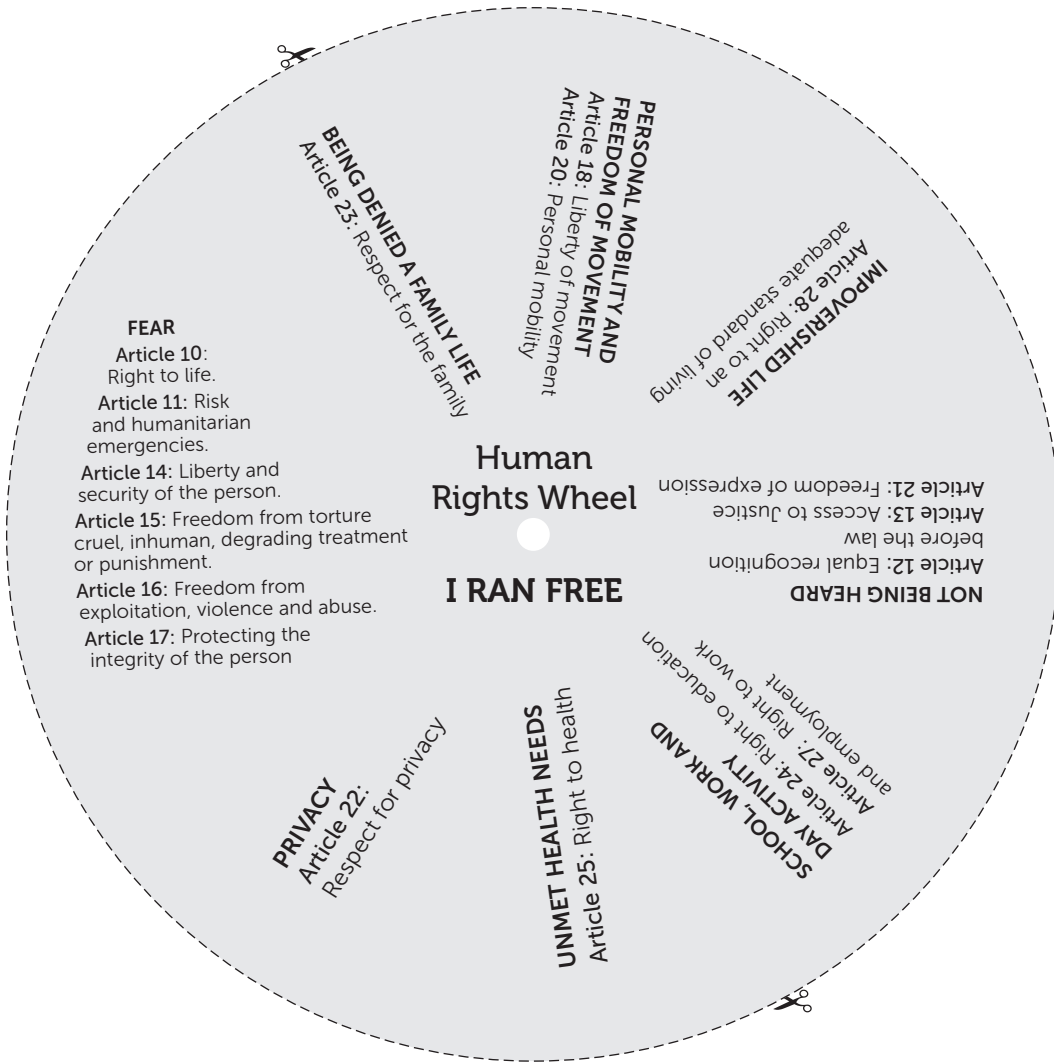
Appendix 1f

Rating your life prior to a review meeting

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

Appendix 2 The Human Rights Wheel and Principles of Human Rights Wheel

Ramcharan (2012) has proposed the following as a quick way of examining human rights compliance and thinking about how to expand opportunity structures. The Principles wheel can be placed on top of the Human Rights Wheel. First question what human rights are not being fulfilled and then examine which principles apply to the person's life, to situations or circumstances. This will give you an assessment of human rights shortfalls in terms of principles and CRPD Articles.



Instructions:

Cut out each wheel along the dotted lines, and placing the green wheel on top of the grey wheel using a pen or paperclip in the centre so they spin freely.

Appendix 3 - Exercises

Page 9

Can you think about how *everyday*, *lifestyle* and *pervasive* choices may apply to the persons for whom you provide services or support? Are there any inconsistencies between the areas of choice in their lives? How can these be resolved?

Page 10

Choose a person for whom you provide services or support:

Is the person showing different reactions to different environments? Are some reactions negative? What is the person communicating to you?

What can you do to reflect ideas that have originated with him/her?

Think of situations in which a person has become enthused about something they have chosen to do. What examples can you point to?

Have you introduced a new experience for which a person has demonstrated enthusiasm and a desire for further engagement? Could this be accomplished?

Page 11

Think of a person for whom you provide services or support. Answer the following questions in relation to one of their **pervasive** rights (e.g. where they live, education, employment, health).

If this person were to be asked to make a choice for the future in relation to this pervasive choice would they be able to do so *based upon their past experiences*?

How might you plan for the choice to be more informed? What sort of plan would help in supporting the person to make their choice informed? How much time would it take to expand their experiences?

Page 13

Think about a person for whom you provide services or support.

What do you see as the main limitations on this person's choices and experiences?

Use the I RAN FREE principles to consider whether the limitations are legitimate or not. How would you address these limitations?

If you cannot overcome these, then what recommendations would you be making for this person in terms of new services, new life experiences, new opportunities?

Page 15

Think of a person for whom you provide services or support who does not communicate verbally.

Is there anything more you can do to support communication with this person?

If not, how much do you know about this person, their indicated preferences, their history and experiences?

How would you advocate for this person given what you know about them? What more would you need to know to advocate more confidently? How might you involve others in supporting decision-making, choices and plans?

Is any of your support competency-inhibiting? In what way? How might this be addressed?

Page 16

Think of a person for whom you provide services or support.

Can you think of something that this person has expressed a desire to do? If they cannot speak for themselves have you discovered something from their life that will give you a clue about the things they might enjoy or grow from? Can you identify a potential area of growth from the capabilities framework?

You know the person's wants or have made an educated guess. Now explain what the person needs in order for them to achieve these.

How will you break this down into smaller steps? How long do you estimate the process will take? How will the person grow after taking each of the smaller steps?

Page 19

How would you presently advise a person with a disability about their service options if they inquired?
 What is the difference under DisabilityCare?
 How can your organisation prepare for this?

Page 20

Think of a person for whom you provide services or support.
 Write notes on their *pervasive* and important *lifestyle* and *everyday* choices.
 List capabilities for that person using the capabilities tool.
 Do you know this person well enough to support their choices? What more can you do to identify these choices?

Page 21

Think of a person for whom you provide services or support.
 How well do you know the disability, community, commercial, business, and leisure services that have been called upon to meet the client's chosen pathway?

Page 22

Considering the information found in Section 1-3.1 of this Guide, how can your organisation adapt its policies to reflect the requirements set out in this material?
 How might you prepare for the meeting with the LAC? Who would you involve?
 How familiar are you with the informal supports provided by people such as family, friends, and circles of support? How far have you sought to tap into natural supports that reflect the pathways and choice of the person?

Page 23

What system of individualised planning does your organisation use?
 How does the system find out about a person's hopes, dreams and wishes?
 Has your organisation undertaken a recent review of individualised planning resources and approaches?

Page 24a

Think of a person with a disability for whom you provide services or support.
 Use the bullet point list to the left to build a strengths-based description of the person, recognising that some strengths will be hidden if a person is not in their optimal environment. How does your list differ from what is presently in the person's case notes?
 How might you use the new information on page 24 of this Guide to support a better pathway to the person's chosen goals?

Page 24b

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 should be identified. The supports provided should be judged against these goals.
 How well are these ideas reflected in your organisation?

Page 25

Think of a person for whom you provide services or support.
 Use *Appendix 1c* to explore the limitations on this person's life experience.
 What can be done to address these identified limitations?
 How might you overcome long held beliefs about a person's capabilities? Use your list of strengths developed in the previous exercise.
 Who should be involved? How can these people and organisations be mobilised?

Page 26

Think of a person for whom you provide services or support.

Use *Appendix 1d* as a tool to explore who is involved in supporting the person's choice-making. Are family, friends, advocates or others involved? Could they do with any further support in their role?

Think back to the pathway that may achieve this person's goals. What are the specific tasks, roles and processes with which you might be involved in supporting this person's choice-making?

In making your decisions have you made sure that the person is as autonomous and self-determined as possible?

Is there a conflict of interest in any decision-making? Does the person need an independent advocate?

Page 29

Think of a person for whom you provide services or support and who has a behavioural support plan.

What reputation does the person have?

Have you explored the person's life history? Do you know the important and positive people and things in their lives over the years?

How can you explore this more without invading the person's privacy?

Use the Personalised Human Rights Resource (*Appendix 1e*) to examine the person's own chosen rights.

Has this changed the service and supports you deliver? Has it helped share information with others who are important in the person's life?

How can you construct a more strengths-based and positive identity in your notes about this person?

Page 30

Are you a human rights-based service?

Think of a person for whom you provide services or support.

Use *Appendix 1f* to examine whether the CRPD Articles are being fulfilled.

When you identify areas that need improvement, take note of the CRPD articles and Principles of Choice that are involved then formulate a plan for making sure these rights are fulfilled as part of the process of delivering support.

How will this approach benefit the person? How might using this approach benefit the provider for which you work?

Page 31

Think of a person for whom you provide services or support.

Is there any hazard avoidance that challenges a person's right to choice in your organisation?

Are there any risk assessments in place for the person?

Is the person experiencing any *blanket policies* that affect their choices?

Can you think of a client who has a dream for which the risk is considered too high?

Have you thought of whether the benefits outweigh the risks?

Have you thought of ways of breaking the risk into smaller parts and dealing with each part in turn?

How can you produce growth for this person without taking risks?

Page 34

Think of a client for whom you provide services or support. Imagine you are nearing a review or another planning meeting with the LAC.

Who have you involved in discussions that take stock of the person's life?

What documentation have you put together to reflect the part you have played in this person's life?

Go back to Exercise 1 and work your way through this resource again, exercise by exercise. This will provide substantial input into the task of ensuring that the people you support achieve their dreams.



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ISBN 978-0-9922717-9-4



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