

Towards Recovery: Hope, Innovation, Co-design

Can choice be individualised?: Reflections on choice in an NDIS era

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Choice, control and self determination

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

(Convention on the Rights of Persons with a Disability 2006 - Article 3 General Principles).

2. Real choices – A recovery oriented mental health practice:

- supports and empowers individuals to make their own choices about how they want to lead their lives and acknowledges choices need to be meaningful and creatively explored
- supports individuals to build on their strengths and take as much responsibility for their lives as they can at any given time
- ensures that there is a balance between duty of care and support for individuals to take positive risks and make the most of new opportunities.

A national framework for recovery oriented mental health services: Guidance for practitioners and providers (2013: p.13)

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Presentation structure

- Background to the study and its outputs
 - Understanding the principles of Choice
 - Introducing ways to think about supporting the key concepts of a recovery model –
 - hope,
 - positive identity,
 - choice and control,
 - building a meaningful life
- (Oades and Caputi, 2011)

Study background



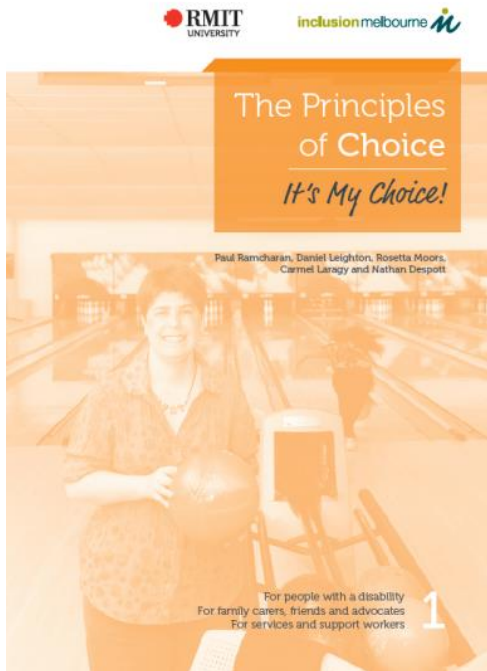
Project funding:

Funded by FaCHSIA, Practical Design Fund, to support the implementation of the National Disability Insurance Scheme– February to May 2013

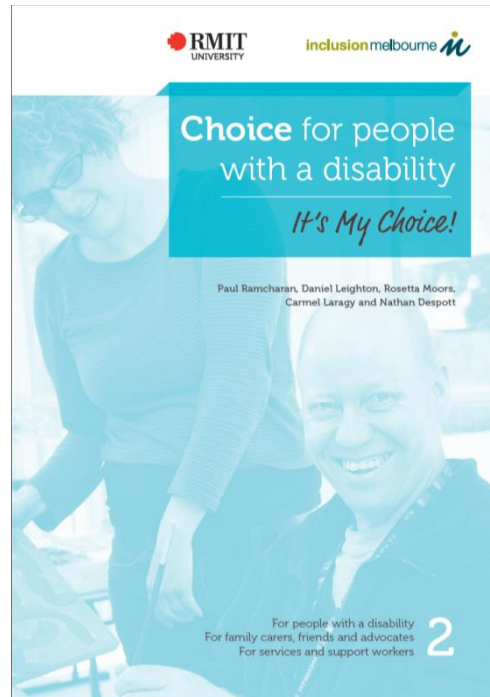
Publication:

Ramcharan, P., Leighton, D., Moors, R., Laragy, C., Despott, N. and Guven, N. (2013) ***It's My Choice Toolkit***. Melbourne; Inclusion Melbourne and Rnit University.

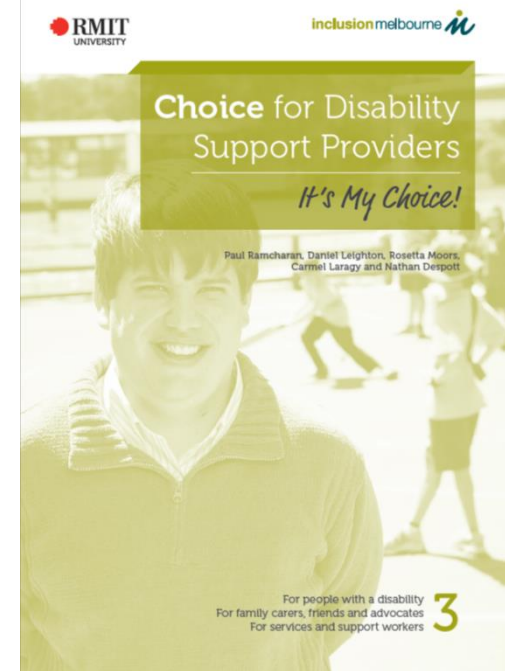
ISBN: 978-0-9922717-9-4



Resource 1
The Principles of
Choice



Resource 2
A guide for people
with a disability,
family carers and
friends



Resource 3
A guide for people
who deliver services
and supports to
people with a
disability

It's My Choice! Toolkit



In Sarah's own time

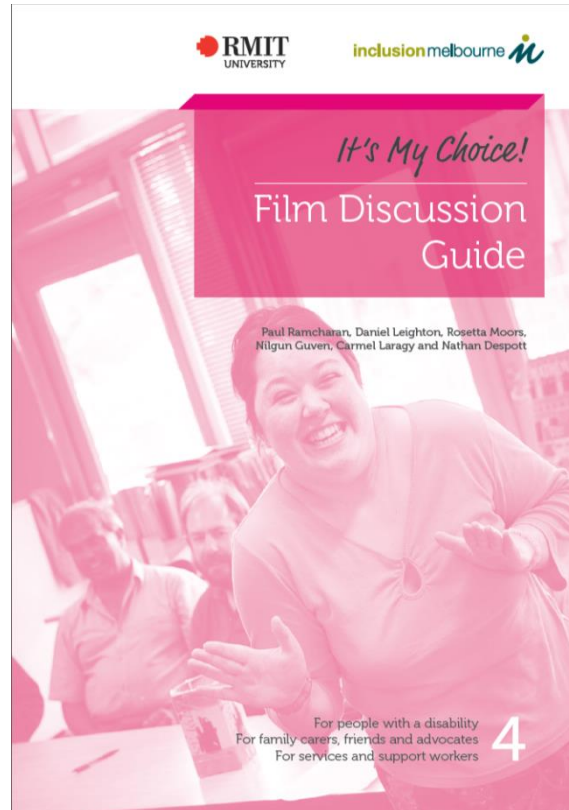


David's artful choices

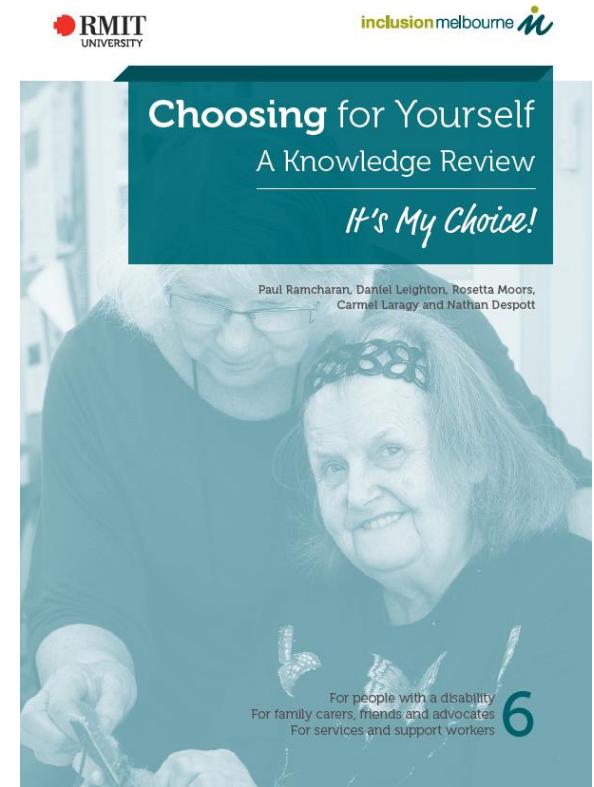


It's not that simple.

Resource 4
Three films on DVD



Resource 5
Film Discussion
Guide



Resource 6
Knowledge review

How the project was undertaken

- Knowledge review of academic literature and existing resources
- Interviews and focus groups with: People with disabilities, family carers, disability service managers and support workers.
- Advice from reference group on development of the resources
- Theatre producer and actors with disabilities workshopped scripts and ideas to represent levels of choices in short scenes to produce a DVD resource
- Professional review, editing and design to ensure 'fit for purpose'

Project Team:

Chief Investigators:

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Daniel Leighton, Inclusion Melbourne

Research Officer: Rosetta Moors, RMIT

Film Director: Nilgun Guven, FOG Theatre

Editor: Nathan Despott

Reference Group:

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Jen Hargrave, Women with Disabilities Victoria

John McKenna, Consultant and Advocate

John Chesterman, Office of the Public Advocate, Victoria

Stella Koritsas, Wesley Mission Victoria

Christina David, Doctoral student, RMIT University

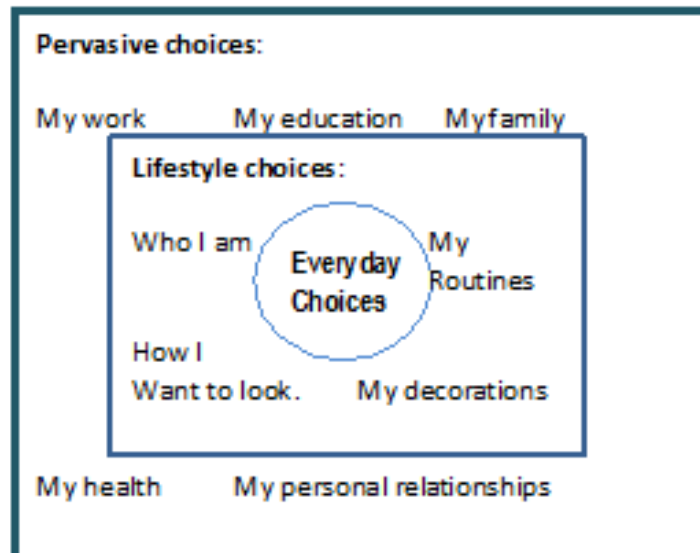
Choice is a 'comfort' term.

- It features in vision statements, policy documents and in practice-based resources without contention.
- Yet it is far from easy to implement.
- 'Choice' suffers from theoretical, practical and organisational problems, including:
 - The idea that people have *total freedom of choice* does not represent reality.
 - Different *levels of choice-making* are seldom taken into account in developing choice-making models.
 - Choice-making is not a single action but an *ongoing activity*.
 - *Disagreements* can occur between individual preferences and those of their family carers, friends and services.
 - There are potential differences *between what services can deliver, and what the person would like*.
 - The place of *human rights* in choice-making and the ways of ensuring both means and ends to choice-making are human rights-based have not been detailed.

Principles of Choice and Autonomy

- **Principle 1** - I have the right to make choices throughout my day. These are called 'mundane' or 'everyday' choices.
- **Principle 2** - I have the right to be who I choose to be. These are called 'lifestyle' choices.
- **Principle 3** - I can choose what I want, my hopes, dreams, and goals. These are called 'pervasive' choices.

Diagram 1: showing how pervasive, lifestyle and everyday choices should not contradict each other.



Sieve 1



OOPS!!

I have people telling me what to eat, what to do as if I do not have a mind of my own;

I have been offered services bore me and I'd rather spend the day doing other things

I have been told how to dress, not to dress in grunge style

I don't get time out when I want it

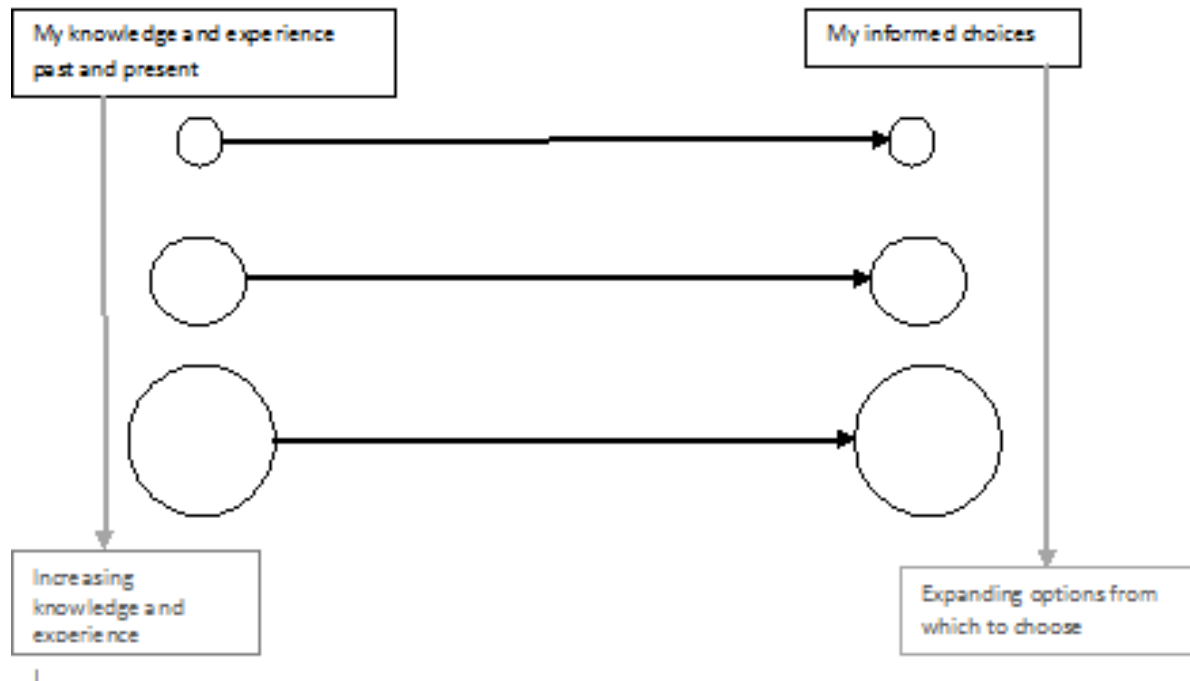
I do not get help with decision making so nothing gets done. Then I get criticised because nothing gets done.

Sieve out some of those choices will you? I don't really have them.

Principles of Choice and Autonomy (cont'd)

- **Principle 4** - 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.

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



Sieve 2



OOPS!!!

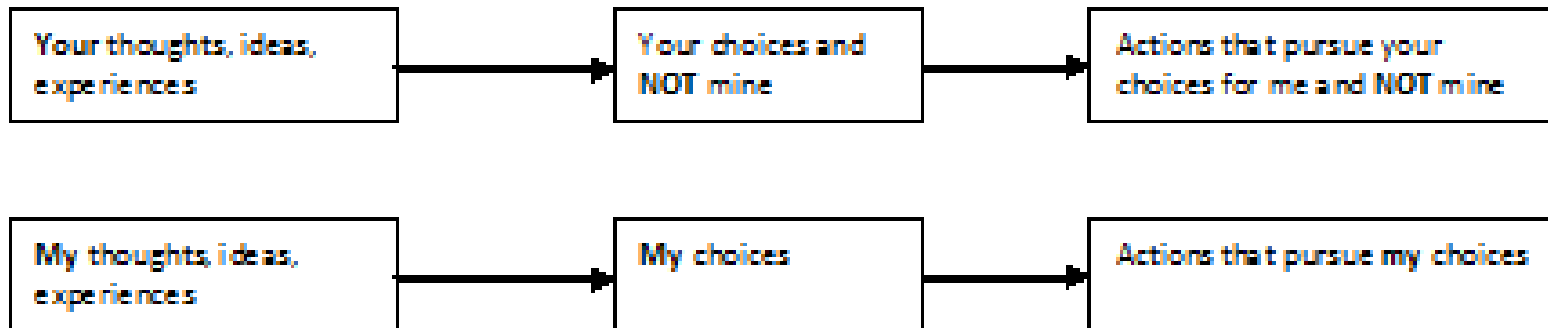
- My experience of the world is subject to the availability of support from others.
- I have not many resources to use in experiencing new things
- Nobody has ever asked me or supported me to do new things

Let's sieve out just a few more choices.

Principles of Choice and Autonomy (cont'd)

- **Principal 5** - All actions to pursue choices start with me. I am the source and *originator* of my own choices. Choice is diverse.

Diagram 2: The importance of 'Origination'



Sieve 3



OOPS!

- I have so many people telling me what I can and cannot do
- I am not able to change things anyway. I am not in control of the agenda of choices
- My experiences have already been impoverished (as you have seen)
- How can I be myself if there is no-one there to support my ideas about being what I want to be?

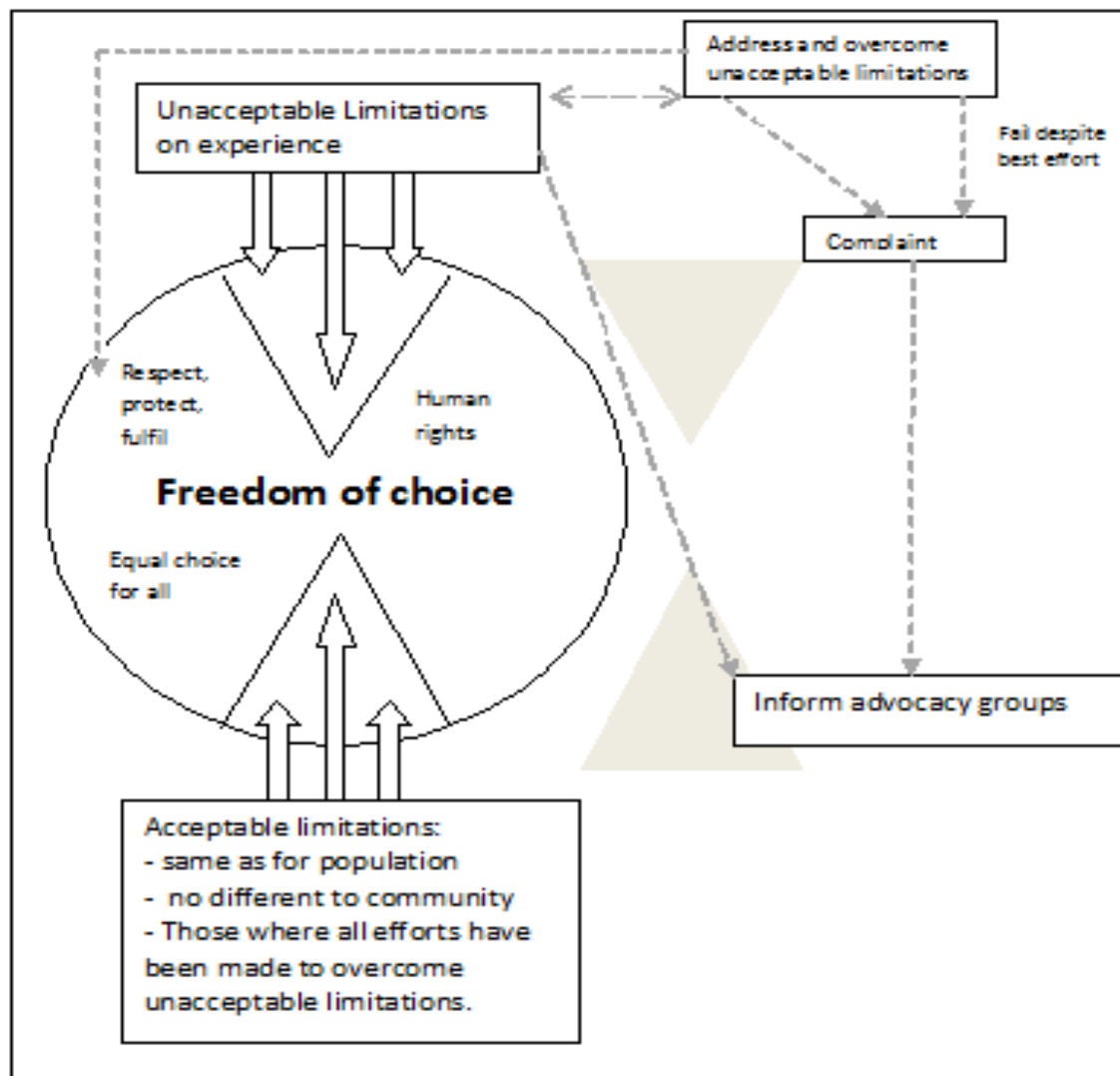
Better sift out some more of these damn choices.

Principles of Choice and Autonomy (cont'd)

- **Principle 6** - Nobody is completely free to choose and pursue any choice they wish. What is therefore important is whether the limitations experienced by a person are reasonable or not.
 - Based on arguments of discrimination and social justice, limitation should be no greater for me as a person with lived experience than it is for others
 - Limitations on my experiences should be no different in form or measure to community 'norms'
 - I have equal human rights to everyone else. In making my choices disability discrimination says it is an offense if these human rights are not respected, protected and fulfilled.
 - 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.

Principle 6 (cont'd)

Diagram 4: - Showing some aspects of the ways in which freedom of choice is and can be limited or enhanced.



| 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) <i>Family/service disagree with person's choice</i> | 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> <ul style="list-style-type: none"> • 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. • Is the choice the person wants to make a key choice? Is it worth demonstrating its viability and testing it in a small way? • 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? • Is what the service/family and the person wants in accordance with human rights? • Is the objection to this choice to do with the family or services 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)? • What are the likely consequences? How can these be managed? • Are there other examples upon which to draw in demonstrating the feasibility of the plan? • Is there a pathway in which smaller steps towards to goal will test its feasibility? |
| 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 Guardian¹. 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> |

| Limitation | Reasonable? | Approach to resolving the issue |
|---|-------------------|---|
| 3. Structural | | |
| a) <i>Inaccessible</i> | 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) <i>Discrimination</i> | Not reasonable | Use disability discrimination legislation |
| c) <i>No relevant service</i> | 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) <i>Local economy (e.g. high unemployment)</i> | Reasonable | People with disability have an equal right to employment. Keep trying and monitor any discrimination. |
| e) <i>Service does not meet DisabilityCare criteria</i> | Reasonable | Raise questions about how such services might be brought under the DisabilityCare umbrella. |
| 4. Service-related | | |
| a) <i>Risk management</i> | 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) <i>Lack of participation in decision-making</i> | Not reasonable | Te 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. ¹ |
| c) <i>Home environment</i> | Not reasonable | This is a plan for the person and not for a home. If the home is fundamentally at odds with the person's human rights or with their pervasive, lifestyle and everyday choice and comfort then a strategy needs to be put in place to change the environment or to move the person to a new home. |
| d) <i>Group characteristics prevent individual choice</i> | 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. |

Sieve 4



OOPS!!

There go many more of my choices

...and do you know, all these damn choices of which you have spoken and which you have taken away: I never even knew I had them in the first place!!

I cannot therefore be **in control**.

How can we understand all this?

Metaphor (Lakoff, 1987) – some of the Bonsai ties have been released, but has this led to a ‘full bloom’? Even if the person is perfect, have they been allowed to fully bloom?

Bonsai

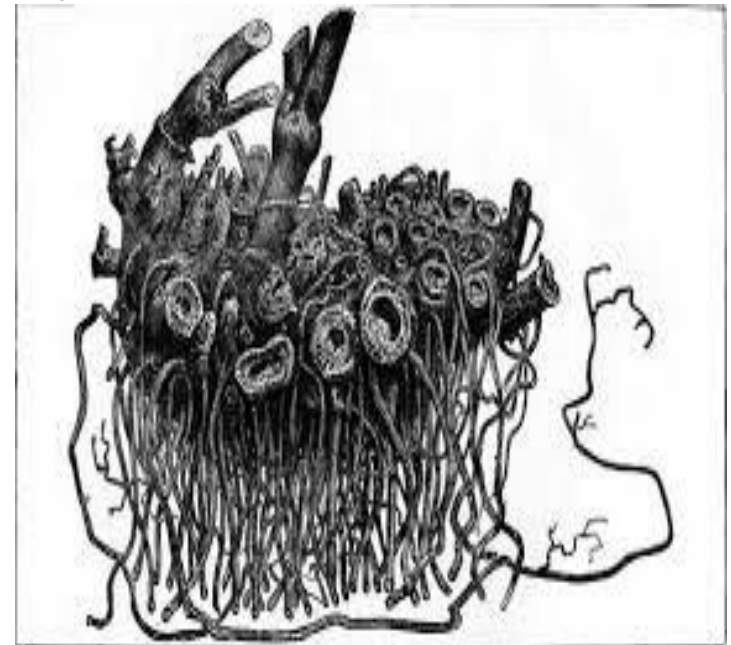
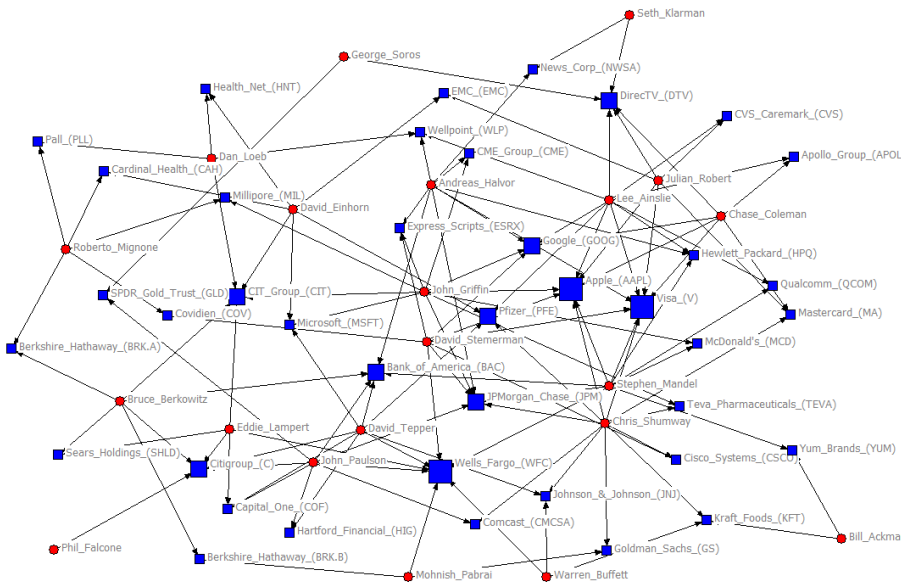
or

Full bloom



Rhizome – Deleuze and Guattari (1980); A ceaseless series of connections between semiotic chains, organisations of power and circumstances

- Introducing the choices that can accrue in a market in which you choose and purchase services that suit will mean the rhizome changes direction and shape. Life may change to some degree but power over what can be bought remains. A huge amount of funds have gone to professionals who assess what funds you receive. They have a powerful influence
- **Co-production** implies that experts by experience lead others to support their expression of choice, lifestyle and identity.



Dispositions within a field of relations (power) – Bourdieu (1990)

- The ‘habitus’ of the person with disability constructed out of relations with family, friends, services, supports and others – It is **co-produced and well-being is socially determined**
- The economic, social, cultural and symbolic resources are **a product of the relationships** the person holds and their control.
- Personalisation gives choice over the purchase of some of these resources and so the person’s ‘habitus will change’. But these and other informal and **latent resources need to be converted into real outcomes** reflecting the self-authored life within a habitus
- Yet the ‘symbolic capital’ (**power**) remains with the state which has to ‘account for its expenditure’.
- Many people think they have really benefited (but, when measured against the embodied practices of mainstream society, this is not so). They show what has been termed **adaptive preferences** and will say ‘This is great’.
- People living in a particular **disposition** won’t criticise because they cannot see its limitations. It is, after all, a comment on their life and who they are.

- 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. **Choice and control** play a central mediating role in this.
- Achieving capabilities means always moving forward and adapting to who we are, what we can potentially do and testing this by **taking risks** and trying new things
- The persistent move towards accomplishing our capabilities gives us **hope and resilience**. It is what makes life meaningful. There is no hope without change.
- Since each person is different in their capabilities and choices so too will the outcome intended for each person differ. This means **equality is structured around diversity**.
- The present changes offer a limited number of opportunities through which people can spend their funds in support of pursuing their capabilities.

Some conclusions:

- Choice of services does not equate to personal choice
- Personal choice is never free choice
- It is vital to convert latent resources into real outcomes that are self-authored. This requires services and supports, where implicated to use co-production in which services work to build the chosen identities and lives of expert by experience based origination.
- In situations in which a person finds decisions hard at any one point there should always be a history to guide others in responding to their non-negotiables, their life choices.
- Networks are as important as services – indeed services may be supporting the continuation of networks
- Outcomes are not just an end point for research – It is the richness of life, its ‘fabric’ and change that make lives meaningful. We need new ways of applying our academic theories around everyday lives rather than privileging the powerful.
- The NDIS provides services for those with significant and enduring problems. For some experts by experience the notion of ‘episodic’ illness reproduces the medical model and denies services. Yet the effects can be equally as long term and problematic.

Thank you!!!!

- Any questions?