



Disability Means Possibility

# Decision Making and Choice

*Challenging Incompetence*



*Highlighting Competence*



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We are taking a fresh  
look at Choice, Duty  
of Care, Risk and  
Decision Making  
Competence

# Traditional Diagnostic Approach to Decision Making Competence

- Competence has to be proven;
- Specialist opinions are sought to make a case;
- Intellectual capacity is the only thing that is considered;
- Competence is viewed as all or nothing;
- Different standards of competence are used for people with disabilities.



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# A functional view of competence

- **Competency is relevant to everyone;**
- **Competency is situation and context specific;**
- **Competency can be influenced, enhanced and suppressed;**
- **EVERYONE is competent in communicating preferences and choices;**
- **Competencies are skills learned through opportunity and practice;**
- **We all seek support from people who know and love us.**

# Factors threatening individual choice and decision making

- **A general increase in risk phobia in our society;**
- **Service cultures and staff value judgments;**
- **Strong OH&S policy and legislation which appear to be in direct conflict with the rights of the people we support;**
- **Organisational systems and structures that reduce choices to a fixed menu;**
- **Outdated perceptions of service providers ‘duty of care’;**



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- Negative assumptions that people can not make choices, particularly those with high support needs;
- System/policy barriers that don't allow for spontaneity and choice;
- Lack of knowledge and clarity about legal rights and systems;
- Fear of litigation;
- A lack of resources and frameworks for supporting decision making with people who communicate unintentionally.

## What people told us:

“a lack of choice about everyday routines such as going to bed, showering, mealtimes, going to the toilet, using the phone, not getting to watch the last quarter of the footy because it finishes too late and staff need to go home or finish a shift”



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- “Nagged constantly about lifestyle issues, such as smoking, diet and weight management, usually by smoking overweight staff!!”
- I went and did travel training, yet I still have to see the psychologist to prove I am competent to travel on my own. The staff were not sure if I understood the risks, yet they take the same risks everyday. I wonder did they have to prove they understood!!!”



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“Not always involved in discussions about medical issues like pressure care, medication, going to the hospital. Needing to insist and be assertive to have a say in these important issues. And even then I am not always listened to, or the information is not given to me so I can understand it, if I cant understand it I cant make a decision about it”



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“I am not involved in discussions about manual handling, transport, and general health issues, like being told I am using MY own wheelchair in an unsafe manner or stating people wont push my wheelchair because it is too heavy ( I have to put up with this even though wasn’t involved in the planning of my chair). Even when I am involved, the OH&S issues are always more important than what I think or want”



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- “I did not feel I had a say in my own life! I have done a person centred plan and we talked about me dreaming and setting goals. BUT I am not able to pursue goals/ dreams due to policy and OH&S concerns.”
- “Not being involved in discussions about my wheelchair prescription or how I might need too, or more importantly like to use MY own wheelchair.”



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“**Sex.....** Well what can I say, just to have a relationship is a major issue, little less sex. I cant get agreement about gaining support from staff, one person will support me, one wont, no-one wants to talk about it. I am usually told it is an OH&S or a Duty of Care issue. I think people hide behind this because they don’t want to help or don’t know how to!”



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# What's Happening in the UK?

# **Mental Capacity Act 2005**

- **Passed by Parliament in April 2005**
- **Covers England and Wales (Scotland passed capacity legislation in 2000)**
- **A Code of Practice is currently being written**
- **Due to come into force in April 2007**

# Mental Capacity Act Principles

- Everyone can make/participate in their own decisions;
- People should be given all the support they need to make their own decisions;
- No one should be stopped from making a decision just because someone else thinks it is wrong;
- Anytime a decision is made for someone it must be done in their best interests;
- Anytime a decision is made for someone it must be as least restrictive as possible.

# Duty of Care/Dignity of Risk

It is time to readdress the balance!





To laugh is to risk appearing the fool  
To weep is to risk appearing sentimental  
To reach out to others is to risk involvement  
To expose feelings is to risk exposing your true self  
To place your ideas, your dreams before a crowd is to risk their loss  
To love is to risk not being loved in return  
To live is to risk dying  
To hope is to risk despair  
To try is to risk failure

But risks must be taken, because the greatest hazard in life is to do nothing  
The person who risks nothing, does nothing, has nothing, and is nothing  
They may avoid suffering and sorrow  
but they cannot learn, feel, change, grow, love, live  
Chained by their attitudes, they are a slave, they forfeited their freedom  
Only the person who risks can be free

--unknown author



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**“The risk that is the focus is more often a potential risk to the organisation than a risk to the individual”**

**David Sykes (OPA)**



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*“Risk management strategy needs to include the risks of denying client rights as a risk category in the same way as managing risks to staff, data, property etc.”*

(David Green, LaTrobe University)



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*“Is the way in which we rightly or wrongly apply duty of care, the new form of manacled straight jackets?”*

*“Is the way we manage OH and S, the new paternalism?”*

*“Is OH and S, the new walls of institutions?”*

(Julian Gardner, Public Advocate)



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**“The number of court cases  
and the level of actual litigation  
in the community services area  
are negligible yet the level of  
fear is huge”**

**David Sykes (OPA)**



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**“If disability service providers are primarily concerned with minimising risk they should get out of the business of supporting people with disability because life is inherently risky”**

**Robert Fitzgerald, Former NSW Community Services Commissioner**



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# Disability Services





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# Take a Chance



With the support of a friend!



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The key is in the  
'listening'

# The dilemma around interpretation

Grove et al suggest that the answer is not to seek a hidden meaning but to work with the person to construct shared meaning. The goal is not to work out what choices the person has already made, but to provide them with the social resources in which to make a choice.



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**All individuals have a will, and  
this will is capable of being  
interpreted and forming the  
basis for competent decision  
making**

**(Michael Bach 2006)**

# Basic Assumptions of Supported Decision Making

- All human beings communicate
- Everyone expresses affective responses to an experience. These can become clear preferences with support.
- These choices and preferences are the building blocks of decisions
- Everyone uses their support networks in making decisions that are difficult for them

# A supported model of decision-making:

The starting point:

*The starting point is not a test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences. Preferences can be built up into expressions of choice and these into formal decisions. From this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices. (Beamer, 2001)*

**Support me in my decision**

**Reflect and document**

**Give me information**

**Get to know me – LISTEN!**

**The decision?**

**Is this decision important to me?**

**What are all my choices?**

**Consider new possibilities and opportunities.**

**I need a range of experiences before I can know what my choices are. You need to help me have a life!**

**I need practice with small decisions**

**I maybe passive and unwilling to choose!**

**This maybe because I have had a life time of not being heard!**

## **Get to know me - LISTEN!**

**Truly “listen” to me. “Listen” to my sounds, my cries, my laughter, my scratches, my smiles, my grimaces, my tapping, my shouts, my silences. Follow my eyes to things that interest, excite or perhaps scare me. Don’t only ‘hear’ the things that you want to hear, rather listen to understand me.**

**Interact with me using MY language**

**Spend time with me doing things I enjoy. You are more likely to learn how I communicate this way because we all communicate about things we enjoy.**

**What is it about these things that I enjoy?**

**Get to know the people who know me, love me and focus on my capacities. They are most likely to know me and the way I communicate intimately.**

**They will know my stories too. My history and my stories will influence the choices I make.**

**Think about my likes, dislikes, culture, values, preferences, life experiences.**

**Have a think about who I am, beyond my disability. If I had control over my life ...**

**What clothes would I wear?**

**What music would I listen to?**

**What car would I drive?**

## **Give me information**

**We all need information to make decisions.  
We need it in a way we are likely to  
understand. Please speak my language**

**I may have problems seeing or hearing you**

**I may need A LOT of time to understand what the choice  
involves. Present the choices in a way I can manage**

**I may not always get everything you say to me. Even if I am  
nodding and saying yes**

**If I sometimes act in ways that challenge you, it may be  
because I am not understanding**

**Please don't judge! I need unbiased  
information.**

## **Reflect and document**

**With me and all those that care about me record very detailed information about how I communicate.**

**You may need to interpret a lot of what I say. You may not be right! Consider using a range of tools like multimedia profiling, personal communication dictionaries, videoing.**

**You can't necessarily ask me directly. So be a good observer. Compare what I communicate in different situations and with different people. Keep a record of my responses over time**

**If people are unclear about what I am saying make a guess and stick to it! Keep a record of how I respond to your interpretation. Review this record with everyone**

**Be clear as to what everyone's hopes, assumptions and agendas are.**

**Review the information regularly**

## **Support me in my decision**

**Base the decision on all the information gathered.**

**My choice may differ from the people who love me. Like anyone, I am likely to choose what is important TO me. The people who love me may choose what is important FOR me.**

**Keep in mind, that I have a right to take risks and make mistakes. Like anyone, I learn from my failures and successes. Perhaps I need an opportunity to experience my choices before I ultimately decide what it is I want.**

**Whatever I choose I will need your support to see it through**

**Allow me to live with the consequences of my decisions**

**Like anyone, my choices may change over time**

**I may need help understanding that sometimes  
I can't have everything I want**

**Because of my life experiences I  
may be intimidated to make a  
choice that is unpopular. Please  
be aware of this.**

**Support me in my decision**

**Reflect and document**

**Give me information**

**Get to know me – LISTEN!**

**What decision do I need to make?**

Is this decision important to me?

What are all my choices?

Consider new possibilities and opportunities.

I need a range of experiences before I can know what my choices are. You need to help me have a life!

I need practice with small decisions

I maybe passive and unwilling to choose!

This maybe because I have had a life  
time of not being heard!

# When thinking about Supported Decision Making ...

What decisions will Jo make on her own?

What decisions will Jo make with the people she trusts?

When will Jo seek help from people beyond her 'circle of support'?



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What is important TO me is  
not necessarily what is  
important FOR me

# Contact details

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