

# WHO DECIDES?

BALANCING RIGHTS  
AND RISK IN  
REHABILITATION  
SERVICES

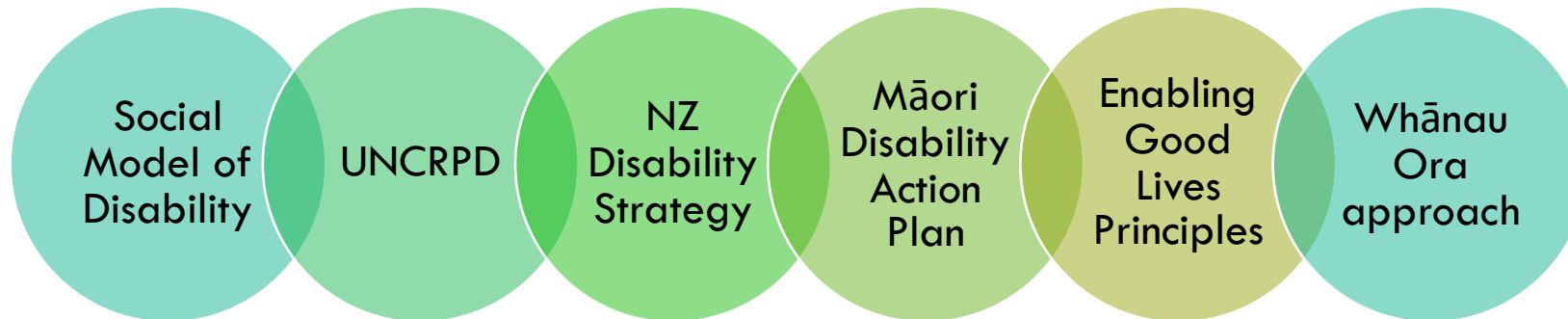
Dr Paul Skirrow  
Prof Jean Hay-Smith  
Dr Rachelle Martin  
Anna Hobman



UNIVERSITY  
*of*  
**OTAGO**  
*Te Whare Wānanga o Ōtāgo*  
NEW ZEALAND

# BACKGROUND

- New Zealand's rehabilitation services are expected to enable and empower people experiencing disability, placing them at the centre of decisions about their care.



- However, disabled people frequently face barriers, including those established and enacted by service providers, to exercise choice and control over their lives.



MA TE HURUHURU,  
KA RERE TE MANU –

ADORN THE BIRD WITH FEATHERS SO IT  
CAN FLY

# BACKGROUND

- Decision making is traditionally conceptualised as balancing several ethical principles
- Recently, some have argued that ‘principle-based’ conceptualisations are simplistic, ignoring complex contextual organisational and social issues
- Existing rehabilitation research is limited and examines ethical principles, rather than how clinicians balance risk and enablement.

# WHAT IS A KEY TENSION?

Risk  
minimisation &  
duty of care

Choice,  
autonomy & the  
dignity of risk

# SOME CONCEPTS TO CONSIDER...

**Ethical principles that have informed medical decision-making:** respect for autonomy, beneficence, non-maleficence, and justice

**Risk to self vs Risk to others**

**Relational ethics:** need for ongoing attentiveness to how values are enacted or thwarted, & how communication / collaboration can be promoted over time.

**WHAT IS THE AIM OF  
REHABILITATION?**

# WHAT ARE SOME RISKS WITHIN REHABILITATION?

*It's a culture and like you say it's perhaps against a lot of [therapists] beliefs and conflicting with the 'keep people safe' mentality. I think it is something that we need to question as clinicians in general. But how far we take that as controlling people – because we think we're keeping them safe but how much we're taking away their choices and freedom? And it's horrible – somebody who could potentially be continent and get to the toilet – to have an accident, you know, it's quite humiliating. So, it's just recognizing the impact that can have. It's perhaps not as talked about as much as how degrading having a fall is.*

**THE WAY WE MANAGE  
'RISKY' SITUATIONS  
MAKE A BIG  
DIFFERENCE TO  
PATIENT OUTCOMES....**

**RELATIONAL  
AUTONOMY.**

**PERSON-CENTRED  
APPROACHES.**

**SELF-IDENTITY  
DEVELOPMENT.**

**LEARNING TO  
LIVE WELL.**

Decision-making capacity

Personal identity flux or  
reconstruction

Emerging understanding of  
implications of change in  
health status

# GAPS IN CURRENT EVIDENCE BASE

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Non-Western understandings of how 'risky conversations' are best approached and/or conducted

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Ethical issues have tended to be considered in terms of discrete events or decision-points - rather than specifically how rehabilitation outcomes (such as self-determination) can be supported

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Understanding of unique NZ context - health and disability service, cultural, legal and political context.

RESEARCH  
AIM &  
METHODS

**Exploring clinician's experiences of balancing safety, risk and client growth in rehabilitation services.**

Using **grounded theory qualitative methods** to explore 'real-life' decision-making of rehabilitation **clinicians.**

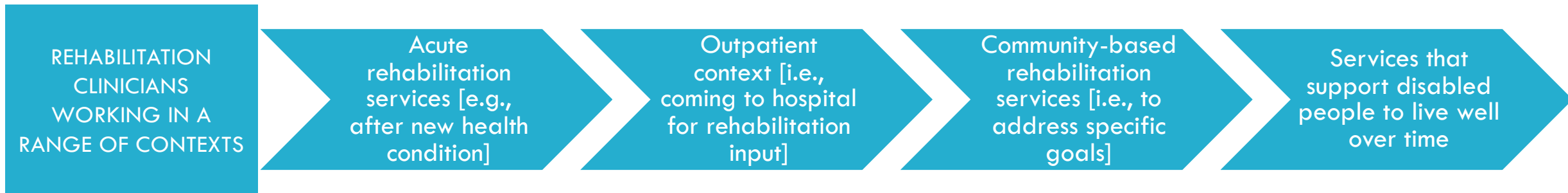
**Interviews** to identify factors supporting or inhibiting clinicians' abilities to promote independence and choice amongst people experiencing disability

## Inclusion criteria

- Rehabilitation clinicians, who are registered under either the Health Professions Competency Assurance Act (2003) or Social Workers Registration Legislation Act (2019),
- At least five years' experience in providing rehabilitation services.
- Currently working in rehabilitation for adults in New Zealand.

## Exclusion criteria

Rehabilitation clinicians working in child or youth rehabilitation settings.



WHO DID WE WANT TO INTERVIEW?

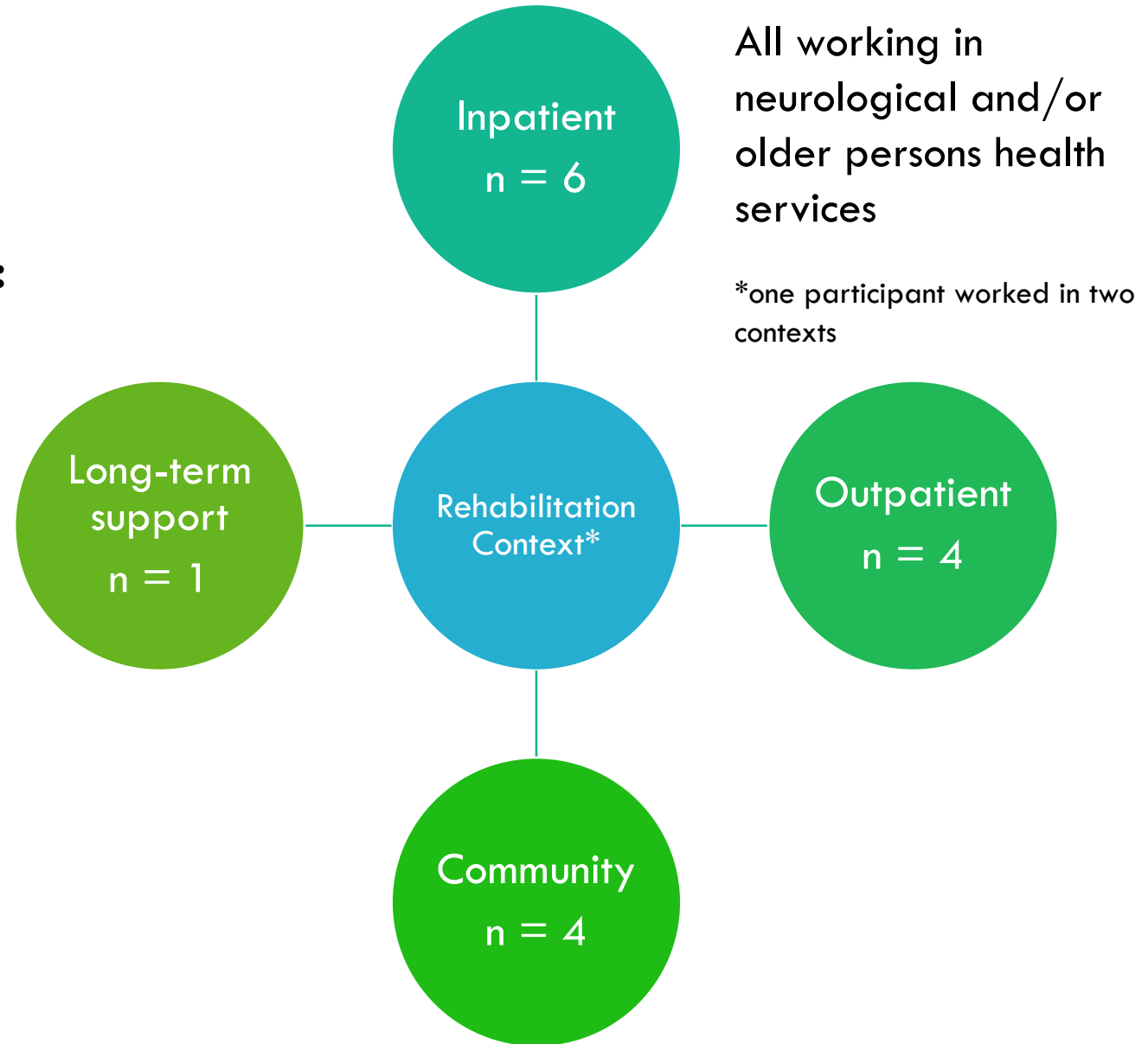
# PARTICIPANTS

14 interviews with conducted with:

- 5 physiotherapists
- 4 rehabilitation physicians
- 2 psychologists
- 2 occupational therapists
- 1 social worker

9 FEMALE

5 MALE



# INTERVIEW QUESTIONS

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What does promoting client independence and choice 'look' like for you in rehabilitation?

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What are the key risks that you find yourself managing in rehabilitation?

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Can you tell me about a time when you needed to act to minimise risk in a way that also limited a person's independence and choice?

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How do you make decisions when client independence and choice are in tension with risk management?

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What makes it easier? What makes it harder?

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Do you have any particular processes that you use to support your decision-making?

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How do you include clients/patients in decision-making?

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How do you include other people (e.g., family/whānau, other members of the team) in decision-making?

# SOME INITIAL THOUGHTS

- PATIENT AUTONOMY SPECTRUM: A person's ability to make choices is significantly influenced by
  - The persons capacity to make their own decisions
  - Context of the rehabilitation service
- CLINICIANS APPRAISAL is central, and influenced by both patient and organisational factors
  - Therapeutic relationship with patient
  - Clinicians experience and role within the organisation impacts their approach, and appraisal

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  - Role of family often not mentioned by participants



# CONTEXT MATTERS: INPATIENT VS COMMUNITY

## Example #1

- Differences in decision-making approaches between clinicians working in community and inpatient rehabilitation services
  - Differences in the degree of autonomy clinicians felt they had to support patient choice and self-determination

## Example #2

- Context impacted therapeutic relationship [*i.e., both enabling and providing a barrier*]
  - Community rehabilitation providers > talked about being able to better empathise with an individual's cultural and personal values, and also described increased complexity managing the expectations of whānau | family as well as the client.

**WATCH  
THIS  
SPACE**

Findings from this phase


Perspectives of people  
receiving rehabilitation

Perspectives of family or  
whānau



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**TAKEAWAYS:  
SOME RESOURCES  
FOR ONGOING  
USE**

# KEY CONCEPTS TO CONSIDER

## FROM PREVIOUS LITERATURE

- The way we conduct ‘risky conversations’ matters! Aim for **decision with** rather than **decision for**.
- Recursive relationship in which decision-making participation assists the dynamic construction of self, and self-concept contributes to the experience of making decisions [Knox et al 2017]
- If HCPs focus too simplistically or narrowly on discrete choice situations, what happens between or behind specific choices may be ignored [Hunt & Ellis 2011]
- Development of a ‘*partnership towards autonomy*’ between patients and HCPs in rehabilitation settings [Hunt & Ellis 2011]

**Table 1. Recommendations associated with the four main professional responses to patient autonomy**

<b>Supporting</b>	<b>Promoting</b>	<b>Respecting</b>	<b>Advocating</b>
<p><b>By acknowledging the importance of relationships</b></p> <ul style="list-style-type: none"> <li>• Develop knowledge about family relationships.</li> <li>• Increase opportunity for dialogue between practitioners and patients and choice (informed consent and knowledge about multiple alternatives).</li> <li>• Look for creative ways to include family members in the rehabilitation process.</li> </ul> <p><b>Through effective teamwork</b></p> <ul style="list-style-type: none"> <li>• Ensure clear communication between rehabilitation team members for how to support patient autonomy.</li> <li>• Be consistent in who is interacting with the patient.</li> <li>• Document the process of supporting autonomy.</li> <li>• Help the patient and their family understand the process and limits of how the rehabilitation team makes decisions.</li> </ul>	<p><b>Through addressing psychological needs</b></p> <ul style="list-style-type: none"> <li>• Monitor psychological health</li> <li>• Consider referring to professionals offering psychosocial support.</li> <li>• Incorporate an awareness of perceptual and emotional factors.</li> </ul> <p><b>By providing patient education</b></p> <ul style="list-style-type: none"> <li>• Being responsive to patients' knowledge, values and interests.</li> <li>• Provide information about local resources, the implications of different treatment options and about patients' rights.</li> <li>• Be transparent about how patients' private information is protected, as well as informing them of any potential conflicts of interest between different stakeholders.</li> </ul> <p><b>Through active participation</b></p> <ul style="list-style-type: none"> <li>• Encourage patients to participate in the decision-making process.</li> <li>• Allow patients to make autonomous choices in daily routines.</li> </ul> <p><b>Through open communication</b></p> <ul style="list-style-type: none"> <li>• Calibrate communication of information to match patients' and families' information needs and capacities to integrate.</li> <li>• Ensure that patients have sufficient and proper information.</li> <li>• In circumstances involving communication impairment, identify relevant experts who can help develop communication skills.</li> </ul>	<p><b>Through sound and thorough assessment</b></p> <ul style="list-style-type: none"> <li>• Appraise any evidence that patient wishes and best interests are incompatible.</li> <li>• Select appropriate evidence-based competency assessment tools.</li> <li>• Gather information concerning patients' life situations to help identify alternative ways to engage with patients.</li> <li>• Re-evaluate the role of surrogate decision-makers over time.</li> </ul> <p><b>Through collaboration and by engaging with different cultural perspectives</b></p> <ul style="list-style-type: none"> <li>• Build trust to develop greater understanding between different conceptions of care.</li> <li>• Include the culturally relevant decision-making unit in the rehabilitation process.</li> <li>• Inquire about specific cultural norms and beliefs.</li> <li>• When an evaluation of capacity is needed, consider patients' history and background, and share this information with the rehabilitation team.</li> </ul>	<p><b>Through involvement in policy changes that are supportive of autonomy</b></p> <ul style="list-style-type: none"> <li>• Take action within healthcare institutions to encourage policy development.</li> </ul> <p><b>Through better training for rehabilitation professionals to respond to autonomy</b></p> <ul style="list-style-type: none"> <li>• Advocate for changes to the training of future clinicians.</li> </ul> <p><b>Through advocating for societal change</b></p> <ul style="list-style-type: none"> <li>• Engage in discussion and debate to draw greater societal attention to health promotion.</li> </ul>

Blackburn, E., Durocher, E., Feldman, D., Hudon, A., Laliberté, M., Mazer, B. & Hunt, M. (2018). **Supporting, Promoting, Respecting and Advocating: A Scoping Study of Rehabilitation Professionals' Responses to Patient Autonomy.** *Canadian Journal of Bioethics / Revue canadienne de bioéthique*, 1(3), 22–34. <https://doi.org/10.7202/1058249ar>

**When a patient's choices entail risks for others: third-party risks, relational ethics, and responsibilities of rehabilitation professionals,**

Disability and Rehabilitation, 43:6, 870-876, DOI: 10.1080/09638288.2019.1637950

**Table 1.** Questions to stimulate reflection and deliberation about situations of third-party risks.

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Questions through the lens of relational autonomy

1. What is the quality of the therapeutic relationship and does it foster shared decision-making?
2. What is the nature (probability and gravity) of the risk?
3. How are these risks perceived from different perspectives and how can mutual understanding be fostered?
4. What efforts have been made to support communication around these risks and to raise awareness of the implications for other people?
5. What concrete steps have been taken to preserve the patient's sense of autonomy?
6. What role can the people closest to the patient play in the situation?
7. What ought to be done to uphold confidentiality and what are the limits of confidentiality in this situation?

Questions through the lens of relational social justice

8. What are the social conditions that shape the patient's ability to make decisions, their empowerment as a moral agent, and how they perceive risks?
  9. Are there social stigmas or barriers that contribute to the situation?
  10. How can the patient's meaningful participation in society be preserved in a way that mitigates risk for others?
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Christine Bigby, Mary Whiteside & Jacinta Douglas  
(2019)  
**Providing support for decision making to adults  
with intellectual disability: Perspectives of family  
members and workers in disability support  
services,**  
Journal of Intellectual & Developmental Disability,  
44:4, 396-409, DOI:  
10.3109/13668250.2017.1378873

**Table 2.** Practical support strategies.

Strategies

**Attention to communication**

*Pitching information and communication at the right level*

"In my daughter's case it is a matter of pictures, showing, doing, tangibility" (family).

"Some [people] might just need information to make a decision, but others will need information explained maybe through pictures or audio or whatever" (worker).

*Awareness of verbal and behavioral clues*

"Oh if there is something she doesn't like to eat, she'll just push it away" (family).

"If she wants to go swimming, she'll get up ... ready to go" (family).

"If he doesn't want to get up, he will go stiff which says to you I'm not interested in getting up for any reason, just want to stay put, so it is about reading his body language, his facial expressions and gestures" (family).

**Education about consequences and practicalities**

*Making it understandable*

"It's breaking it down into little steps, so this is the first thing we have to consider and then, if you have a solution for that, then this is the next thing we have to consider ... just take a little step at a time because sometimes that's all you can do" (family).

*Do the research – present the options and pros and cons*

"My view is to research it so I can see a big picture" (family).

"I assemble a collection of appropriate items for this particular decision" (family).

"I'll search and I'll bring him some brochures and I'll give him as much choice as – stuff he hasn't even considered – I'll give to him to ... so he can broaden his ... you know thing for life ... For example you want to go in- a hot air balloon ... riding on a motorbike. And this particular person did" (worker).

*Explain consequences of decisions and that priorities can be undermined by small decisions*

"We do say 'okay so you wanted this certificate, well these are some classes you can do for that are you happy to do that class?'" (worker)

"... so you provide as much information to them as possible so that they can make an informed decision" (family).

"... [asking] what do you see as the outcome for that? What are some of the consequences? What do you hope to achieve out of it?" (worker).

"... if we have a student come to us and their goal, their first plan was to learn this particular skill, but now they're ... saying 'art all day, art all day, art all day'. And they're meant to be doing work ready skills or independent living skills. I can't then say 'no you can't do art', but I have to say 'hang on what other things do you want to learn.'" (worker).

**Listening and engaging to ensure all options are considered**

*Attentiveness to will and preference*

"listen to what they say" (family).

*Taking the time*

"... repetition ... and this is what happens, we've got to talk about it and she's got to digest it and she's got to think about it and I say 'now remember, we talked about that ... and this is the next ... what do you think'" (family).

"... it takes a lot of time and energy to go through that process" (family).

"you need patience, time" (worker).

"... over a time span that might even be two weeks if you've got that sort of time" (family).

"Every new decision takes time. It's not like oh well he's learned now to make decisions and that's going to work, no it is not going to work faster" (family).

**Creating opportunities**

*Active reframing that invites participation – what do you think*

"Where have you been? Where would you like to go back? What did you like about this place ... and just looking at all those little things ... What do you think? Really that was 99 percent 'What do you think? What do you think? What do you think?' (worker).

*Providing a sounding board to talk through*

"I think you all do it too when you have to say you don't realize, you're talking during your classes and they are expressing their concerns and wishes. And you talk it through with them, just that process of having a sounding board" (worker).

*Acknowledging low expectations and building confidence*

"... [lack] 'ambition ... so that if you asked them 'what would you like to have for a Christmas present?' she doesn't have an aspiration or ambition or a desperate need to have a particular item" (family).

"... they're not used to making those decisions or haven't been given the choice or the power to make decisions- (even) something simple" (worker).

"So, you can't just say well she can't make decisions because she's intellectually disabled, in actual fact she can make decisions and she makes some good decisions" (family).

"... they're saying what they think you want to hear" (family).

# SOME READINGS...

- Christine Bigby, Mary Whiteside & Jacinta Douglas (2019) Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services, *Journal of Intellectual & Developmental Disability*, 44:4, 396-409, DOI: 10.3109/13668250.2017.1378873
- Blackburn, E., Durocher, E., Feldman, D., Hudon, A., Laliberté, M., Mazer, B. & Hunt, M. (2018). Supporting, Promoting, Respecting and Advocating: A Scoping Study of Rehabilitation Professionals' Responses to Patient Autonomy. *Canadian Journal of Bioethics / Revue canadienne de bioéthique*, 1(3), 22–34. <https://doi.org/10.7202/1058249ar>
- M. Cardol, B. A. De Jong & C. D. Ward (2002) On autonomy and participation in rehabilitation, *Disability and Rehabilitation*, 24:18, 970-974, DOI: 10.1080/09638280210151996
- Evelyne Durocher, Elizabeth Anne Kinsella, Carolyn Ells & Matthew Hunt (2015) Contradictions in client-centred discharge planning: through the lens of relational autonomy, *Scandinavian Journal of Occupational Therapy*, 22:4, 293-301, DOI: 10.3109/11038128.2015.1017531
- Matthew Hunt, Stephen Clarke & Raphael Lencucha (2021) When a patient's choices entail risks for others: third-party risks, relational ethics, and responsibilities of rehabilitation professionals, *Disability and Rehabilitation*, 43:6, 870-876, DOI: 10.1080/09638288.2019.1637950
- Matthew R. Hunt & Carolyn Ells (2011) Partners towards autonomy: risky choices and relational autonomy in rehabilitation care, *Disability and Rehabilitation*, 33:11, 961-967, DOI: 10.3109/09638288.2010.515703
- Lucy Knox, Jacinta M. Douglas & Christine Bigby (2017) "I've never been a yes person": Decision-making participation and self-conceptualization after severe traumatic brain injury, *Disability and Rehabilitation*, 39:22, 2250-2260, DOI: 10.1080/09638288.2016.1219925