



Preliminary evaluation of the La Trobe Support for Decision Making Practice Framework

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With acknowledgement to team members, Terry Carney, Shih-Ning Then, Ilan Wiesel, Elizabeth Smith.

Overarching purpose of our program of research

- Context of paradigm shift about decision making and people with cognitive disabilities
 - right to participate in decision making
 - right to have the support needed to participate
- Contribute to people with cognitive disability receiving good decision-making support.
- Build capacity of supporters to provide effective decision-making support
- Develop a demonstrably effective capacity building tool for decision-making supporters of people with cognitive disabilities
- Fill the void that exists in terms of evidence based, effective and flexible resources, training and support for decision-making supporters of people with cognitive disability.
- Address a major policy challenge. Putting NDIS aims of choice and control about own lives and types of services into practice.

Aims

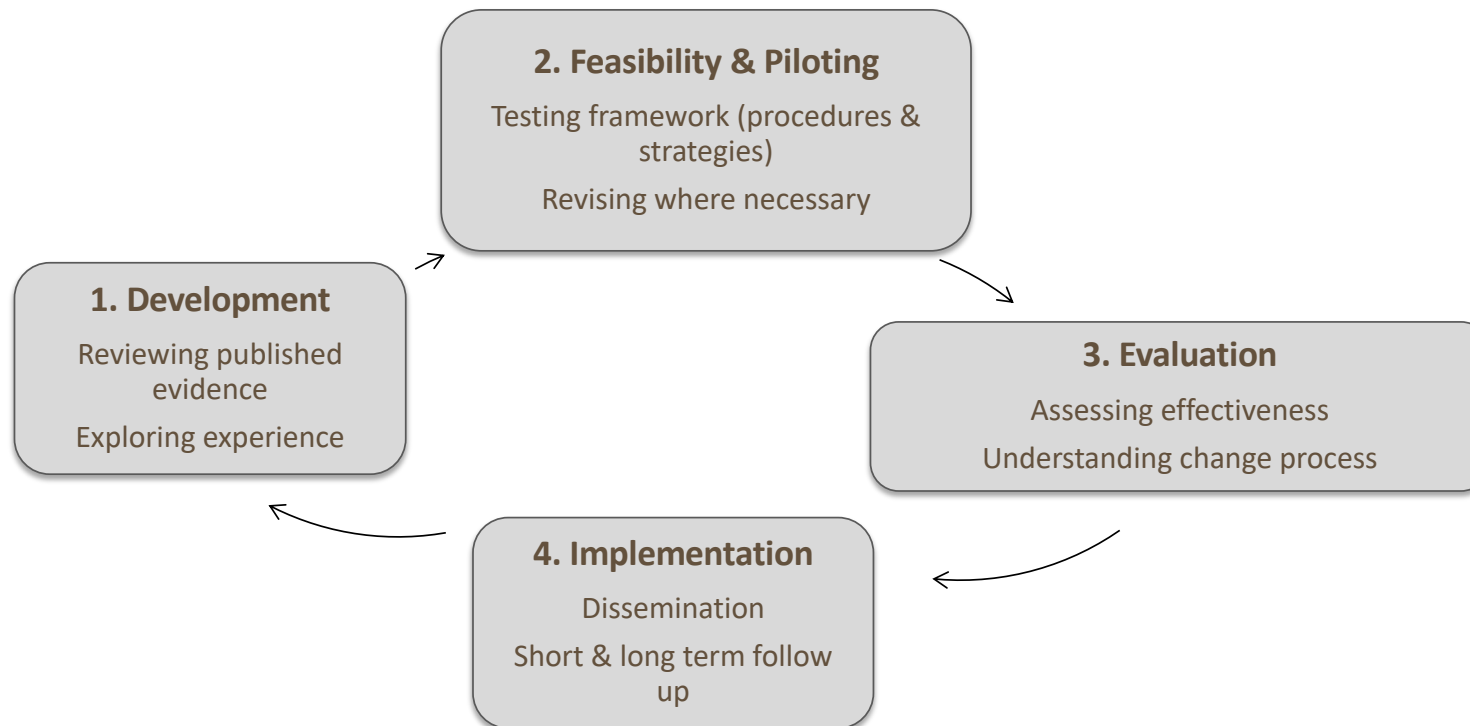
- Develop and trial an evidence-based support for decision making practice framework. (Framework)
- To increase capacity of supporters to enable people with cognitive disabilities to participate in decision making, and provide effective support for decision making

Research Questions

- Understand the relevance of the Framework to decision supporters and explore their experience of using it in their day to day practice
- Impact of training in the Framework
 - increase the capacity of supporters to enable the person to participate in decision making
 - enable supporters to use the processes of effective support

Development of the Framework

- Four phase approach modelled on Medical Research Council guidance for developing and evaluating complex interventions (Craig et al., 2008)



Features of Decision Support

1. Development

Reviewing published evidence

Exploring experience

Evidence from phase 1

- A complex process with interacting and overlapping components – iterative rather than linear
- Shaped by the context
- Support needs change with every decision
- Involves multiple players, the person with cognitive disability, supporters, and others influencing or impacted
- Each part of the process requires tailoring to the individual
- Implementing the decision may not rest with decision supporters. (Bigby et al., 2015)

La Trobe Support for Decision Making Practice Framework



Training and Mentoring



3. Evaluation

Assessing effectiveness
Understanding change process

- One day interactive workshop – exploring the framework and sharing experiences
- Follow up mentoring – using current examples from practice
- Online resources with illustrative clips based on research findings

The La Trobe Support for Decision Making Practice Framework Learning Resource

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About this resource

This online learning resource is about support for decision making. It will present the first evidence-based framework to guide you through the process of supporting people with cognitive disabilities to make decisions. Using this framework will help you to enable the people you support to exercise choice and control in their own lives.

Evaluations

3. Evaluation
Assessing
effectiveness
Understanding
change process

Separate studies using similar mixed methods

ARC Linkage randomised control study of training

- 76 dyads supporter and decision maker - 55 people with intellectual disability 21 people with acquired brain injury
- 5 supporters of a person with intellectual disability

Victorian Traffic Accident Commission (TAC)

- 10 experienced support coordinators

Queensland Public Trustee

- Work in progress - training for all frontline staff in version of the training adapted for financial decisions

Leadership plus

- Work in progress – training and follow up case studies of paid supporters involved in DSS trial of support for decision making for NDIS decisions

Today preliminary findings from TAC and ARC studies



Building Capability to support Client Decision Making

TAC Project No: T005

Living with Disability
Research Centre



Background

TAC

- New Service Model Framework (SMF)

La Trobe Living with Disability Research Centre

- La Trobe Support for Decision Making (SDM) Framework

Project Aim

- translate existing evidence on the SDM Framework by training a small cohort of Independence claims employees to apply the approach to their client planning interactions and deliver services consistent with contemporary disability practice

Objectives

- **Design and deliver a quality training program** to Independence claims employees on the La Trobe Support for Decision Making (SDM) Framework
 - Encourage clients to create their independence goals and manage their plan for attaining them
- **Assess the training-specific impact** on the capability of Independence claims employees to be effective supporters of decision making
- **Identify the critical facilitators, barriers and key learnings** from implementing the training with claims employees to inform iterating and improving the training module for broader roll-out across TAC claims divisions.

Design: Pre – Post, Mixed Method

Pre-measure Online Survey

- Decision making style (DMQ, 22 items; vig, h-vig, procrast, bp)★
- SDM confidence rating (SDM-CR, 0-10 rating) ★
- Decision Support Questionnaire (DSQ-sup, strategies 32 items)★
- Recent SDM Experience & responses (ERQ, 10 items)

SDM Training + Mentoring

- 2 x 4 hr face to face sessions
- Training feedback: Content
- 1 x 45 min phone mentoring session

Post-measure Online Survey

- SDM-CR
- DSQ-sup
- Recent SDM Experience & responses (ERQ)
- Thematic analysis of mentoring transcripts

Quantitative Measures

Measure	Focus	Subscales	Number of items	Response format
DMQ (Mann et al., 1997)	Personal decision coping patterns	Vigilance Hyper-vigilance Buck-passing Procrastination	6 5 5 6	3-point scale: 0 - not true at all, 1 - sometimes true, 2 - true for me
SDM-CR	Confidence providing support for decision making	NA	1	0 to 10 point scale: 0 - worse possible 10 - best possible
DSQ-sup (Douglas & Bigby, 2016)	Strategy use consistent with supported decision making principles	Reliability $\alpha = .812$	32	4-point scale: 1 - Never or Rarely 2 - Sometimes 3 - Often, 4 - Usually or always.
ERQ-sup (Douglas & Bigby, 2016)	Responses in recent SDM situation	Scenario description + actions	10	3-point scale: 1 - No 2 - Partly 3 - Yes

Participants

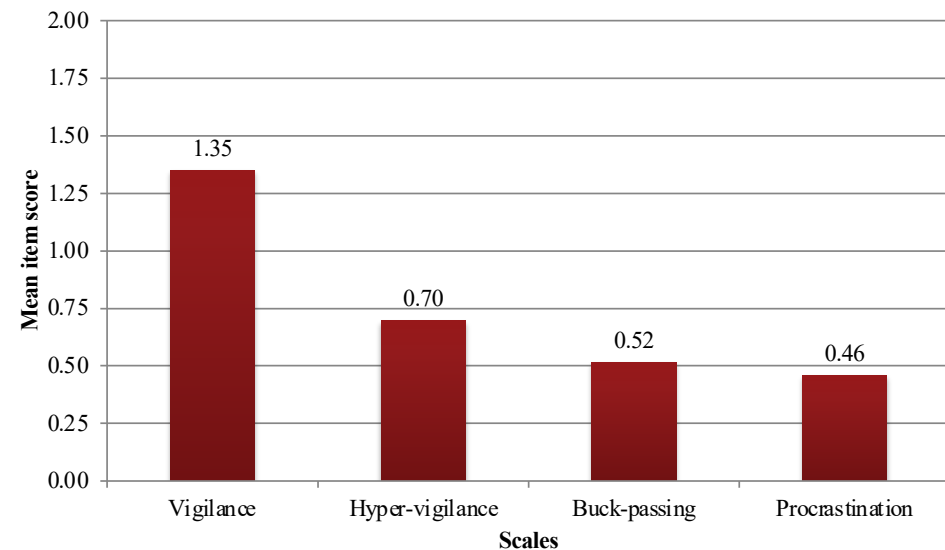
- 10 Independence claims employees (in SMF trial)
 - 9 support coordinators:
 - 4 early
 - 3 active
 - 1 RTW
 - 1 specialist
 - 1 team manager (not included for data analysis)

Pre-training personal coping style

Strong on vigilance

- sound, rational decision making
- clarify objectives
- canvass alternatives
- search thoroughly for relevant information
- assimilate information in an unbiased manner
- evaluate alternatives carefully

Decision Coping Pattern



Note: Scoring 0=not true at all, 1=sometimes true, 2 = true for me

Results



- Training evaluation
- Confidence
- Strategy Use
- Mentoring
 - Thematic Analysis
 - SDM coding

Response to training

Most beneficial aspects

Theme	No.	Example Quotes
Building SDM knowledge	7	Legislation and world standards and definition and breakdown of what supported decision making is La Trobe's model of supported decision making how to approach supported decision making
Applying SDM to real cases	7	Talking about specific client scenarios and trouble-shooting a suitable approach to SDM Application to real scenarios Discussing the videos Videos were great

Aspects to improve

Theme	No.	Example Quotes
Amount of practical activities	6	More work on understanding and applying the framework More practical examples and reviewing how to manage more difficult situations Perhaps participants could bring their own scenarios to work through/discuss
Amount of discussion	4	Unstructured discussion At times, the conversation got off track, although these were still useful

Take-away Messages

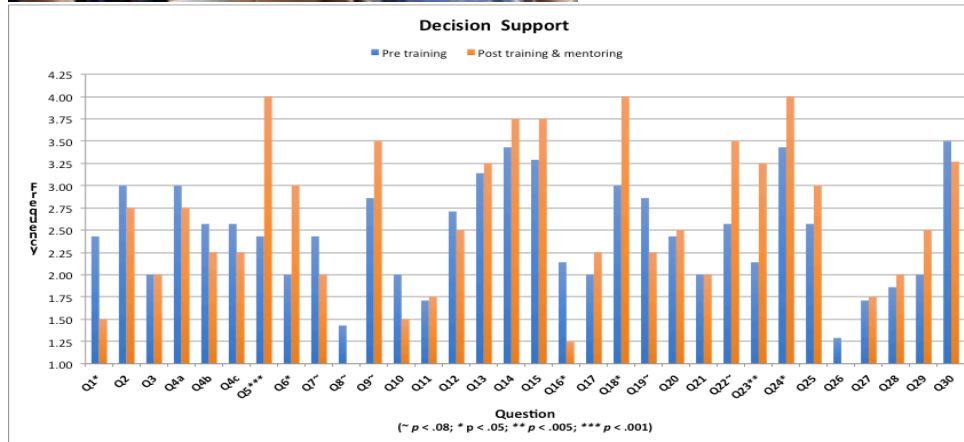
Theme	No.	Example Quotes
Taking back to practice	8	<ul style="list-style-type: none">• <i>Understanding what support for decision making means for me in my role</i>• <i>Make sure family are aware of alternative options other than substitute decision making</i>• <i>Get to know the client</i>• <i>Start with support and consideration of a person's ideas and help them to make a plan to take steps toward it</i>• <i>Help client communicate their will and preferences</i>• <i>Identifying when a client may be able to participate in decision making more than what they are</i>• <i>Achieving SDM is difficult, many players in the game, aspects of SDM can still be applied, even when substitute decision making is in place</i>• <i>Will and preference</i>• <i>SDM....is a basic human right</i>

Coordinators' Confidence



Significant increase in confidence $p = .02$

Strategy Use (DSQ)

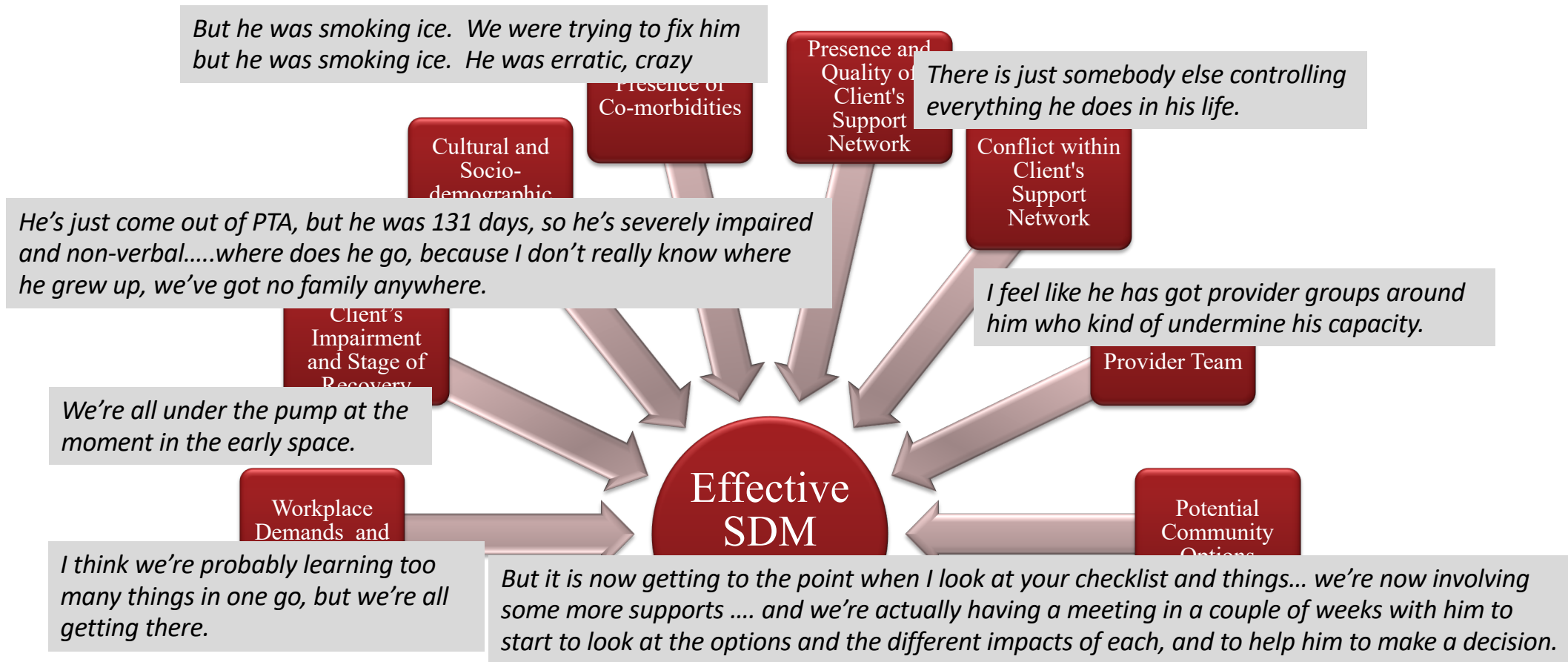


- Significant change ($p < .05$) on 7 items
- Trend towards change ($p \leq .08$) on a further 5 items

Changes reflected improved use of SDM principles and strategies

- Reduced reliance on best interest rather than will and preferences
- Move towards practice that supports the client's right to participate in decision making
- Checking the client wants to be supported to make the decision
- Considering the significance of the decision and the consequences of the outcome with the client
- Not choosing for the person
- Working through each of the steps involved in the decision with the person.
- Considering their own potential influence

Mentoring Thematic Analysis: *facilitators, barriers, key learnings*



Support for Decision Making Checklist	
SDM	Evidence in Mentoring Session
Steps	
→ Found ways to know the person	
→ Identified the decision	
Described the features of the decision	
→ Explored the person's preferences	
Identified constraints	
Refined the decision with constraints considered	
→ Identified whether conflict existed	
Identified whether a formal process was needed	
Reached a final decision	
Identified associated decisions	
Selected advocates to implement the decision	
Checked the person's preferences were maintained during implementation	
Principles	
→ Commitment	
Orchestration	
→ Reflection & Review	
Strategies	
Attention to communication	
Listened and engaged	
Created opportunities	

Levels of use ■ strong, ■ high, ■ medium, ■ low

Discussion

What we learned

- Support Coordinators: Suited ++ to implementing SDM
- Training had a positive impact
 - Confidence
 - Skill
- SMF Trial

What's needed

- Tailoring of training to specific context
 - Case scenarios
 - Online resource
 - Internal community of practice
- Increased SDM uptake: Families, Health professionals, Support workers
- Opportunities to compare with ARC Linkage Findings

Questions and Comments

ARC study – parent supporters of people with intellectual disability.

Research questions

Understand relevance of framework to parents and experience of using it in their day to day practice

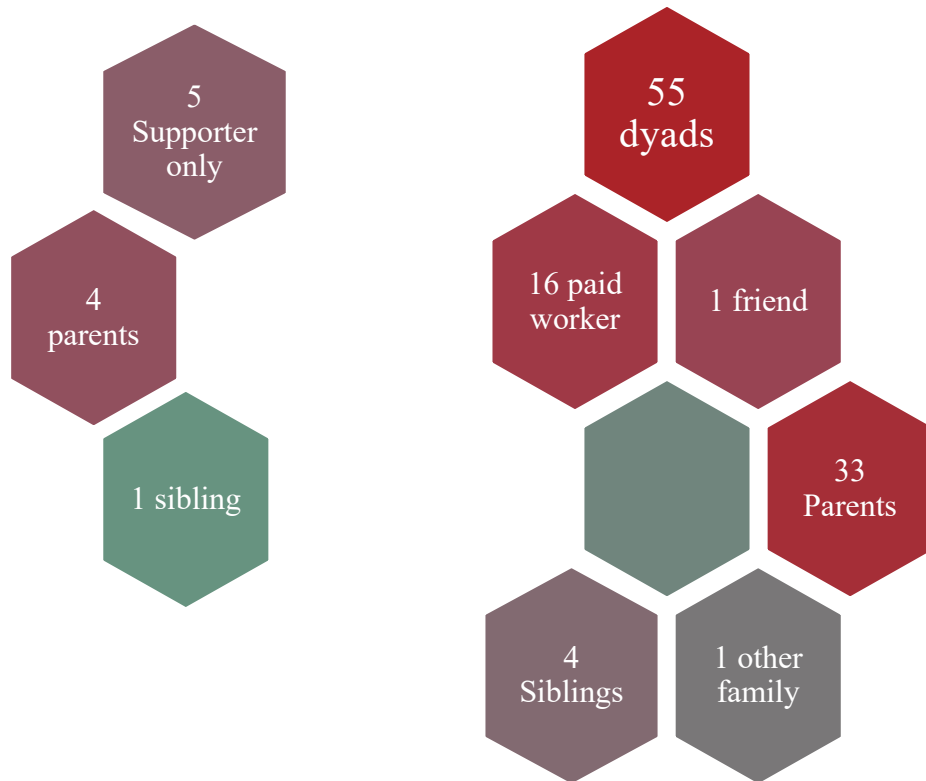
- What were their reflections on the training and the framework
- Had they applied learning (knowledge, skills and attitudes) to their support practice. i.e are they using the principles, steps and strategies of the Framework

Methods

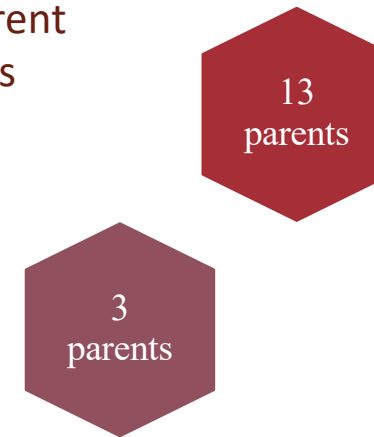
- Semi structured interviews about approach to support using a specific decision each time
- Pre- post training and then 5, 6, 12 months
- 1-5 mentoring sessions
- Same measures as TAC study
 - Decision Support Questionnaire
 - Confidence

Participants – sub-group of parent supporters of people with intellectual disability

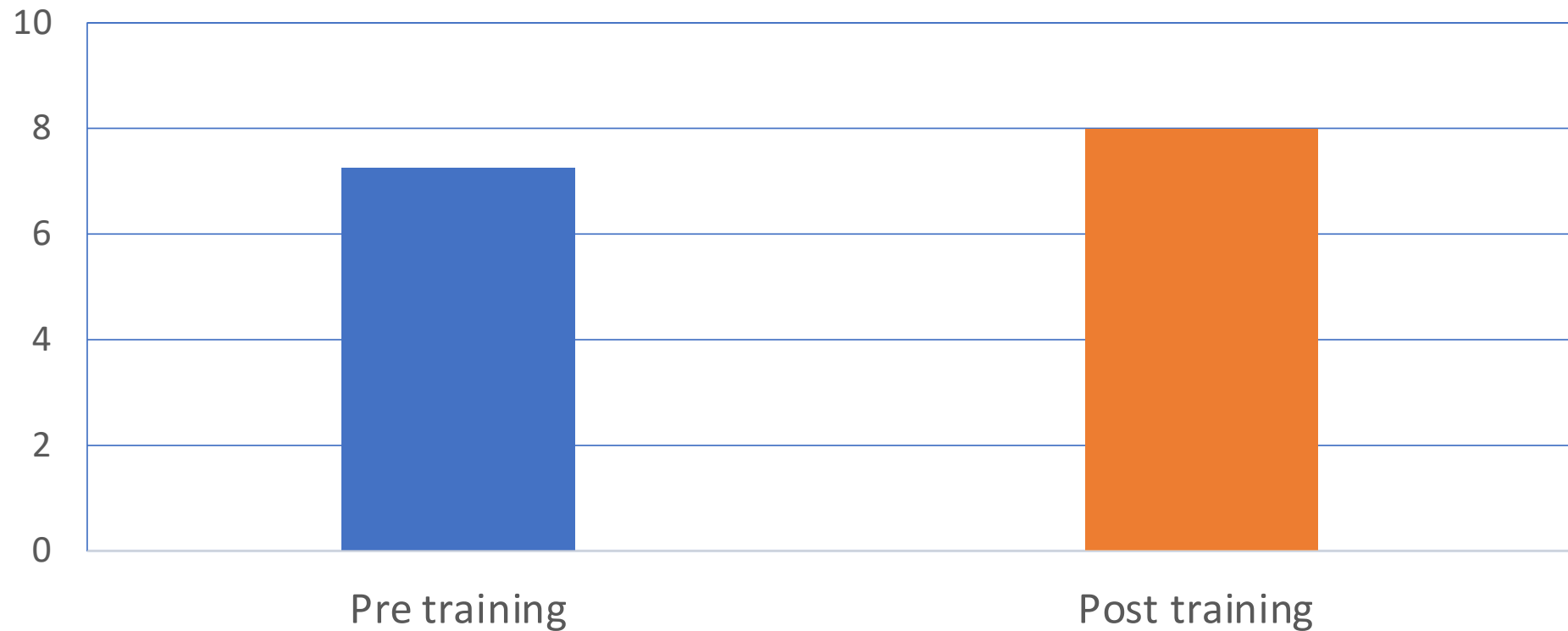
All participants



Trained parent participants

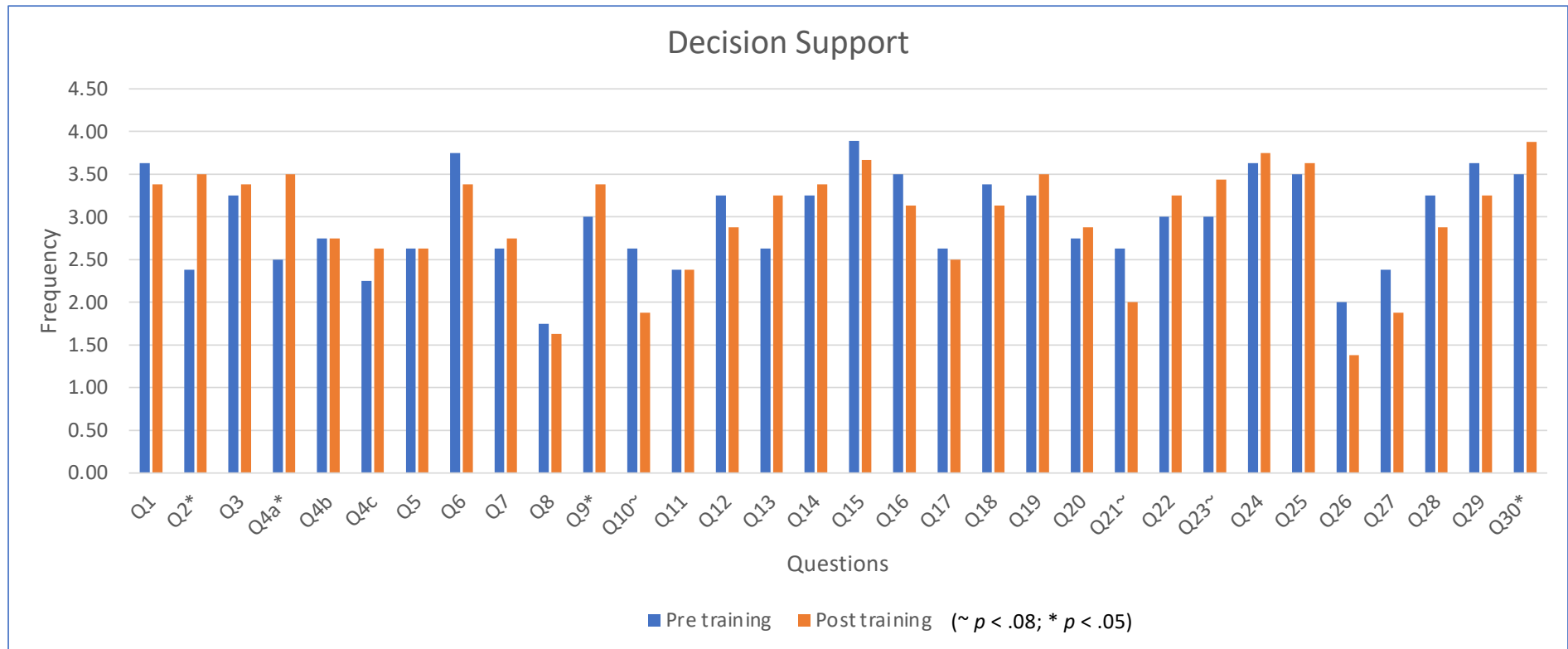


Supporter confidence



Increased post training but much higher pre- training 7.25 than TAC support coordinators 5.0

Pre- and post-training decision support strategies: Frequency of Use



Significant changes decision support strategies

- 2. Consult other people who know the person in different situations
- 4. (a) Seek advice from a professional/expert
- 9. Rely on what the person wants or prefers?
- 10. Make the decision with the person on the spur of the moment?
- 21. Take the option that the person will least resist?
- 23. Think about how you might be influencing the decision?
- 30. Help the person act on/proceed with the decision to be made?

A catalyst for reflecting on processes of decision support, “made me stop and think”

Reflected on their support and influence

But I just think I've got to be a bit more aware of my own opinions of things, so just stand back a step and say is this really what Caleb might want...I think it's made me stop and give it a bit more thought. ...it's made me think, hang on, I've got to be aware that sometimes. (Gabby, 2)

I think that the mentoring has really helped with reflecting more about how you can impact someone or how you do it (Misha 3)

I reflected on the fact that virtually everything that Sally does has been decided by me... The fact that she's in work is because I have a goal for Sally that work should be part of her life. ...When you think of just those couple of days and those key things, they were goals that I have set. I didn't really engage Sally in the decision-making process other than to say, you know, "Wouldn't it be a good idea if you went and got a job?" (Bernice, 2).

Affirming commitment to rights

I can see the need to relinquish control, to support her independence, and for her to make more and more of her decisions. Yeah. To be less directive and allowing things to happen sometimes. (Jodie, 5)

Recognising what is difficult and why

It can take a lot of energy, to try to make sure that Heather's preferences are being taken into account as fully as possible. Very easy to be I don't know, lazy. Take the easy route and [about] some of the more day to day decisions, convince yourself, oh no, she doesn't want to go outside right now, she can just stay inside. (Brett, 3)

Because it's really hard to be disciplined, to continue asking open-ended questions and continue to pass over responsibility. But I feel confident to know I can do it if I turn my mind to it and keep disciplined... it is a discipline, it's not a natural tendency. (Raymond, 3)

Lack of external reinforcement for good practice

...And they don't really ask us whether the person that we're making the decision for has been consulted. There isn't any form that you get saying, "Did you speak to the participant about this? Do they agree?" It's nowhere. So they're perpetuating the old system, which is that parents act for children, and that doesn't matter how old the children are...Sometimes planners don't even talk to him. They just talk to me. (Kate 7)

Taking a more deliberate approach to support, 'having a structure'

Probably when we talked about it initially, I just wasn't thinking as consciously as I perhaps am now.

I do feel that the training, the wheel, just helped give me a framework for thinking about decision making and things to consider. Yeah, so some of those, I might have done anyway, I wasn't doing everything, so it's just made it a bit clearer. (Jodie, 5)

Having a shared language

I think it's been really fruitful because we've got two parents that think differently like we all think differently, and it's been helpful to give us a structure to think along the same lines. (Raymond 3)

Step 3 - More attention to understanding preferences.... active listening

...just not that we didn't really listen to what he was saying before, but really - I don't know how to explain it, but really listening now. Like, taking on board what he's saying and trying to go deeper and deeper, and peel off the layers, and trying to discover what he's actually saying.... Trying to ask him more questions, and questions that he'll understand better, in a different format, and really trying to get into the root of it basically...sort of coming at it in a different way, rather than just a direct hit, which doesn't always sit well with him. So, I feel I'm in a better position to do that. I'm more patient, I'm able to listen more and hear what he's actually saying, and not what I think he's saying. (Joanne 2)

More specific strategies and greater confidence in person's own voice

...and it's different because Tamara's very much involved and she's really chuffed previously pre-mentoring... it wouldn't have unfolded like this and I can just see she's really, really chuffed about being the centre of it. ... I guess I'm just learning that when she says she wants something to happen she's pretty correct...she doesn't comprehend perhaps the implications of things. But intuitively she's strong...I think I'm learning to go with her gut feel on things (Misha, 3)

Step 6 - Attention to associated decisions

I think it's probably encouraged us to place more value on those decisions and I guess it's like that thing about then she'll come up, show me a recipe that's in a magazine and say, "I want to do that." And rather than saying "Well, we'll do it tomorrow." Because we've got to buy the ingredients and it takes two hours to cook, like doing all the planning associated with implementing that decision. Now I'm more prone to say, "Well, who do you want to do it with or where do you want to do it? I try to tease, that sort of bringing into it and let her make choices. (Raymond, 3)

Applying the principle of orchestration – involving others

Encouraging the person to seek advice from others

So, on occasion, they've been able to raise things with Danielle that I would not be able to. So, I've become aware that that's a very useful technique because she's more likely to listen to other people than me on some matters. ... And I've sometimes said you might talk to Jenny about those things. She can help you as well as go through the options and then you can make your decision independently. (Mary 3)

Seeking information from others from different contexts

Anica and I aren't the only ones who spend time with Heather and watch her closely and try to interpret what's going on. There are others, and that intentionally drawing them in to the conversation is important and has been beneficial ...one thing I've noticed and probably paid more attention to than I would have... is whenever I get a chance, I ask one of Heather's new friends what kind of day they think Heather had...Bree said Heather loved the bus, she hated the beach. It's very clear, no filtering or particular way of framing it. She just said what she saw. It's quite helpful in that sense. (Brett mentoring)

Greater expectations of others to support decision making

...we do tell them, "We expect you to have a conversation with Brendon, don't make all his choices for him. Encourage him to speak to you, express himself, like speak in longer sentences, express ideas and things that he wouldn't necessarily talk to us about perhaps." (Joanne, 2)

Step 2 - Identifying decisions and creating more opportunities

I think making a conscious plan, on my part, to give her those options, and not just for me to pull the bread out of the freezer and make a sandwich. Because the important thing is to provide Sally with practice decision-making (Bernice, mentoring)

It's also about how I communicate with him. It's not just about support for decision-making, it's how you explain what the decision entails. And sometimes I just don't get there so I need to learn more about that. I don't quite know how to do that but I'll get there. I'll find something. I'll work something out. (Kate, 5)

Adjusting knowledge about the person as confidence grew

Step 1 Knowing the person

- Affirmed their deep knowledge of the person
- Had adjusted knowledge as they matured
- Readjusted knowledge as person's confidence increased and their own support changed

He's making more and more decisions himself. Like, smaller ones but he's taking ownership of them a little bit more. So, in terms of what he wants to eat, where he wants to eat sometimes if we're not eating at home, what he wants to wear ... He just beams. He's a different person. There's a smile on his face. His shoulders are upright and it's like, "I'm choosing this and I'm making it happen. I'm not waiting for someone else to lead me."...(Joanne mentoring)

He's the one who's saying, 'No, I don't - I need you to do it this way. No, you can't do that. No, I want to do this myself. You just stand to one side and catch me if I fall,' ...So yeah, that's been really good. He's really developed in the - I think he's developed from the last 12 months... He's certainly engaged more - he doesn't wait to be told now. He wants to be involved and he wants to tell you what he thinks, and that's great. (Kate, 6)

Discussion

Framework is relevant for parent decision supporters - evidence of many of its components in their support practices

Training in the Framework

- generated self-reflection and means for self-assessment
- provided structure and guidance for decision support practice
- prompted more deliberate use of steps and principles associated with effective decision support
- prompted changed practice by parents and increased confidence of person supported
- Provides further insights into complexities and demanding nature of decision support
- Cannot assume all parents are familiar with the concepts in UNCPRD
- Highlighted if support for decision making schemes are to be implemented supporters require investment in building capacity of supporters - training and opportunities for problem solving through mentoring and possibly peer support or communities of practice
- Highlighted need for external reinforcement of good practice and accountability

Conclusions

Demonstrated the value of the Framework and training in shifting practice of supporters in two contexts

Evaluative focus has been processes of support – shift toward greater participation of the person and effective support strategies

Support for decision is a process rather than an outcome

What about the people supported – for whom self report difficult - need for in depth case studies and observation of change over time

Comparing the two sets of preliminary findings

- Training and mentoring must take account of the different roles and context of supporters
- Trainers need to be familiar with the unique characteristics of people being supported
- Supporters' style and confidence in decision making may be important factors to understand

Provides a means of external accountability of support practice

To date the Framework is having impact and now embedded as part of TAC training for coordinators

Further analysis of paid supporters from the ARC study will add to richness of findings

Acknowledgements



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- NSW Department of Family and Community Services (FaCS)
- NSW Office of the Public Guardian
- NSW Trustee and Guardian
- Queensland Office of the Public Advocate
- Queensland Mental Health Commission
- Queensland Public Trustee
- Queensland Office of the Public Guardian
- Victorian Traffic Accident Commission

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<http://www.supportfordecisionmakingresource.com.au/>

Practice Framework

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Supporting Inclusion of people
with cognitive disability

