



# **Final Report**

Building capability to support client decision making

TAC Project No: T005

# Building Capability to support Client Decision Making Final Report

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Professor Jacinta Douglas, Professor Christine Bigby and Dr Elizabeth Smith
Living with Disability Research Centre
La Trobe University

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# **Executive Summary**

Supported decision making enables people with cognitive disabilities to participate in making decisions about their own life. It empowers a person to participate and gain life experience in making choices and exercising control based on their will and preferences. In the context of implementing the new Service Model Framework (SMF), the TAC engaged the La Trobe Living with Disability Research Centre to build the capability of Independence claims employees to apply the La Trobe Support for Decision Making (SDM) Framework in their interactions with clients.

# Aim of the project

To 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.

# **Method and Design**

<u>Training-specific change</u> in the primary participant group was measured using a mixed method (quantitative and qualitative) within group, pre- *vs* post- intervention (i.e., repeated measures) comparison design

<u>Participants</u> were nine Independence claims employees participating in the Service Model Transformation (SMT) trials and currently managing TAC claims of adult clients (18 – 65 years) with a principal diagnosis of acquired brain injury. Consistent with the new Independence service model, claims employees were working with clients to develop, implement and review their Plan. The group comprised 9 coordinators who were very experienced and held tertiary level health professional qualifications. Four were early support coordinators, three active support coordinators, one return to work coordinator and one specialist support coordinator.

<u>The training program</u> included four components: online pre-training assessment, delivery and evaluation of the face-to-face training package over two workshops, individual mentoring sessions with each participant and online post-training assessment.

#### Results

All coordinators participated in the pre-training evaluation, the first SDM training session and one individual mentoring session. The second training session was completed by 8 coordinators and the post-training evaluation was completed by 5 of the 9 coordinators.

Trainer feedback ratings across participants and across all individual items were uniformly high with all ratings 4.00/5.00 or above. Content feedback tended to be lower and showed more variability across items ranging between 3.00 and 4.00.

Thematic analysis of the qualitative data from the evaluation generated three themes describing the beneficial aspects of the training: building SDM knowledge, applying SDM to real cases and discussing issues, four themes describing aspects that participants considered could be improved: amount of practical activities, length of training, amount and focus of discussion, and level of training and a final theme capturing aspects of SDM which coordinators saw as important to include in their current practice: taking back to practice.

Coordinators reported a decision coping style that aligned well with the principles underpinning the SMT Process and indicated that they were well suited to effectively implementing the La Trobe SDM Framework.

Coordinators' confidence in their ability to provide support for decision making increased significantly from a mean score of 5.2 to 8.0 (p = .02) on a scale of 0 to 10 over the period of time from pre-training to post-training which included participation in one mentoring session

Comparison of the pre- and post- assessment measures was consistent with positive change towards increased use of strategies that support client participation in decision making and improved use of SDM principles and strategies.

Transcripts of mentoring sessions provided important insights into practice challenges experienced by coordinators in the domain of SDM. These challenges reflected eight themes broadly conceptualised as factors that impact application of SDM principles in practice: i. workplace demands and supports, ii. severity of client's functional impairment and stage of recovery, iii. cultural and socio demographic

factors, iv. presence of comorbidities, v. presence and quality of client's support network, vi. conflict within client's support network, vii. quality of client's provider team, and viii. potential community options.

The mentoring sessions showed that coordinators had clearly incorporated SDM steps, principles and strategies within their practice, albeit at variable levels of use. The areas that were least well developed tended to be less clearly aligned with coordinator responsibilities.

Overall these results demonstrate that training in SDM can have a measurable impact on the professional practice of TAC claims staff working with clients with acquired brain injury. The steps, strategies and principles within the La Trobe SDM Practice Framework align well with the SMT Process currently underway in the organisation.

### Limitations

Nine coordinators participated in the project and while pre-training, training and mentoring data collection was completed by all participants, only 5 participants completed the final post-training measurement phase. In addition to being small in number, the group was very experienced with tertiary level health professional qualifications. Both design and group factors increase the risk of bias in these findings and thus generalisability beyond this group is limited and will need to be supported by further evaluation

### Recommendations

La Trobe's Living with Disability Research Centre is currently completing a large national ARC funded RCT investigating the impact of implementing the La Trobe SDM Framework on supporters and those they support. The RCT is using the same measures and mentoring regime as this TAC evaluation. Thus, it will be possible to compare these TAC findings with the RCT results from a range of supporters and a range of people with cognitive disability.

The Living with Disability Research Centre has also recently completed the online SDM learning resource that can be freely accessed through our website <a href="http://www.supportfordecisionmakingresource.com.au/module-1.html">http://www.supportfordecisionmakingresource.com.au/module-1.html</a>. This resource could be utilised to support further rollout of SDM to TAC staff.

The mentoring sessions included within this evaluation have also provided invaluable evidence from which to craft practice development case scenarios specific to the TAC practice context (appendix 5). These scenarios can be used to augment the audio-visual, case-based examples of people with acquired brain injury that are already included within the face-to-face and online training resources. Such cases could provide the content for ongoing professional development and mentoring within the organisation.

The field of supported decision making is a rapidly developing and challenging practice arena. It is best served by making sure that all those who provide support to an individual are aware of the principles and practice implications. In the case of TAC clients, provision of information to families and all those who work with the client (e.g., health professionals, support workers) is warranted.

#### Introduction

# Background

The TAC Independence division is implementing a new Service Model Framework underpinned by contemporary disability practice to support the mission to become the world's leading social insurer. Supported decision making is one principle of contemporary disability practice and it was the focus of this project as described in the Tasking Statement (T005). Supported decision making is a strategy that enables people with cognitive disabilities to participate in making decisions about their own life. It is based on the premise that providing the right level of support (e.g. tailored and varied in intensity) will compensate for decision making difficulties. Most importantly, supported decision making empowers a person to participate and gain life experience in making choices and exercising control based on their will and preferences.

Support for decision making is a complex process with multiple players (e.g., the person with cognitive disability, the supporter, others influencing or impacted by the decision) across a range of components (e.g., identifying the decision; implementing the decision) that requires ongoing tailoring across multiple factors (e.g., the personal attributes of the individual with cognitive disability including his or her life stage, the characteristics of the physical, social and organisational environment). The La Trobe Support for Decision Making (SDM) Practice Framework (Douglas & Bigby, 2020; see appendix 1) is based on substantial evidence collected systematically across a series of studies designed to explore the experience of decision making from the perspective of people with cognitive disabilities and those who support them to participate in decision-making. This body of research has given rise to 13 published articles [2-14] that together build a rich understanding of support for decision making in the lives of people with cognitive disabilities. Taken together the findings demonstrated that:

...people with cognitive disabilities have a "positive" or "successful" experience of decision-making support, if support is provided by one or more individuals with whom they have a trusting relationship; who have a knowledge of their history and goals (including previous

decisions and outcomes), and the nature of their impairment and level of functioning; who are flexible and use variable strategies to tailor their support to the unique needs and characteristics of each individual; and who collaborate with the individual to reach their desired outcome. [13] (p. 40).

In the context of implementing the new Service Model Framework, the TAC engaged the La Trobe Living with Disability Research Centre to build the capability of Independence claims employees to apply the La Trobe Support for Decision Making Framework in their interactions with clients. The TAC acknowledged that being able to effectively and competently apply the Support for Decision Making framework required the development of specialized skills and expertise and defined the following aims and objectives within the Project Tasking Statement.

# Aims and objectives

#### Aim

To translate existing evidence on the Support for Decision Making 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**

- 1. To design and deliver a quality training program to Independence claims employees on the La Trobe Support for Decision Making (SDM) Framework.
- 2. To assess the training-specific impact on the capability of Independence claims employees to be effective supporters of decision making.
- 3. To provide expert advice to the TAC on how to approach and embed measuring the impact and outcomes of training from a range of perspectives; claims employee, the client or their representative (e.g. family, friend or support worker), and potentially service providers.
- 4. To 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.

# Research design and methodology

#### Consultation and collaboration with the TAC

The research design and methodology was developed in collaboration with the TAC in order to tailor the content and delivery of the training to reflect: 1) the characteristics of TAC clients, 2) the role of independence claims employees, and 3) the features of supported decision making in the context of the TAC's current Service Model Transformation (SMT) process. This consultation took place at the TAC Melbourne offices on 14 February 2019.

# Delivery of intervention and measurement of intervention (training) impact

Support for decision making training is clearly aligned with the client's Plan process (Plan Development, Implementation and Review) in the SMT framework and was delivered in that context, as proposed by the TAC. The project was approved by the La Trobe University Human Ethics Committee prior to commencement.

# Primary participant group

Participants were required to be Independence claims employees who were participating in the SMT framework trials and currently managing TAC claims of adult clients (18 – 65 years) with a principal diagnosis of acquired brain injury and residing in a community setting. Consistent with the new Independence service model, claims employees were working with clients to develop, implement and review their Plan. The group included 9 women and one man, 7 of whom had more than 5 years experience working at the TAC (4 with 5-10 years; 3 with greater than 10 years) and 3 had less than 5 years experience. Nine participants were support coordinators (4 early support coordinators, 3 active support coordinators, 1 return to work coordinator, 1 specialist support coordinator) and the final participant was the team manager who participated in training but did not contribute data to analysis of results.

# Support for Decision Making Training

The support for decision-making process is conceptualised as comprising seven components or steps, delivered through individually tailored strategies and informed by three principles. Figure 1 is a schematic representation of the process. However,

it is emphasized that the real world is less ordered and although the steps are depicted as separate elements in the figure, they are considered parts of an iterative process, can often occur simultaneously and re-occur in the context of a single decision process.

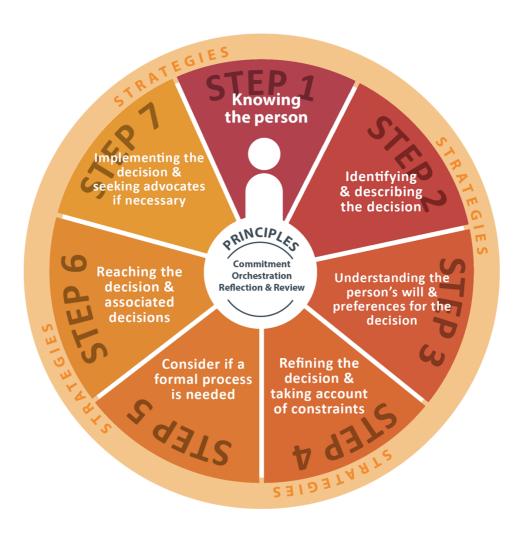


Figure 1. The La Trobe Support for Decision Making Framework

Following consultation with the TAC Independence service model project team, the Support for Decision Making Training was reviewed and revised to include three cases that specifically involved three clients with acquired brain injury who were residing in a community setting. The client decision making scenarios were presented in video format within the training package. The training was delivered

over two 2 x 1/2 days (4hrs plus break), face-to-face training workshops (26 March 2019, La Trobe City Campus; 5 April 2019 TAC offices Geelong).

The training program included the following four components.

<u>Pre-training structured measurement</u> included collection of employee individual and work-related characteristics (e.g., sex, work role, years experience with the TAC) and 4 quantitative measures:

- The Melbourne Decision Making Questionnaire (DMQ) (Mann et al., 1997),
- the SDM Confidence Rating (SDM-CR),
- the Decision Support Questionnaire Supporter version (DSQ-sup)
   (customized measure, research version Douglas & Bigby, 2016), and
- the Experience Response Questionnaire Supporter (ERQ-sup) (customized measure, research version - Douglas & Bigby, 2016).

These measures are described in detail in appendix 2 and summarized in table 1. Pre-training measurement was completed via online survey (Qualtrics) to enable participants to provide the data efficiently and conveniently in their individual contexts.

Table 1. Characteristics of quantitative measures

Measure	Focus	Subscales	Number of items	Response format
DMQ	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 to10 point scale: 0 - worse possible 10 - best possible
ERQ-sup	Responses in recent SDM situation	Scenario description + actions	10	3-point scale: 1 - No 2 - Partly 3 - Yes
DSQ-sup	Strategy use consistent with supported decision making principles	NA	32	4-point scale: 1 - Never or Rarely 2 - Sometimes 3 - Often, 4 - Usually or always.

<u>Delivery of the training package</u> (see attachment A1.1 for copy of presentation slides with embedded links to audio-visual materials). Evaluation of the training workshop delivered face-to-face was completed after the second training session (see appendix 3 and attachment A3.1). The training evaluation focussed on 2 elements of the training: i. the content and ii. the trainer. The content section contains 9 Likert items (5-point scale from 5 *strongly agree* to 0 *strongly disagree*) and 2 open-ended questions; the trainer section has 9 Likert scale items and 1 open ended question. The evaluation form finishes with a broad open-ended question inviting the respondent to make other comments.

The training materials are now available in a structured online learning resource; the link to which is included in appendix 1. A link to a related online resource which covers enabling risk and was included for reference during the workshops is also included in appendix 1).

Individual mentoring sessions were delivered to each participant to facilitate self-reflection, development of competency to apply the framework in client interactions and embed new skills within work practices. Prior to mentoring sessions, two checklists (La Trobe SDM Checklist, Identifying and Describing Decisions) were distributed to participants to guide the mentoring discussion (see appendix 4). A scheduling roster for mentoring sessions was made available to participants with multiple daily options specified from May through July. Individual sessions were 45 = 60 minutes long and centred around discussion of current practice exemplars identified by the participants. Mentoring sessions were recorded and transcribed verbatim. Although we had planned for up to 4 mentoring sessions post-training for each individual, this was not possible due to the time commitments of the support coordinators. All nine support coordinators participated in one mentoring session each.

<u>Post-training structured measurement</u> involved re-administration of the SDM-CR, the DSQ-sup, and ERQ-sup after training and mentoring. Participants were also given the opportunity to make additional comments about their experience of the training.

# Evaluating training-specific impact on Independence claims employee capability

Training-specific change in the primary participant group was measured using a mixed method (quantitative and qualitative) within group pre- vs post- intervention (i.e., repeated measures) comparison design (see figure 2). Quantitative measures comprised four self-report questionnaires (DMQ, SDM-CR, DSQ-sup, ERQ-sup). The ERQ yields both quantitative and qualitative data. Mentoring sessions were recorded and transcribed verbatim and data was analyzed using an inductive thematic approach, following the process described by Braun and Clarke (2006). The La Trobe SDM Checklist was also used as a template to code transcript data to the components of the practice framework.

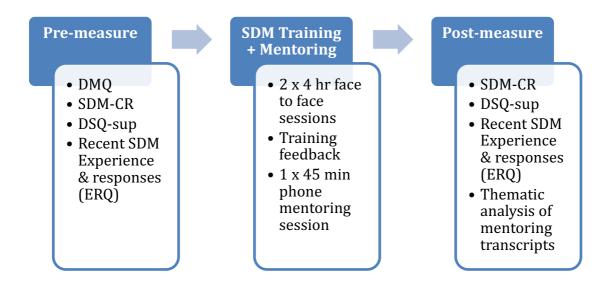


Figure 2. Evaluation design and measures

# **Results**

Table 2 displays the number and proportion of support coordinators who participated in each phase of the project. All coordinators participated in the pre-training evaluation, the first SDM training session and one individual mentoring session. Post training evaluation was completed by 5 of the 9 coordinators.

Table 2. Support coordinator participation across the phases of the project

Pre-training Evaluation	SDM Tr Sess		Training Feedback		Mentoring Session	Post-training Evaluation		
Qualtrics	1 2		Content Trainer		Content Trainer			Qualtrics
9	9	8	8	7	9	5		
(100%)	(100%)	(89%)	(89%)	(78%)	(100%)	(55.5)		

# Decision coping style demonstrated by support coordinators

The decision coping pattern of the employee group is shown in Figure 3. The pattern

is characterised by a strong emphasis on Vigilance that in turn supports sound and rational decision making. Decision makers in this group clarify objectives to be achieved by the decision, canvass an array of alternatives, search thoroughly for relevant information, assimilate information in an unbiased manner, and evaluate alternatives carefully before making a choice. None of the items on the Procrastination and Buck-passing scales had a mean score above 1.0. Two items on the Hyper-vigilance scale yielded a mean score above 1.0 (item 1, item 22) and both items related to the perceived negative impact of time pressure on decision making.

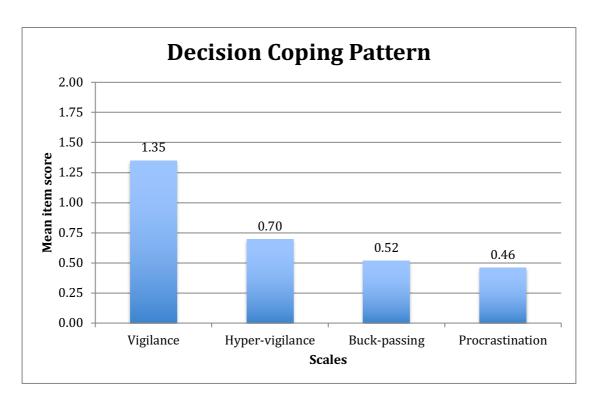


Figure 3. Decision coping pattern demonstrated by support coordinators (n = 9)

# Training feedback

Nine coordinators were present for session 1 of the training and eight were present for session 2. Evaluation of the training occurred after the second training session. Eight of those who attended completed the content section of the evaluation form and seven the trainer section. Descriptive statistics across participants on the quantitative evaluation are shown in table 3; descriptive statistics for each item are included in appendix 3. Trainer related ratings across participants and across all

individual items were uniformly high with all average ratings 4.00 or above. Content ratings tended to be lower and showed more variability across items ranging between 3.00 and 4.00.

Table 3. Training evaluation results across participants

Descriptive Statistic	Content (n=8)	Trainer (n=7)
Mean	3.5	4.54
Standard Deviation	0.5	0.42
Range	2.2-4.0	3.7-4.9

Results of thematic analysis of the qualitative data generated through the openended questions of the evaluation is shown in tables 4 and 5. Three themes together described the beneficial aspects of the training from the coordinators' perspectives: building SDM knowledge, applying SDM to real cases and discussing issues.

Comments coded within the first two themes were made independently by 7 of the 8 coordinators and reflected strong endorsement of the opportunity to build and apply knowledge in the area. The opportunity to discuss related issues was acknowledged as beneficial by 2 participants.

Four themes described the aspects that participants considered could be improved: amount of practical activities, length of training, amount and focus of discussion, and level of training. Four participants commented that the length of training and the amount and focus of discussion could be reduced and one described the level of the first session as being pitched to low. Most participants saw the opportunity to apply SDM principles and strategies of SDM as a benefit of the training but also saw it as an aspect that could be improved by the inclusion of more practical examples, including difficult situations and case scenarios. One participant suggested bringing their own scenarios for discussion as a way forward. This desire for applied practice is the reason for the mentoring component that has been built in to the La Trobe SDM training package.

The goal of mentoring sessions within the training is to apply the SDM framework to the real examples experienced by those who provide support for decision making. In the final post training and mentoring feedback opportunity, the benefit of mentoring sessions was identified by 3 of the 5 participants who made additional comments and

recommendations: 'continuous mentoring sessions as needed,' 'more training or mentoring around supported decision making for clients with challenging behaviours and clients that are non-verbal or only able to communicate basic needs, wants and feelings,' and 'more working through some actual decision making we are doing with clients. This was a great opportunity but came at a time when we are very bogged down with a new way of working.'

Table 4. Thematic analysis of responses to open-ended training evaluation items

Most beneficial aspects							
Theme	Number of participants	Example Quotes					
Building SDM knowledge	7	<ul> <li>Legislation and world standards and definition and breakdown of what supported decision making is</li> <li>La Trobe's model of supported decision making</li> <li>how to approach supported decision making</li> <li>Clarifying the importance of checking persons preferences and will</li> <li>Dignity of risk</li> <li>Understanding what support for decision making means for me in my role</li> </ul>					
Applying SDM to real cases	7	<ul> <li>Talking about specific client scenarios and trouble-shooting a suitable approach to SDM</li> <li>Application to real scenarios</li> <li>Discussion on actual cases</li> <li>Discussing the videos</li> <li>Videos were great</li> <li>The videos were beneficial to watch</li> </ul>					
Discussing issues	2	<ul><li>The general discussion</li><li>All discussion was interesting and engaging</li></ul>					

<u>Table 4 cont. Thematic analysis of responses to open-ended training evaluation items</u>

		Aspects to improve
Theme	Number of participants	Example Quotes
Amount of practical activities	6	<ul> <li>More practical how to</li> <li>Need training in the how and what to do -principles are clear</li> <li>I felt like there wasn't a lot offered that I can practically apply in my role</li> <li>More work on understanding and applying the framework</li> <li>More practical examples and reviewing how to manage more difficult situations</li> <li>Perhaps participants could bring their own scenarios to work through/discuss</li> </ul>
Length of training	4	<ul> <li>Felt full day was excessive</li> <li>Some info could be condensed</li> <li>Reduce length</li> </ul>
Amount and focus of discussion	4	<ul> <li>Sometimes we went off track</li> <li>Unstructured discussion</li> <li>We went off topic (e.g., we talked about active support quite a bit)</li> <li>At times the conversation got off track, although these conversations were still useful</li> </ul>
Level of training	1	First session was pitched a bit low i.e. we already know how to get to know clients

Finally, analysis of the training feedback about the 'take-out messages' perceived by participants revealed one major theme: *taking back to practice*. This theme captured multiple aspects of SDM coordinators saw as important to include in their current thinking and practice. All 8 respondents identified appreciation of one or more features of SDM to add to or emphasise in their knowledge and skills. (see table 5).

Table 5. Thematic analysis of responses to 'take-out message' evaluation item

Take-out messages										
Theme	Number of participants	Example Quotes								
Taking back to practice	8	<ul> <li>Understanding what support for decision making means for me in my role</li> <li>Make sure family are aware of alternative options other than substitute decision making</li> <li>Get to know the client</li> <li>Start with support and consideration of a person's ideas and help them to make a plan to take steps toward it</li> <li>Help client communicate their will and preferences</li> <li>Identifying when a client may be able to participate in decision making more than what they are</li> <li>Achieving SDM is difficult, many players in the game, aspects of SDM can still be applied, even when substitute decision making is in place</li> <li>Will and preference</li> <li>SDMis a basic human right</li> </ul>								

# Pre vs post training and mentoring evaluation of self-reported coordinators' outcomes

# **SDM Confidence**

Coordinators' confidence in their ability to provide support for decision making increased significantly from a mean score of 5.2 to 8.0 (p = .02) on a scale of 0 to 10 over the period of time from pre-training to post-training including participation in one mentoring session (see figure 4).



Figure 4. Pre- and post-training confidence levels

# <u>Decision Support Questionnaire – Supporter version (DSQ-sup)</u>

Figure 5 shows the pre and post profiles for responses on the DSQ-Sup and table 6 provides the mean and standard deviations for items on which significant change (p < .05) or a trend towards change (p < .08) was demonstrated. The profile is consistent with positive change towards increased use of strategies that support client participation in decision making.

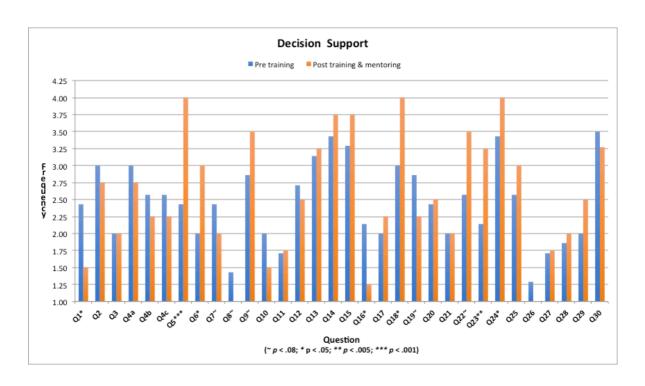


Figure 5. Pre- and post-training decision support strategies

Significant change (p < .05) was demonstrated on 7 items and a trend towards change  $(p \le .08)$  on a further 5 items of the Decision Support Questionnaire. These changes all reflected a change in strategy use that was consistent with improved use of SDM principles and strategies. For example, there was a significant reduction in frequent reliance on coordinators' interpretation of best interest rather than will and preferences to guide decision. Overall, significant changes demonstrated a consistent move towards practice that clearly supported the client's right to participate in decision making. Coordinators moved from sometimes to always checking the client wanted to be supported to make the decision and they reported always considering the significance of the decision for the client and the consequences of the outcome with the client. They reduced the frequency of choosing for the person from sometimes to never or rarely and showed a concomitant increase to relying on the client's preferences usually or always. Coordinators no longer used avoidance strategies and moved to usually or always working through each of the steps involved in the decision with the person. Finally, data showed a substantial increase in self-reflective practice with the frequency of considering their own potential influence increasing from sometimes to often.

Table 6. Items demonstrating significant change following training and mentoring

Item	Pre-training Mean (SD)	Post-Training Mean (SD)
*1. Rely on what you think is best for the person?	2.43 (.79)	1.50 (.58)
***5. Check the person wants your support to make the decision?	2.43 (.54)	4.00 (0.0)
*6. Emphasise options that are not risky? ~7. Let the person try out several options to inform the decision?	2.00 (0.0) 2.43 (.54)	3.00 (1.4) 2.00 (0.0)
~8. Avoid making the decision with the person by doing something else?	1.43 (.54)	1.00 (0)
~9. Rely on what the person wants or prefers?	2.86 (.69)	3.5 (.58)
*16. Choose for the person based on your knowledge of the person?	2.14 (.69)	1.25 (.25)
*18. Consider the consequences of the outcome with the person?	3.00 (1.0)	4.00 (0.0)
~19. Point out a range of options for the person?	2.86 (.69)	2.25 (.50)
~22. Work through each of the steps involved in the decision with the person?	2.57 (.98)	3.50 (.58)
**23. Think about how you might be influencing the decision?	2.14 (.38)	3.25 (.50)
*24. Consider the significance of the decision for the person?	3.43 (.54)	4.00 (0.0)

Note. ~ p < .08, \* p < .05, \*\* p < .005, \*\*\* p < .001

# Recent SDM Experience & responses (ERQ)

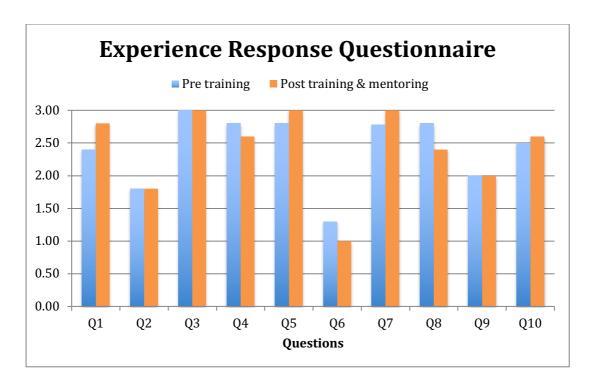
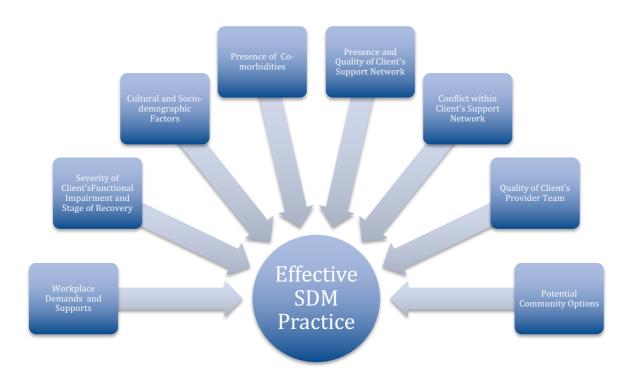


Figure 6. Pre- and post-training Experience Response Questionnaire

Figure 6 shows the pre- and post-profiles for responses on the ERQ-Sup. At pretraining evaluation, the coordinator group demonstrated a profile that was broadly consistent with SDM principles. No items generated statistically significant changes at post-training. However, three items (items 5, 6 and 7) showed noteworthy positive changes in a direction consistent with use of SDM practice. Item 5 moved to responses that reflected unanimous agreement post-training to asking about the choice that the decision maker wanted to make. Item 6 moved to responses across the group that demonstrated coordinators did not indicate to decision makers what choice they thought should be made and item 7 moved to unanimous agreement about helping the decision maker to think about a range of choices before choosing. Where post-training change could be identified in the SDM recent experience review task, change consistently reflected more interaction about and facilitation of decision making and less direct identification of the preferred choice from the supporter's perspective. Overall, these changes led to a small but measurable change in the supporters' satisfaction with the decision outcome reached.

# Analysis of mentoring transcripts

All nine support coordinators participated in a mentoring session. Mentoring session transcripts provided important insights into practice challenges experienced by coordinators in the domain of SDM. These challenges reflected several themes. For the most part, these themes were introduced by coordinators as barriers, but alternatively could be more broadly conceptualised as factors on a continuum each of which can impact SDM practice. Figure 7 illustrates the factors identified as acting as barriers or facilitators of effective SDM practice.



<u>Workplace conditions</u> could act as both a barrier and a facilitator to practice. In the context of the roll out of the new SMT trials, coordinators conveyed a sense of managing two sources of demands (regular workload + SMT trial requirements) that at times were perceived as overwhelming and stressful.

So, it's a real challenge. I'm really finding just getting the business as usual stuff done a challenge, let alone doing any of the analysis and surveys we have to do and feedback stuff.

It's been intense but I'm alright. .... Trying to get my head around the things that we need to do, and also the new clients, and the new way of working and all of that.

I think we're probably learning too many things in one go, but we're all getting there. All the meetings and things like that are quietening down a little bit and I think they're recognizing some of our challenges.

Regular workload was frequently described as unpredictable, especially in the case of participants in early support roles where coordinators had little control over having new clients and clients could be discharged from hospital with little notice.

We're all under the pump at the moment in the early space. We've got a lot of new clients and a lot of new clients coming in and then trying to manage that along with our other clients as well.

In the early space we're always getting new clients and new claims and that's something you can't really have control over.

I've always thought that the business doesn't really understand the environment in which we work in the early space. ...... Things can change so quickly. Like I'm going out to see a client after this and I just spoke to his OT and I'm going out for planning, a planning meeting to talk about what his options were for discharge, and she rang me and said he's going home (on date 2 days ahead) and I'm like 'What?" So, everything needs to happen so quickly. So, there's actually no structure to your workload. There is no accurate predictions. It's all fluid. Everything is fluid

Caseload demands fluctuated across the range of coordinator roles and crises or obstructions to effective practice could develop without warning. Time was for the most part perceived as a rare and precious resource, over which the individual had little direct control. This situation was recognized as even more troubling in the context of the SMT trial.

Yeah and just the amount of time that we're spending out, like this morning I had to do a survey that's only meant to take 20 minutes, it took an hour because you have to feedback. .... And last week we had to drive to Geelong to be present at a meeting that was for an hour. So I drove 4 hours to be present at a meeting for an hour and I just went – it's so stressful wasting – I know it's not a waste but it's just like -

Although team leadership and supports were highly valued, individuals frequently felt unwilling to identify work-related stressors as they recognized these were not specific to their own situation, but rather shared by colleagues in similar positions.

Everyone's busy and everyone has challenges and the clients keep coming in.

I debrief with a couple of people that are very experienced in what I do and understand.

Coordinators expressed a strong sense of loyalty to the organization, its vision, the SMT principles and their colleagues. Equally, they demonstrated a strong commitment to the clients with whom they worked. The group was exemplary in many ways and characterized by a high level of skill and practice insight with considerable experience that informed their ongoing practice.

I feel like I'm not doing my best – I feel like I'm reacting and not giving the best service that I can to my clients when I'm run off my feet. Yeah and I also feel I'm letting the pilot down because I'm not putting as much time into actually giving them feedback that I think is really important.

The severity of a client's functional impairment was a factor that had a substantial impact on practice. Executive function deficits, particularly insight, initiation and inhibition, shaped ongoing practice challenges in the SDM and planning space. The early stage of recovery, especially when disorders of consciousness were prolonged, presented challenges to SDM practice. These challenges were exacerbated by <u>lack of a support network</u> around a client or <u>conflict</u> within a client's family and support network. These factors added ongoing complexity to negotiating the SDM steps and

identifying the client's will and preferences in order to support choice and control in plan development.

I have a client who's really challenging. He lived just on the border in a small town and the hospital haven't been able to find any family members. Apparently, he has a daughter and an ex-partner in another state, but the ex-partner has indicated that she doesn't want to be involved. So, there is a friend apparently that lives about 20 minutes from him, but yeah, he's kind of not the next of kin, can only provide so much input because he doesn't really know that much. So yeah, that will be tricky. He's just come out of PTA, but he was 131 days, so he's severely impaired and non-verbal. In terms of him going back to where he was living, that is probably quite unlikely. So then where does he go, because I don't really know where he grew up, we've go no family anywhere. There is that one friend, who I guess would know him a little bit, that might be able to give me a little bit of an idea of him as a person and what he likes and doesn't like.

<u>Cultural and socio-demographic factors and presence of co-morbidities</u> are long acknowledged indicators of complex needs and practice challenges. These challenges were clearly evident within the mentoring session data and recognized and effectively responded to by support coordinators.

But he was smoking ice. We were trying to fix him but he was smoking ice. He was erratic, crazy, and then he went to a day-hab, came out, new person, completely sane person. There's so much he can do now, there's so much. It was the ice that was preventing most of it. He still has a million treaters, but when the worker thought that there was nothing she could do with him I said, "Well have you talked to him about things he likes and even volunteer work as a way to get to a job?" and when she did he came up with two ideas that were completely reasonable and in the means he could do, and he said he was happy to call them with the connections he already has.

But I'm really trying to help him explore what the different options are and the impacts of those, and the financial impacts and the time and what it's going to require, will he need to retrain, and finding the best ways to help deliver that to him too. That's the example I had of the one that I'm struggling with the most in terms of facilitating a decision because he's so anxious and he's getting quite defensive with me and we're just not getting anywhere.

Providers as well as family members also played a significant role in shaping coordinators' SDM practice efforts. In some situations, coordinators considered that clients were prevented from having 'a voice' in the decision making process by family, established provider teams and long term experience of not participating in decision making. This lack of alignment was noted to create stress, reduce motivation and decrease the range of options available for clients to pursue. Finally, lack, or scarcity of community options to match with clients' goals and preferences also acted as a barrier to implementing clients' decisions.

I feel like he has got provider groups around him who kind of undermine his capacity.

So, a few things have come up with this client. He has his mum and his stepfather as financial administrators, but they're not guardians. So, he doesn't have a guardian as far as I am aware, and his stepfather, right from the get-go he's been quite assertive like sort of writing him off a bit and suggesting he's not capable of doing things, or not even giving him the chance to be involved and be engaged. They're just operating in his best interest and not letting him have a voice.

Full on put a stop to it. .....It was kind of just making decisions on behalf and I just thought, I don't want to rock the boat too much, because I'm only new to the team, but I'm just sort of - my ears have pricked up on a few things that, yeah, they're not even allowing him to have a say.

I feel like the biggest challenge to implementing that (option) is the providers thinking it's not realistic and people making decisions based on his best interest.

There is just somebody else controlling everything he does in his life. Yeah, when I meet him next, I might just talk to him specifically about whether he does get to choose what he does with his carers or goes along and does whatever they suggest, and then sort of start to gain a bit of an understanding of what it is he likes to do when he goes out. Even that's a start to make sure - if I share that information with his agency and his carers, then maybe that will change and engage him in stuff that he actually wants to do when he goes out of the house.

Yeah, and it's really challenging too because I've got a lot of clients who have been in our system for five, ten years and they're really used to people making decisions for them and being really heavily guided, and through this whole pilot process and really trying to put them in the driver's seat, but they are really used to people making decisions for them or telling them what to do.

But it is now getting to the point when I look at your checklist and things... we're now involving some more supports .... and we're actually having a meeting in a couple of weeks with him to start to look at the options and the different impacts of each, and to help him to make a decision.

# Evidence of SDM steps, principles and strategies in practice

Table 7 depicts the strength of evidence related to the practice application of SDM steps, principles and strategies based on analysis of the content of the mentoring sessions.

<u>Table 7. Strength of evidence of SDM practice steps, principles and strategies in</u> mentoring sessions with support coordinators

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						

Note. Levels of use strong, high, medium, low

The mentoring sessions showed that coordinators had clearly incorporated SDM steps, principles and strategies within their practice, albeit at variable levels of use. The areas that were least well developed tended to be less clearly aligned with

coordinator responsibilities and distributed across a range of potential supporters in the person's life (e.g., family, hospital staff, providers, guardians).

# **Discussion and Practice Implications**

This project set out to translate existing evidence on the La Trobe Support for Decision Making (SDM) Practice Framework by training a small cohort of Independence claims employees to apply the approach to their client planning interactions. Results showed that the decision coping pattern of the participant group was characterized by a strong emphasis on Vigilance coping strategies that support sound and rational decision making. Decision makers with this type of decision coping pattern clarify objectives to be achieved by a decision, canvass an array of alternatives, search thoroughly for relevant information, assimilate information in an unbiased manner, and evaluate alternatives carefully before making a choice. Participants with this type decision coping style are well suited to applying the steps, principles and strategies of the SDM practice framework because they align with their personal decision-making preferences. This type of decision coping style also aligns well with the principles underpinning the Service Model Transformation Process and indicates that the Independence claims employees who participated in this pilot project were well suited to effectively using the La Trobe SDM Framework. Alternatively, the data also suggests that people with elevated scores on the hypervigilance, buck-passing and procrastination subscales are likely to be less well suite or need more support to make the move to practice reflecting a SDM approach.

Post-training evaluation showed the training had a significant and measurable positive impact on the participants' performance. Their confidence in their ability to provide support for decision making increased significantly and by more than 50%. They showed improved use of SDM steps and principles and a significant increase in their use of strategies that clearly supported the client's right to participate in decision making. They also showed a substantial increase in self-reflective practice with the frequency of considering their own potential influence on a client's decision making increasing from sometimes to often.

The positive changes in practice demonstrated on quantitative measures were also

clearly evident in qualitative data. After training, change on the SDM recent experience review task consistently reflected more interaction about and facilitation of decision making and less direct identification of the preferred choice from the coordinator's perspective. Transcript analysis of mentoring sessions also showed that coordinators had clearly incorporated SDM steps, principles and strategies firmly within their practice.

Overall these results demonstrate that training in SDM can have a measurable impact on the professional practice of TAC claims staff working with clients with acquired brain injury. The steps, strategies and principles within the La Trobe SDM Practice Framework align well with the Service Model Transformation Process currently underway in the organisation.

### Limitations and Recommendations

As is the case with all evaluation research, these findings need to be considered in the context of the limitations of the project. The study was a small pilot project utilizing a mixed method (quantitative and qualitative) within group pre- vs postintervention (i.e., repeated measures) comparison design. Nine coordinators participated in the project and while pre-training, training and mentoring data collection was completed by all participants, only 5 participants completed the final measurement phase. In addition to being small in number, the coordinators were volunteers who were selected to participate in the SMT pilot trial. This group was very experienced with tertiary level health professional qualifications. Both these design and group factors increase the risk of bias in the findings and thus generalisability beyond this group is limited. Further research is needed to better understand the impact of SDM training on those who are trained and also needs to include those who are supported. As La Trobe's Living with Disability Research Centre is currently completing a large ARC funded RCT investigating the impact of implementing the La Trobe SDM Framework using the same design, measures and mentoring as this TAC pilot but with anextended follow-up, it will be possible to compare these TAC findings with results across a range of supporters and the people with cognitive disability who are supported to participate in decision making.

La Trobe's Living with Disability Research Centre has recently completed the online

SDM learning resource that can be freely accessed through our website <a href="http://www.supportfordecisionmakingresource.com.au/module-1.html">http://www.supportfordecisionmakingresource.com.au/module-1.html</a>. This resource could be utilised to support further rollout of SDM to TAC staff.

The mentoring sessions included within this evaluation have also provided invaluable evidence from which to craft practice development case scenarios, specific to the TAC practice context (see appendix 5). Such scenarios would augment the audiovisual case-based examples of people with acquired brain injury that are already included within the face-to-face and online training resources. Such cases could form the basis of ongoing professional development and mentoring within the organisation. Finally, the field of supported decision making is a rapidly developing and challenging practice arena. It is best served by making sure that all those who provide support to an individual are aware of the principles and practice implications. In the case of TAC clients, provision of information to families and all those who work with the client (e.g., health professionals, support workers) is warranted to maximise the outcome of efforts to support those with acquired brain injury to participate in decision making that has a substantial impact on their lives.

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The La Trobe Support for Decision Making Practice Framework

# Open access publication

Douglas, J. & Bigby, C. (2020). Development of an Evidence-based Practice Framework to guide Decision Making Support for People with Cognitive Impairment due to Acquired Brain Injury or Intellectual Disability. *Disability and Rehabilitation*, 42(3), pp. 434-441 https://doi.org/10.1080/09638288.2018.1498546

<u>Presentation slides</u> (see attachment 1.1)

# <u>Structured learning online resource for frontline workers, practitioners and family supporters</u>

Bigby, C., Douglas, J.M., & Vassallo, S. (2019). The La Trobe Support for Decision Making Practice Framework. An online learning resource. Retrieved from:

# Related research

https://www.latrobe.edu.au/lids/research/effective-disability-services/decision-making

# Related online resource: Enabling Risk

Bigby, C., Douglas, J.M., & Vassallo, S. (2018). Enabling Risk: Putting Positives First. An online learning resource for disability support workers. Retrieved from: <a href="https://www.enablingriskresource.com.au">www.enablingriskresource.com.au</a>

# Pre- and post-training evaluation measures

The 4 quantitative measures used in the project are described below.

Melbourne Decision Making Questionnaire (DMQ) (Mann et al., 1997) is based on decision-coping patterns derived from Janis and Mann's conflict theory of decision making. It consists of 22 items distributed across four scales (vigilance – 6 items, hyper-vigilance - 5 items, procrastination – 5 items and buck-passing – 6 items). Items are scored on a 3-point scale: 0 - not true at all, 1 – sometimes true, 2 – true for me. Each of the scales has been shown to have good to excellent psychometric properties (Mann et al., 1997).

A high score on the <u>Vigilance</u> scale is consistent with decision makers who: clarify objectives to be achieved by the decision, canvass an array of alternatives, search painstakingly for relevant information, assimilate information in an unbiased manner, and evaluate alternatives carefully before making a choice. Vigilance is associated with a moderate level of psychological stress and according to conflict theory, is the only coping pattern that allows sound and rational decision making.

<u>Hyper-vigilance</u> is consistent with decision makers who search frantically for a way out of dilemmas and when under time pressure can impulsively seize upon hastily contrived solutions to achieve immediate relief. The full range of consequences of choices is overlooked because of emotional excitement, perseveration, and limited attention. Hypervigilance is associated with severe psychological stress.

<u>Procrastination</u> and <u>buck-passing</u> are associated with high stress and incomplete, often biased evaluation of information, leading to faulty decisions. They are both consistent with avoidant coping style. <u>Procrastination</u> is consistent with decision makers who tend to waste time on trivial matters, delay or put off making decisions or having made decisions put off acting upon them. Buck-passing is associated with leaving decisions to others and not

- taking responsibility and a general reluctance to make decisions.
- 2. <u>Support for Decision Making-Confidence Rating (SDM-CR)</u> requires the respondent to make a global confidence rating with respect to providing support for decision making to people with cognitive disabilities. The rating scale ranges from 0 to 10: 0 worse possible confidence, 10 best possible confidence.
- 3. Recent SDM experience and responses questionnaire (ERQ) (research version Douglas & Bigby, 2016) has 2 components which together provide a record of what the supporter did in a recent SDM scenario. The first component asks respondents to describe a recent support experience. Following the description of the situation, respondents answer 10-items about what they did during the experience using three categories: 1 No, 2 Partly, 3 Yes.
- 4. <u>Decision Support Questionnaire supporter version (DSQ-sup)</u> (research version Douglas & Bigby, 2016) is a customized 32-item scale developed to measure the frequency of use of support strategies. The items focus on providing support for decision making and the content of the items was derived from systematic review of the literature and the qualitative research evidence obtained from a series of studies with people with cognitive disabilities and their supporters (refs). Respondents are required to circle the frequency of use of the strategy described in each item, where: 1 = Never or Rarely, 2 = Sometimes, 3 = Often, and 4 = Usually or Always. Respondents are reminded to consider all the decision support situations they have encountered.

# **Training Evaluation**

The training evaluation comprised 2 sections: i. content of the training and ii. the trainer. The content section contains 9 Likert scale items and 2 open ended questions and the trainer section has 9 Likert scale items and 1 open ended question. The evaluation form finishes with a broad open-ended question inviting the respondent to make other comments (see attachment A3.1)

# **Item Level Descriptive Statistics**

Section 1: Content (8 respondents)

Resp	Q1 Met	Q2	Q3 Able	Q4	Q5	Q6	Q7	Q8	Q9
	Expect	Useful	to apply	Cont	Org	Read	Lev+pac	Discuss	Overall
1	4	4	4	4	4	4	3	4	3
2	3	4	4	4	5	5	2	2	4
3	3	3	4	4	4	4	4	5	3
4	4	4	4	4	4	3	3	4	3
5	4	4	4	4	4	4	4	4	4
6	2	4	3	4	4	3	5	5	2
7	2	3	4	3	5	5	2	5	3
8	2	3	3	3	2	2	1	2	2
Mean	3.00	3.63	3.75	3.75	4.00	3.75	3.00	3.88	3.00
SD	0.87	0.48	0.43	0.43	0.87	0.97	1.22	1.17	0.71

Section 2: Trainer (7 respondents)

Resp	Q13			Q16					
	Enc	Q14	Q15 Def	Enc	Q17	Q18	Q19	Q20	Q21
	Part	Clear	Terms	Qns	Know	e.g's	Comm	Learn	Overall
1	5	5	5	5	5	5	5	4	4
2	5	5	5	5	5	5	5	5	4
3	5	5	5	5	5	4	4	4	4
4	5	4	4	4	5	4	4	4	4
5	5	5	5	5	5	5	5	5	4
6	5	5	5	5	5	5	5	3	5
7	5	4	3	4	4	4	3	3	3
Mean	5.00	4.71	4.57	4.71	4.86	4.57	4.43	4.00	4.00
SD	0.00	0.45	0.73	0.43	0.35	0.49	0.73	0.76	0.53

# Mentoring Checklists

# La Trobe Support for Decision Making Framework

	Identifying and Describing Decisions	
SCOPE	What is the decision that needs to be made?	
	<ul><li>Why does it need to be made?</li></ul>	
	<ul><li>What are the possible options?</li></ul>	
	<ul> <li>How much will it impact on the person's life?</li> </ul>	
WHO'S INVOLVED	Who should be involved in supporting the person to	
	make the decision? (e.g. family, partner, friends,	
	support staff)	
	<ul> <li>Are there formal organisations involved? (e.g., the</li> </ul>	
	criminal justice system or health system)	
INFLUENCES	What are the constraining factors that will influence	
	the decision? (e.g., financial constraints, people's	
	attitudes)	
TIMEFRAME	What is the timeframe to make the decision?	
	Does it need to be made now, by a certain date, or	
	can it be made later?	
CONSEQUENCES	What are the potential consequences of choosing	
	one option over another?	
	What could the outcome of this decision look like for	
	the person?	

Support for Decision Making Checklist		
I HAVE (tick box that applies)	I DID THIS BY(insert explanation)	
☐ 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		
Applied the Principles:		
☐ Commitment		
☐ Orchestration		
☐ Reflection & Review		
Used the Strategies:		
☐ Attention to communication		
☐ Educated about consequences		
and practicalities		
☐ Listened and engaged		
☐ Created opportunities		

# Case scenarios specific to the TAC practice context

How would you support a client to make a decision in the following example situations?

- 1. A new client in hospital is being discharged and requires ongoing allied health and attendant care support on discharge.
- 2. You start working with a new client who is engaged with a vocational provider and no other supports. Through getting to know the client, he voiced he was not at a point where he felt ready or confident in his ability to consider work and he was really struggling just to get through each day due to cognitive issues. On further discussion with the client about how he came to be involved in voc, he identified that it wasn't his decision (he had just been automatically referred post hospital).
- 3. Shared supported accommodation house had been sold and all clients needed to be relocated, the choices were minimal given the lack of SSA for TAC clients. There was a choice for this client to move home with his wife, whom he had not lived with for 30 years, he did stay there every weekend.
- 4. Your client is working full time, however is not physically managing the role. He is concerned he will need to go off work soon due to pain, and doesn't want to let his employer know he is not managing. You have been trying to help him decide on a different work pathway, however he is very anxious and concerned about being unemployed in the meantime.
- 5. Decision regarding Supported accommodation vs Living at home. Requested by family as a strategy to meet their needs, rather than those of the client.
- 6. You have just spoken to a client and you learned that he had self-discharged from hospital following a recent fall. He made the decision against advice by the hospital who felt that he needed further transfer practice and to be linked in with a nurse at home prior to discharge. You asked him how things were going

- at home and he indicated that he was fine. You mentioned the concerns from the hospital and he said he felt that their recommendations were unnecessary.
- 7. A 15 year old client with a serious brain injury who wants to travel on the school bus without paid support. There is significant opposition to her decision from providers.
- 8. Your client with a severe brain injury wants to go home and be able to manage looking after his kids once discharged.