

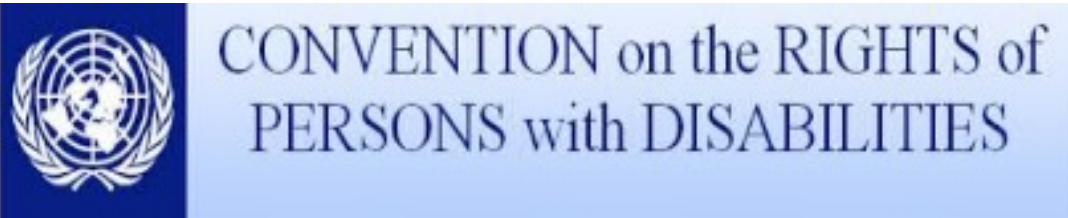


# Development and Preliminary Evaluation of the Decision Support Questionnaire (DSQ)

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# The right to participate in decision making



• 2006

- Persons with disabilities enjoy **legal capacity on an equal basis** with others in all aspects of life.
- Signatory nations agree to develop “appropriate measures to **provide access** by persons with disabilities to the **support** they may require in exercising their legal capacity.”



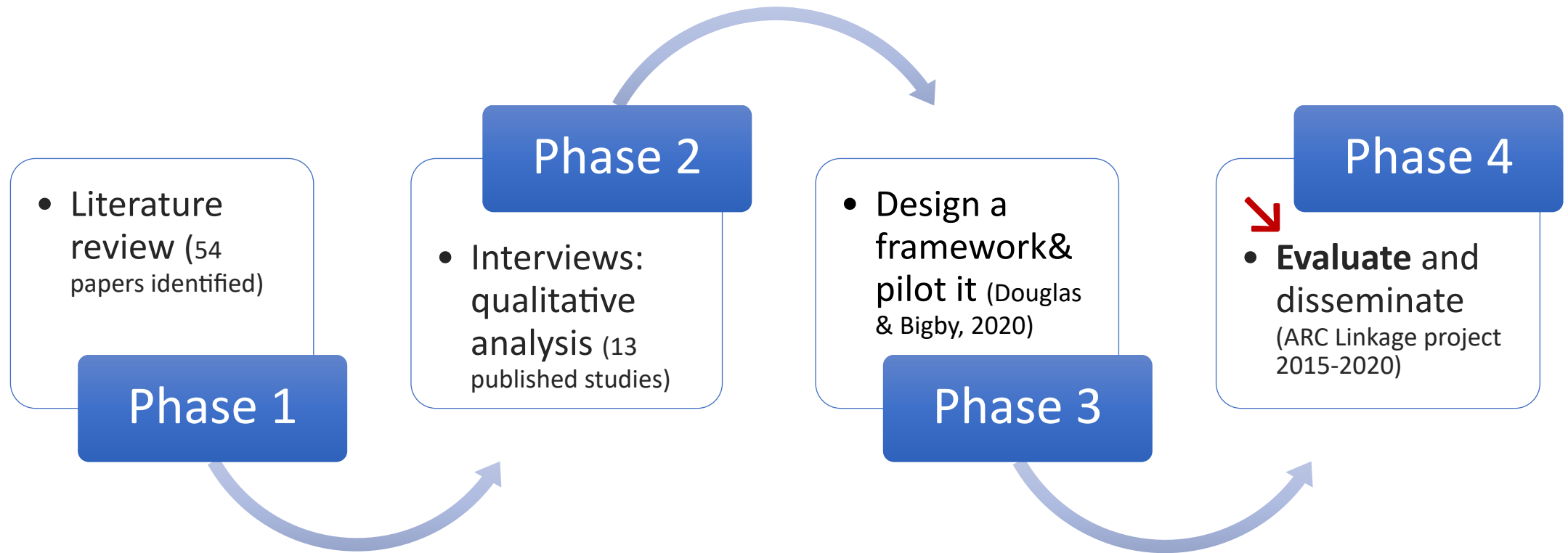
• 2014

- Persons who require support in decision-making must be **provided with access to the support** necessary for them to make, communicate and participate in decisions that affect their lives (principle 2)
- The **will, preferences and rights** of persons who may require decision-making **support** must direct decisions that affect their lives. (principle 3)

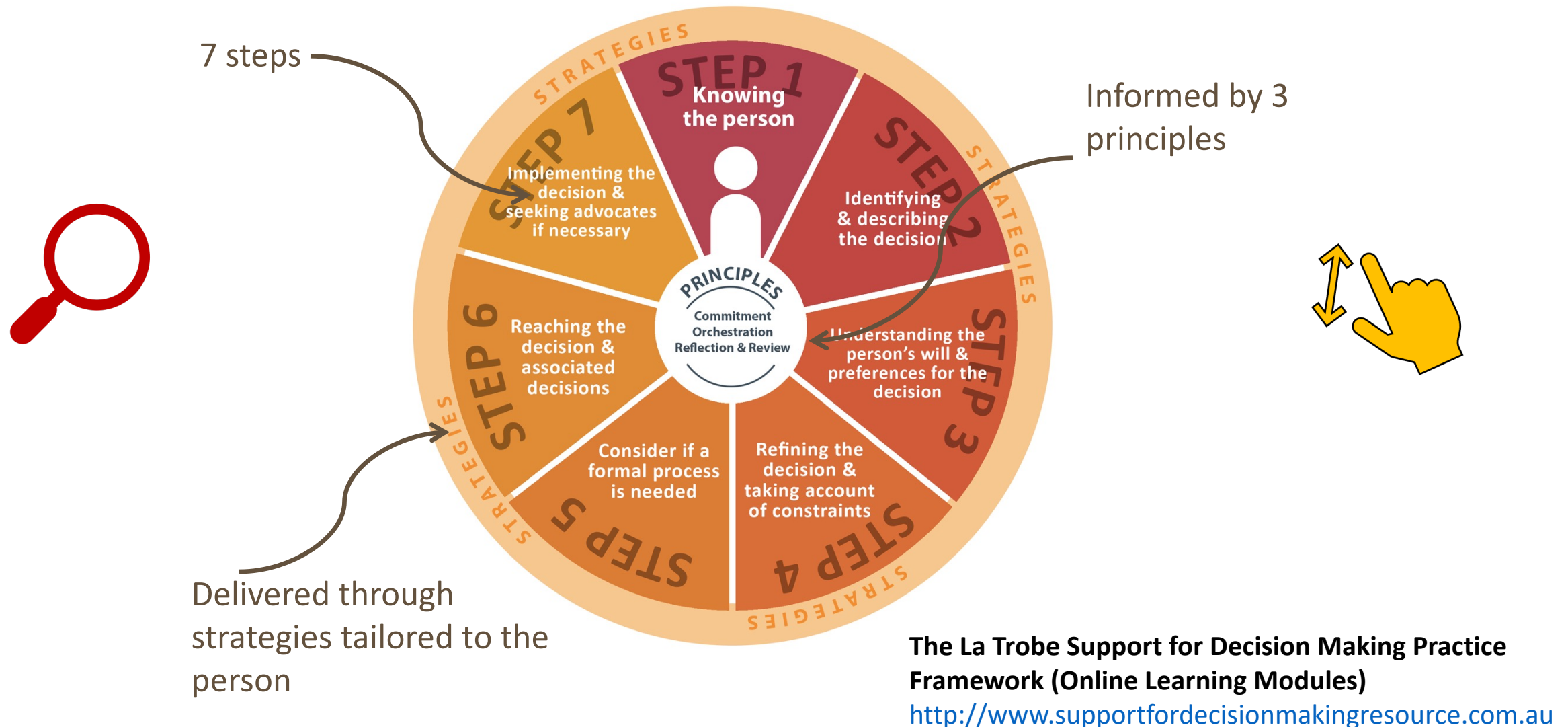
## Support for decision making (SDM)

- enables people with cognitive disabilities to participate in making decisions about their life
- empowers a person to gain life experience in making choices and exercising control based on their will and preferences
- is a complex multifaceted process
- La Trobe SDM practice framework provides an evidence-based guide for engaging in effective support for decision-making with people with cognitive disability

# Development of the La Trobe Practice Framework (Douglas & Bigby, 2020)



# The SDM practice framework (Douglas & Bigby, 2020)



# Aim

- Develop and complete preliminary psychometric evaluation of a self-report questionnaire that enables:
  - supporters of people with cognitive disability to
    - identify the support strategies they use
    - the frequency with which they use these strategies
  - researchers and program developers to
    - reliably and validly measure the support strategies used by supporters
    - assess training-specific impact on the capability of supporters to be effective supporters of decision making

# Development of the Decision Support Questionnaire

(research version 2016)

## Item Content & Selection

- Strategies identified through research
- Experience of people with cognitive disabilities and their supporters
  - People with intellectual disability, people with ABI, and those who support them
- 7 studies, 13 published papers\*

## DSQ Structure

- 32 items
- Modified Likert-type scale: four possible levels of response for each question  
(1) never or rarely    (2) sometimes    (3) often    (4) usually or always
- Change in frequency of strategy use can be monitored over time and in response to participation in training programs

\*Douglas & Bigby, 2020; <https://doi.org/10.1080/09638288.2018.1498546>

# Decision Support Questionnaire: Instructions and example Items (research version 2016)

**Instructions:** The following questions ask about providing support for decision making. For **every** question please circle the response which best answers the question, where:

**1 = Never or Rarely   2 = Sometimes   3 = Often   4 = Usually or Always**

Make sure you consider all the decision support situations you have encountered with person you support.

17. <b>Make a decision that feels right to you?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	
18. Consider the consequences of the outcome of with the person?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	
19. <b>Point out a range of options for the person?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	
20. Explore new experiences with the person that are relevant to the decision?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	
21. <b>Take the option the person will resist least?</b>					
22. Work through each of the steps involved in the decision with the person?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	
23. <b>Think about how you might be influencing the decision?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	



# Evaluation of the Decision Support Questionnaire

(research version 2016)

## Content Reliability

- Internal consistency
  - evaluates the degree to which the items are all measuring the same underlying construct:
  - *decision making support strategies*
- Cronbach's coefficient alpha
  - average correlation among the DSQ items (recommended range 0.7 – 0.9) (Tavakol & Dennick, 2011)

## Construct Validity

- Sensitivity to change (responsiveness)
  - ability to accurately assess change in an outcome due to intervention or developmental effects (Ebesutani, et al., 201)
  - the most convincing evidence of construct validity is documentation of within-subject changes on the measure after an effective intervention
  - the degree to which the DSQ items changed in the theoretically proposed direction following a training intervention

# Results



- Content Reliability (n=39)
- Construct Validity
  - 2 studies
  - Support Coordinators (n = 10)
  - Parents (n= 23)

# Reliability: Participants (n=39)

## Supporters

- 30 women and 9 men.
- 31 supported adults with intellectual disability
- 8 supported adults with ABI The
- average age: 52 years (range 24 – 71 years)
- support roles:    19 parents        2 partners        15 support workers  
                             2 siblings        1 adult child

## The adults they supported

- average age: 34 years (range 18 – 64 years)
- Average length of relationship 20 years (range 1 – 50 years)

## Content reliability: Cronbach's alpha (n=39)

Cronbach's Alpha*	Cronbach's Alpha Based on Standardized Items	N of Items
.812	.821	32

\*95% confidence interval: .715-.887

- DSQ has high internal consistency with low random error (.36) in the scores.
- An instrument cannot be valid unless it is reliable, so on to validity!

# Construct validity

## Responsiveness

- Sensitivity to change

Does the DSQ accurately assess change in decision support strategies following training based on the ***La Trobe Support for Decision Making Practice Framework?***

## Two studies

1. Participants: Support coordinators (n = 10) of adults with acquired cognitive disability due to severe traumatic brain injury (TBI)
  - Guiding hypothesis: *changes will reflect improved use of SDM principles and strategies.*
2. Parents of adults with intellectual disability (n = 23)
  - Item specific hypotheses: specified change in 19 items, no change in 13 items.

# Participants

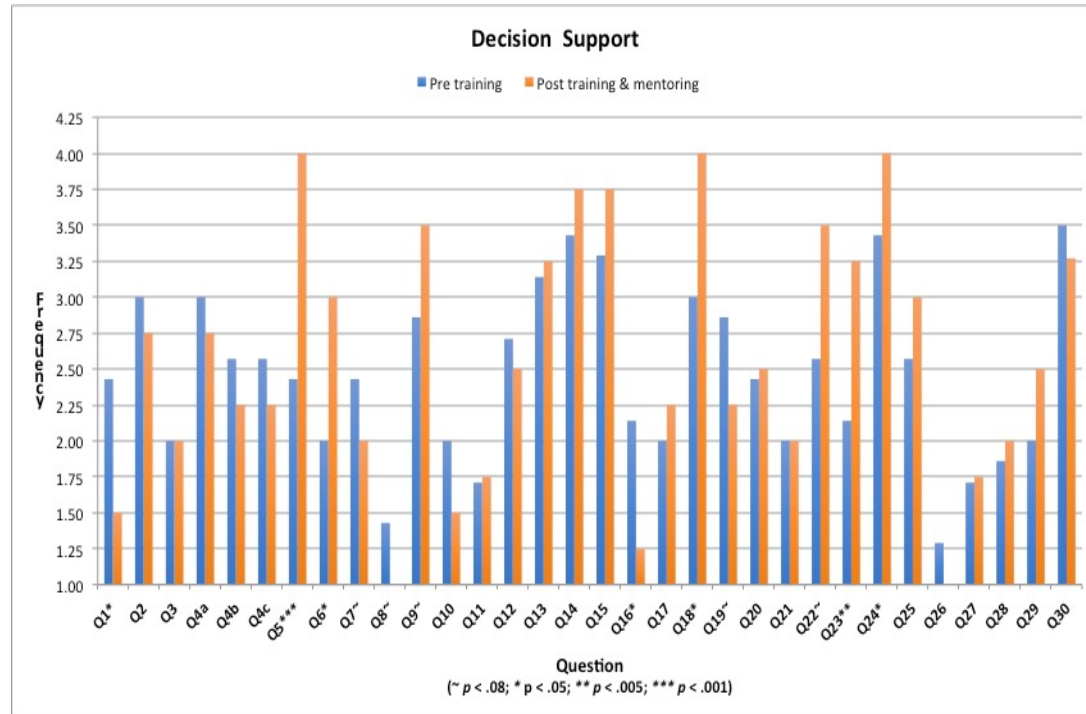
## Study 1

- 10 support coordinators (9 women, 1 man)
- held tertiary level health professional qualifications
- 7 > 10 and 3 < 5 years experience
- currently managing TAC claims of adult clients (18 – 65 years) with a principal diagnosis of ABI
- currently working with clients to develop, implement and review their Plan
- Role: 4 early, 3 active, 1 RTW, 1 specialist, 1 team manager

## Study 2

- 23 parents who regularly provided decision support for their adult child with intellectual disabilities
  - Aged from 47 to 74 years (M 58)
  - 18 (75%) were mothers
  - Adults they supported ranged in age from 18-39 years (M 27)
    - Most adults (19) lived at home with one or both of their parents.
    - Parent-report of severity of intellectual disability ranged from profound to mild.

# Study 1: Support coordinators's pre- vs post-training strategy use (DSQ)



- Reduced reliance on interpreted best interest; increased reliance on person's 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

- Significant change ( $p < .05$ ) on 7 items
- Trend towards change ( $p \leq .07$ ) on a further 5 items

**All changes reflected improved use of SDM principles and strategies**

# Study 2: Hypotheses for parents' pre- vs post-training frequency of strategy use (DSQ)



## 10 items will increase in frequency

- **Consult other people** who know the person in different situations
- **Seek advice** from a professional
- **Rely on what the person wants or prefers**
- **Weigh up advantages and disadvantages** of options with the person
- Think about the decision with respect to **the person's life goals**
- **Consider the consequences** of the outcome with the person
- Point out a **range of options** for the person
- **Explore new experiences** with the person that are relevant to the decision
- **Work through each of the steps** involved in the decision with the person
- **Review similar situations** that you know the person has experienced

## 9 items will decrease in frequency

- Emphasise **options that are not risky**
- **Avoid making the decision** with the person by doing something else
- Make the decision with the person on the **spur of the moment**
- **Focus on easy options**
- **Choose for the person** based on your knowledge of the person
- Make a decision that **feels right to you**
- Take the **option the person will resist least**
- **Shift attention away from the decision** to something else that needs to be achieved
- **Rely on what you think is best** for the person



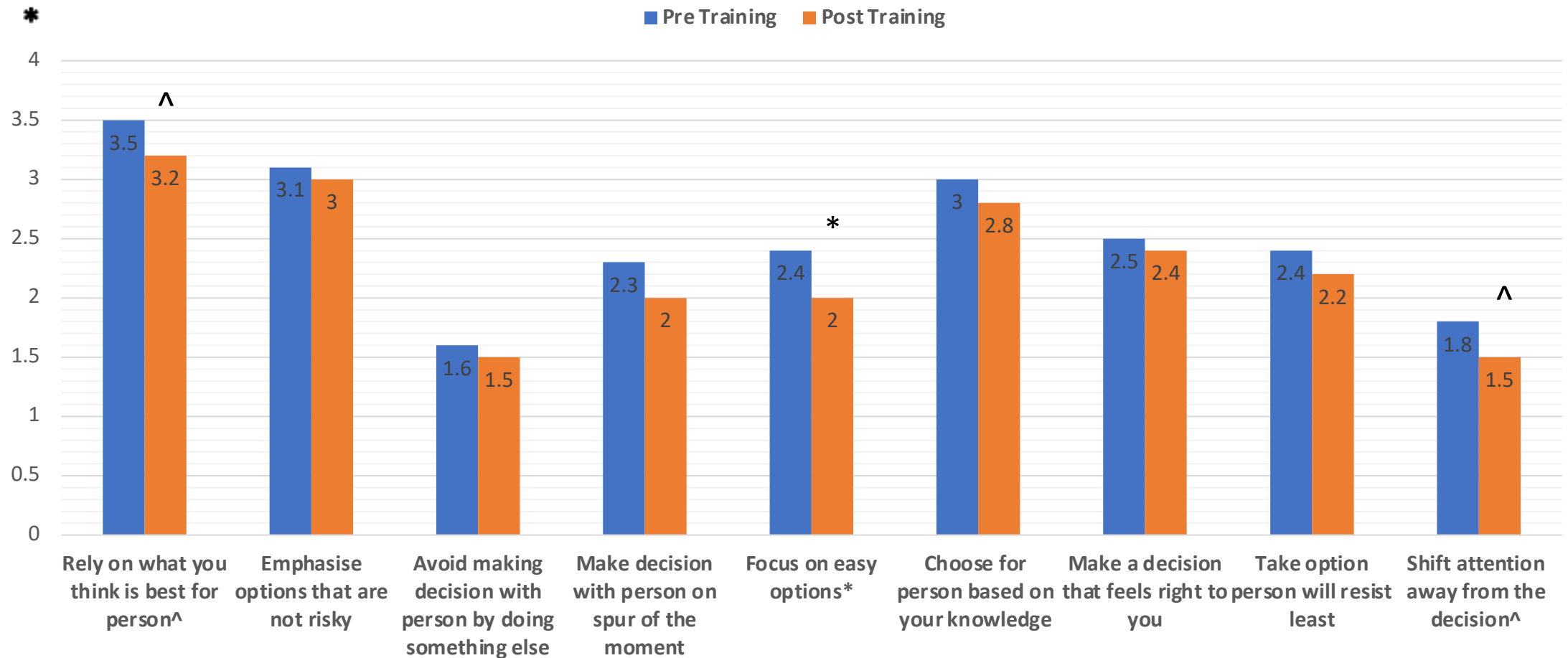
# Strategies expected to increase after training

(\* $p < .05$ ; ^ $p < .07$ )



# Strategies expected to decrease after training

(\* $p < .05$ ; ^ $p < .07$ )



# DSQ Sensitivity to change

## Hypotheses

- 10 items will show increased frequency of use
- 9 items will show decreased frequency of use.
- 13 items will show no change

## Results

- 6 strategies showed increased frequency of use (4 significant/trend)
- 1 strategy decreased
- 3 showed no change
- 9 strategies showed decreased frequency of use (3 significant/trend)
- 13 showed no change

# Summary of results: Validity of the DSQ

## Responsiveness

- Sensitivity to change

Does the DSQ accurately assess change in decision support strategies following training based on the *La Trobe Support for Decision Making Practice Framework*?

## Two studies

1. 10 support coordinators

Guiding hypothesis: changes reflect improved use of SDM principles and strategies

- ✓ All changes reflected improved use of SDM strategies (significance/trend in 12 items)
- ✓ Coordinators' confidence to provide support for decision making increased significantly ( $p = .02$ )

2. 23 parents

Item specific hypotheses: specified change in 19 items, no change in 13 items

- ✓ 28/32 items changed as hypothesised
- ✓ Parents' confidence to provide support for decision making increased significantly ( $p = .03$ )

# Evaluation of the Decision Support Questionnaire

(research version 2016)

## Content Reliability

- Internal consistency
  - ✓ Cronbach's coefficient alpha = .812 (95% con interval: .715-.887)
  - ✓ recommended range 0.7 – 0.9)
  - ✓ Low random error (.36)
  - ✓ items measuring the same underlying construct

## Construct Validity

- Sensitivity to change (responsiveness)
  - ✓ ability to accurately assess change in an outcome due to intervention
  - ✓ changes after training reflect improved use of SDM principles and strategies in two groups (support coordinators and parents)
  - ✓ the most convincing evidence of construct validity is documentation of within-subject changes on the measure after effective intervention

# Limitations and future research

- Small sample size
  - Reliability
  - Validity
    - Factor analysis
      - Underlying structure of the measure
      - Ideally need 5-10 participants per item (160 -320 participants)

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**Thank**

**you**

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