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

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\textbf{AUSTRALIAN RESEARCH COUNCIL} Linkage Project (LP150100391)
The right to participate in decision making

**CONVENTION on the RIGHTS of PERSONS with DISABILITIES**

- 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.”

**Australian Government Australian Law Reform Commission**

- 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)

See: Douglas & Bigby (2020); Then, Carney, Bigby & Douglas (2018)
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)

**Phase 1**
- Literature review (54 papers identified)

**Phase 2**
- Interviews: qualitative analysis (13 published studies)

**Phase 3**
- Design a framework & pilot it (Douglas & Bigby, 2020)

**Phase 4**
- Evaluate and disseminate (ARC Linkage project 2015-2020)
The SDM practice framework (Douglas & Bigby, 2020)

7 steps

Informed by 3 principles

Delivered through strategies tailored to the person

The La Trobe Support for Decision Making Practice Framework (Online Learning Modules)
http://www.supportfordecisionmakingresource.com.au
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](https://doi.org/10.1080/09638288.2018.1498546)
**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**.

<table>
<thead>
<tr>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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</thead>
<tbody>
<tr>
<td>17. Make a decision that feels right to you?</td>
<td></td>
<td></td>
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<tr>
<td>18. Consider the consequences of the outcome of with the person?</td>
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<tr>
<td>19. Point out a range of options for the person?</td>
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<td>20. Explore new experiences with the person that are relevant to the decision?</td>
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<tr>
<td>21. Take the option the person will resist least?</td>
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<tr>
<td>22. Work through each of the steps involved in the decision with the person?</td>
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<td></td>
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<tr>
<td>23. Think about how you might be influencing the decision?</td>
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Evaluation of the Decision Support Questionnaire (research version 2016)

<table>
<thead>
<tr>
<th>Content Reliability</th>
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<tbody>
<tr>
<td>• Internal consistency</td>
</tr>
<tr>
<td>• evaluates the degree to which the items are all measuring the same underlying construct:</td>
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<tr>
<td>• decision making support strategies</td>
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<tr>
<td>• Cronbach’s coefficient alpha</td>
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<tr>
<td>• average correlation among the DSQ items (recommended range 0.7 – 0.9)</td>
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<td>(Tavakol &amp; Dennick, 2011)</td>
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<thead>
<tr>
<th>Construct Validity</th>
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<tr>
<td>• Sensitivity to change (responsiveness)</td>
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<tr>
<td>• ability to accurately assess change in an outcome due to intervention or developmental effects (Ebesutani, et al., 201)</td>
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<tr>
<td>• the most convincing evidence of construct validity is documentation of within-subject changes on the measure after an effective intervention</td>
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<tr>
<td>• the degree to which the DSQ items changed in the theoretically proposed direction following a training intervention</td>
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</table>

*Douglas & Bigby, 2020; [https://doi.org/10.1080/09638288.2018.1498546](https://doi.org/10.1080/09638288.2018.1498546)*
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
- 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)

<table>
<thead>
<tr>
<th>Cronbach's Alpha*</th>
<th>Cronbach's Alpha Based on Standardized Items</th>
<th>N of Items</th>
</tr>
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<tbody>
<tr>
<td>.812</td>
<td>.821</td>
<td>32</td>
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*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)

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