

Mr Alan Cameron AO
Chairperson
NSW Law Reform Commission
GPO Box 31
SYDNEY NSW 2001

04 NOV 2016

Dear Mr Cameron,

Review of the *Guardianship Act 1987* (NSW): Question Paper 1: Preconditions for alternative decision-making arrangements

Thank you for inviting the Department of Family and Community Services (FACS) to comment on Question Paper 1: Preconditions for alternative decision-making arrangements. FACS welcomes this opportunity to participate in this first stage of the review of the *Guardianship Act 1987* (NSW) (Guardianship Act).

FACS, on behalf of the Minister for Disability Services, administers the *Disability Inclusion Act 2014* (NSW) which sets out key objectives for how it supports vulnerable people and families across NSW. This includes services to enable people to participate in social and economic life, through FACS' own services, and through funding non-government organisations to deliver specialist support services.

FACS has also developed and funded a range of supported decision-making pilots and research programs to enhance the decision-making capability of people with disability. This is an effective strategy for preparing people in NSW for transition to the National Disability Insurance Scheme (NDIS) by July 2018.

Relevance of the review

The review is part of the NSW Government's broader commitment to look at the interoperability of NDIS legislation with NSW legislation.

FACS' client groups are affected by the current regulatory decision-making regime under the Guardianship Act. The overarching focus areas of Question Paper 1 may have a significant impact on how the law operates in relation to people with disability in the context of full rollout of the NDIS.

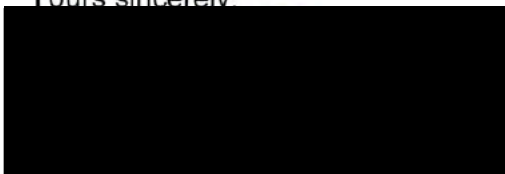
These areas are:

- inquiry into the current legislative approach to capacity and whether the Act provides enough guidance on how capacity is defined and how decisions about regulating decision-making are made
- inquiry into whether the Act's emphasis on disability through its terminology and through its link between a person's disability and substitute decision-making arrangements, should be reformed
- inquiry into 'best interests' decision-making and whether there is an alternative statutory precondition for substituted decision-making arrangements.

FACS' responses and proposed reforms on each of these inquiry areas are outlined in the enclosed submission.

If you would like to discuss FACS' submission on Question Paper 1, please contact Christine Higgins at the Legislative Reform & Right to Information team at

Yours sincerely



Michael Coutts-Trotter
Secretary

Encl.

Submission to NSW Law Reform Commission

Review of the Guardianship Act 1987 (NSW): Question Paper 1: Preconditions for alternative decision-making arrangements

1. Publication of submission

- 1.1 The Department of Family and Community Services (FACS) welcomes this opportunity to respond to *Question Paper 1: Preconditions for alternative decision-making arrangements (QP1)* and consents to the publication of this submission.

2. Context of submission

- 2.1 FACS has reviewed Question Paper 1 in the context of the current transitional stage of the NSW rollout to the National Disability Insurance Scheme (**NDIS**).
- 2.2 FACS considers there is the need for consistency and interoperability between the NSW legal regime of the *Guardianship Act 1987 (NSW)* (Guardianship Act) and the Commonwealth's *National Disability Insurance Scheme Act 2013 (Cth)* (**NDISA**). The preconditions of 'capacity', disability, and 'best interests' decision-making in the Guardianship Act could be reformed to complement the NDIS framework.
- 2.3 On a broader scale, there may be merit in scoping how the review could propose new legislative or regulatory provisions to operationalise the National Quality and Safeguards Framework (**Q&S Framework**) in such a way that creates clarity for how NDIS participants and their guardians would interact with these two systems.
- 2.4 As part of its obligations under the *Disability Inclusion Act 2014 (NSW)* (**DIA**), FACS oversees a range of support services that are designed by individualised decision-making and funding arrangements to develop decision-making capacity and autonomy in people with disability, to prepare for transition to the NDIS.
- 2.5 FACS has also developed and partnered on a range of supported decision-making programs and research to inquire into the impact of this approach on people with disability, and their carers. FACS has referred to key findings and example case studies from these initiatives in this submission, as these provide a strong evidence base for demonstrating that a person's access to appropriate support is a relevant factor in influencing their decision-making capacity (see **Attachment A** and **Attachment B**).
- 2.6 FACS has not commented on every question asked by QP1, however, FACS may further comment on the preconditions for alternative decision-making arrangements in 'Question Paper 2: Decision-making models'.

3. FACS' general comments

- 3.1 QP1 presents alternative approaches to how the preconditions are currently defined and applied in authorising substitute decision-making arrangements.
- 3.2 The conceptualisation of 'disability' and 'decision-making' is now positioned against the contemporary reform framework which is informed by the principles of the Convention on the Rights of Persons with Disabilities (CRPD): participation and self-determination; inherent universal rights versus demonstrated ability to exercise those rights; protection from harm versus dignity of risk; capacity versus incapacity; 'will and preferences' versus 'best interests' decision-making.

- 3.3 The review of the Guardianship Act presents NSW with a significant opportunity to examine its legal decision-making regime as part of the NSW Government's priorities for people with disability in NSW. Reforming the Act's statutory assumptions about 'incapacity' and 'disability' in consideration of this contemporary context can enforce positive expectations in the community, and affirm the NSW Government's commitment to inclusion.
- 3.4 FACS considers that this review is about confirming the place of the legislative regime for substitute decision-making within the human rights framework that now underpins disability law reform generally.
- 3.5 FACS considers that guardianship can and should continue in this contemporary context, however, this review highlights that a more robust and transparent legal framework for how capacity is determined and applied is now required.
- 3.6 FACS supports reform which aligns the Guardianship Act with the disability rights objects and principles set out in the DIA; and the 'choice and control' framework of the NDISA. FACS considers that the Guardianship Act requires greater clarity for people with reduced decision-making capacity and their carers who access this regime. Any reform should align with the Q&S Framework, which is underpinned by the human rights principle of 'choice and control'.
- 3.7 Reform also needs to be pragmatic to ensure the decision-making regime is accessible and flexible enough for ordinary people with reduced capacity to have their wishes and preferences respected; and for service providers to work effectively with them.

4. FACS' key proposals for reform

4.1 FACS proposes the following reforms to the preconditions:

Capacity

- The Guardianship Act should set out a statutory presumption of capacity.
- The Guardianship Act should incorporate a statutory test for capacity for the purposes of determining when a person lacks decision-making capacity.
- The statutory test should be a functional test for capacity which identifies key elements or conditions of decision-making capacity.
- The statutory test should be informed by guiding principles which confirm the rights of people to make decisions, and should recognise that access to appropriate support is a mandatory consideration for determining the question of capacity.

Disability

- FACS supports the removal of the link to disability in determining the need for guardianship orders but cautions against creating uncertainty in the law. The removal of the link to disability must not lead to conceptual ambiguity and prevent the Act from operating to achieve its legitimate purposes.

Best interests

- FACS considers that the Guardianship Act should retain the 'best interests' precondition for substitute decision-making arrangements but should provide further information on what is required by decision-makers.

5. Precondition: capacity

Question 3.6 Statutory presumption of capacity

Should there be a statutory presumption of capacity?

- 5.1 Although this does not follow the order of QP1, FACS has addressed this question in the first instance because in FACS' view, this question presents the starting point for responding to the issues that follow.
- 5.2 The Guardianship Act should contain an explicit presumption of capacity. This is a significant measure for protecting the legal capacity of vulnerable persons in the legal context providing for the appointment of alternative decision-making arrangements. It reinforces the right of all persons to autonomy in decision-making. This would also strengthen the law's alignment with broader rights-based reforms in NSW.
- 5.3 This is important in the current service context of the inclusion agenda and transition to the NDIS. In this transition, disability will become the business of a much wider range of service providers who may be inclined to be conservative or risk averse in their work with people with decision-making impairments.
- 5.4 The review may wish to consider whether to incorporate a statement of principles into the Act, to elaborate on the meaning of the presumption. This will provide significant guidance to the transitioning disability support sector in NSW.
- 5.5 These principles could reinforce the human rights language of 'equality before the law', and could outline the key elements of how to respect the right of an adult person in the context of the jurisdiction of the Act.
- 5.6 The principles could be incorporated into the Guardianship Act through acknowledgements, such as the acknowledgements provided by section 5 of the Queensland *Guardianship and Administration Act 2000* (Qld).

Question 3.1: Elaboration of decision-making capacity

Should the *Guardianship Act* provide further detail to explain what is involved in having, or not having, decision-making capacity?

If the *Guardianship Act* were to provide further detail to explain what is involved in having, or not having, decision-making capacity, how should this be done?

- 5.7 Both the review's Background Paper and Question Paper 1 cite the CRPD Committee's General Comment No. 1: Equality Before the Law (2014) that argues that guardianship regimes do not conform to the CRPD. General Comment 1 also asserts that compliance with the Convention means:
'perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity'.
- 5.8 This issue is complex because all substitute decision-making regimes in Australia, and arguably internationally, operate by establishing mental incapacity or impairment as the grounds for authorising an alternative decision-making arrangement.
- 5.9 The benefit of identifying the view outlined by General Comment 1 is in repositioning this legal assumption against the human rights obligations under the CRPD. The paradigm shift to a human rights understanding of disability in international and

domestic law and policy reform, has, to some extent, conceptualised the legal determination of 'incapacity' for people with disability as a form of discrimination.

- 5.10 FACS, however, notes that General Comment 1 is an interpretation of these obligations, and is not binding. In this context, FACS considers that the question for the 'capacity precondition' is how and when the law can limit a person's legal capacity by authorising a substitute decision-maker in his or her place.
- 5.11 FACS argues that compliance with the obligations under the CRPD can be shown where the limitations on legal capacity are legitimate and proportionate for safeguarding rights and interests; and where the limitations are not applied in a discriminatory way to a particular target group of persons, such as people with disability.
- 5.12 FACS considers that providing further detail on explaining capacity is one way to align the Guardianship Act to the broader human rights obligations. In particular, the Act should provide further guidance on the circumstances in which a person is found to lack decision-making capacity, to the extent that they need a substitute decision-maker.
- 5.13 FACS supports a functional test of capacity, noting there is currently no legislative definition of capacity/incapacity in any Australian guardianship jurisdiction, and the general law does not prescribe a fixed standard of 'capacity' for 'self-management'. This is because there is no universal 'test' for the assessment of whether a person is incapable of 'managing his or her own affairs' (*A v A* [2015] NSWSC 1778 at par [76]).
- 5.14 A functional test positions a person's lack of decision-making capacity as the basis on which a person's legal capacity may be limited, not their status as a person with disability or cognitive impairment.
- 5.15 The Act should identify standard elements or 'conditions' for demonstrating decision-making capacity in the areas to which the Guardianship Act applies: 'self management' of financial affairs (financial management); 'managing his or her person' (guardianship); and in demonstrating consent to medical treatment.
- 5.16 The statutory conditions should consider the general law's conceptualisation of incapacity (amended here from principles developed by various judgments cited in *A v A* at par [65]):
 - (a) incapacity should be strictly understood and governed by the purposes of the guardianship regime, that is, to ensure that vulnerable people who cannot make decisions are protected from harm and from being denied access to outcomes or benefits they would otherwise be able to obtain (e.g. medical treatment to alleviate illness; access to services)
 - (b) of central importance is the 'functionality of management capacity', not the person's status as a person who may or may not lack 'mental capacity' or be 'mentally ill'; or particular reasons for their incapacity
 - (c) the focus of the statutory jurisdiction should be protection of a particular person, not the benefit to the State or other persons
 - (d) the 'personal affairs' are those of the person under scrutiny, in their particular circumstances
 - (e) the inquiry into the particular issue on which the person's management is in question can focus on the reasonably foreseeable future

5.17 The *Mental Capacity Act 2005* (UK) referred to in QP1 sets out a codified test of capacity that may be useful as a guide for NSW. The UK model identifies what constitutes a person's *inability* to make decisions according to four elements or conditions:

'... a person is unable to make a decision for himself if he is unable—

(a) to understand the information relevant to the decision,

(b) to retain that information,

(c) to use or weigh that information as part of the process of making the decision, or

(d) to communicate his decision (whether by talking, using sign language or any other means).'

5.18 FACS proposes that the Guardianship Act should acknowledge that a person can have 'impaired capacity' but still demonstrate capacity to make a particular decision. An example of this approach is the Queensland *Guardianship and Administration Act 2000* which speaks of the 'capacity of an adult with impaired capacity to make decisions' (section 5(c)).

5.19 FACS' supported decision-making programs have clearly demonstrated that a person with impaired capacity can drive their own decisions, or at least express their preferences to achieve a particular outcome, where they have access to appropriate support:

"Simple resources can make a big difference"

Carla* recently had a lengthy admission to hospital for leg surgery. During her admission she was physically restrained by staff and twice transferred to a mental health unit. Carla and her supporter felt that Carla's bad experience at hospital was mostly about hospital staff not understanding how Carla could be best supported. The hospital had Carla's support plan but it was a large document and was misplaced by staff. In response - with guidance of the SDMP facilitator and assistance from her supporter - Carla decided to write a one page story that she could give to hospital staff the next time she needed to go to hospital. This might help them to give her the support she needed. Carla adapted the 'important to/ important for' tool to write her story. It told the story of who she was, why she might become anxious, and how best to support her if she did become anxious. She felt it would give her more control over the support she would get the next time she is in hospital. Carla and her supporter are thinking about other situations in which the tool may also be used.

*Name changed ('My Life, my decision' - Supported Decision-Making Pilot)

5.20 FACS has considered each of the elements in the UK model against the decision-making capacity indicators highlighted by the 'My Life, my decision' evaluation (set out at Attachment A):

(a) The individual must understand the information relevant to the decision to be made, or action to be undertaken.

“Seemingly simple decisions can be made complex when there is a lack of support available to work through and implement decisions”

Mandy* lived in a group home with drop in support. She made a decision to get an iPad and her financial manager approved the cost. Mandy had limited natural supports and chose her keyworker as her supporter to buy the iPad. The facilitator worked with Mandy and the keyworker around implementing the decision. Mandy took initiative by getting a quote and later found another cheaper quote. Her supporter and other staff at the group home reported a number of obstacles: they were too busy, there were greater priorities for Mandy, the supporter went on holiday, and there was a concern that Mandy would lose the iPad.

**Name changed ('My Life, my decision' - Supported Decision-Making Pilot)*

(b) The individual must be able to use and weigh (ability to reason about) the information in making a decision.

“Supporters have a key role to play in helping individuals to weigh up their choices”

David* is in his early 30s and is eager to move out of his parents' home and live in a group home. David's supporter (and mother), Lisa, believed that for David to make an informed decision he needed to better understand the consequences of moving. David agreed to write a list of his rights and responsibilities thinking about the differences between living at home and living in a group home. This was done by drawing a line down a piece of blank paper and simply thinking about what the move would look like. Five months later, after several sessions with his supporter and facilitator, David repeated the exercise. David's second list was much more detailed. He was able to see the marked improvement in his ability to think through his decision by comparing the two lists he had made. This has provided David with a transferrable skill, enabling him to better communicate his preferences.

**Name changed ('My Life, my decision' - Supported Decision-Making Pilot)*

(c) The individual should bear the dignity of risk.

“Balancing dignity of risk and duty of care is a challenging part of the supporter role”

Abdul* enjoyed living in his group home but sometimes became angry and would leave the house and walk to a local park to cool off. He always returned. Staff at the home feared Abdul would be hit by a car on these walks and, for his own safety, wanted to prevent him walking alone in the streets. The facilitator worked on the decision with Abdul and with his keyworker, who was also his supporter. Abdul clearly articulated how to cross the road safely (look both ways and cross if there were no cars). His supporter noted that the park was close and there was only one road to cross, and the road was not busy. The facilitator encouraged the supporter and staff at the group home to consider Abdul's right to go for a walk when he chose to, whether he was angry or not and suggested reviewing Abdul's road crossing skills for any additional training needs. Helping the person to manage risk and to carry risk is hard but necessary work.

**Name changed ('My Life, my decision' - Supported Decision-Making Pilot)*

(d) *The individual must be able to appreciate the nature of the situation and identify the consequences of their decision.*

“Making decisions for yourself can give you insights into the consequences of your actions”

Chantelle* chose her group home keyworker as her supporter. Part of her income is managed by the NSW Trustee & Guardian (NSWTG). The facilitator and financial manager initially visited Chantelle at home with her supporter where Chantelle noted that she tended to impulse buy. While Chantelle ‘shopped’ at the chemist, her medications and other items she purchased were put on a tab and paid for by the NSWTG. Chantelle decided she wanted to pay her own chemist bill. The facilitator worked with Chantelle, her chosen supporter and the NSWTG to make this happen. Together a plan was developed. Chantelle negotiated with the chemist to receive her bill fortnightly. This made it easier to budget than monthly. Chantelle started paying her account in cash. Chantelle came to see that buying toiletries and other non-medical items at the chemist was more expensive than buying them at the supermarket. She changed to purchase these items at the supermarket and saved money as a result. Chantelle is keen to look at other areas in her life where she might be able to make more decisions for herself, and perhaps save even more money!

*Name changed (‘My Life, my decision’ - Supported Decision-Making Pilot)

(e) *The individual must be able to make decisions autonomously and voluntarily, without coercion.*

“Getting to know the person and the impact of important relationships in their life is an important part of being able to provide appropriate support”

We look to Michael*, a young man who likes to spend time with friends and family and values his relationships highly. Michael, like many young men, wants to develop his independence and self-reliance. Michael chose a paid supporter and started to think about ways to become more independent, such as learning catching the bus to his day service and exercising by walking around the block by himself. Concerns were expressed by other people in Michael’s life about the risks to Michael travelling unaccompanied on the public bus. Michael’s paid supporter felt the pressure of balancing Michael’s wants and needs with those being expressed by other people in his life. Whilst the UN convention clearly sets out that people with disability should be afforded the right to make their own decisions, the reality of implementation in practice can be far more difficult, especially when a person’s decision may impact heavily on those around them. In Michael’s situation – whilst he wanted to catch the bus to his day service this would not have been possible without the support of other people in his life. As a result the decision was put on hold. While, the option was available to Michael to continue to look at this decision, he decided to work on other decisions.

*Name changed (‘My Life, my decision’ - Supported Decision-Making Pilot)

(f) *The person is able to communicate the decision*

Case example: Edward

Edward has severe intellectual disability and does not use words to communicate. Some funds were available to support Edward to make some more social connections with people in his local community. As he had little experience of the many different activities he might participate in each week his support worker brought pictures of different activities where

people did things together, such as a painting group, a yoga class, a drama group, a bike club, and the senior citizens having lunch in the RSL club. They visited some of the groups and places, and took pictures of Edward at each place. At each place the support worker observed Edward's reactions and how other people had responded to Edward, and compiled more detailed information about the costs and regularity of each group. Each week they reviewed the pictures and photos until after six months, having weighed all the different places, costs, observations of Edward and other people at the various places, they decided together that Edward would enrol in the drama group for a term.

Support for Decision Making: A Practice Framework (La Trobe University and FACS research)

6. Precondition: disability

Question 3.2: Disability and decision-making capacity

How, if at all, should a person's disability be linked to the question of his or her decision-making capacity?

Question 3.3: Defining Disability

If a link between disability and incapacity were to be retained, what terminology should be used when describing any disability and how should it be defined?

- 6.1 FACS supports reform to the Guardianship Act which signals the broader policy emphasis on decision-making as a right and considers that the Act should reflect this position. From this perspective, FACS considers that the law should be clear that a finding of decision-making inability is according to the objective proposed functional test, and not assumed by whether a person has a disability. The Commission may wish to consider whether, and how, the Act could reflect the many contextual variables which affect a person's decision-making competence, such as: their age, education, and relevant knowledge and experience; and the nature and consequences of the specific decision.
- 6.2 However, the Commission should consider whether removing the link to 'disability' would create conceptual ambiguity and prevent the Act from fulfilling its legitimate purposes. From a service delivery context, FACS approaches the link between disability, functional incapacity and decision-making capability as integral to conducting a care assessment to ascertain a person's needs and vulnerabilities. Removing the consideration of disability (or the underlying impairment, whatever its cause or type) in the framework for authorising alternative decision-making arrangements may create uncertainty for decision-makers (including family members who are carers), and service providers.
- 6.3 FACS proposes that this could be overcome if the 'disability status' test is replaced by the proposed functional test for capacity which focuses directly on the decision to be made. This removes the legal distinction on the basis of 'disability' and may counter any concerns from people and groups in the NSW community that consider that the Act targets people with disability.
- 6.4 However, FACS notes that this would be a significant departure from guardianship regimes in Australia (and internationally), which ordinarily maintain the link between the individual's underlying impairment and decision-making capacity. By way of legislative

example, the ACT explicitly asks and answers this question in section 5 of its *Guardianship and Management of Property Act 1991*:

When does someone have impaired decision-making ability?

For this Act, a person has impaired decision-making ability if the person's decision-making ability is impaired because of a physical, mental, psychological or intellectual condition or state, whether or not the condition or state is a diagnosable illness.

- 6.5 The Mental Capacity Act also maintains the link between the 'impairment' and the incapacity:

For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.

- 6.6 In that Act, the link to the individual person's 'underlying impairment' has drawn public attention and critique that this discriminates on the basis of disability (for further information, see the reports available here:

<http://www.parliament.uk/business/committees/committees-a-z/lords-select/mental-capacity-act-2005/> . The arguments put forward in this public debate are directly relevant to the question of whether the link to disability should be removed from the NSW regime and are worth considering for this review.

- 6.7 Terms of Reference 5 to this review also asked whether the language of 'disability' is the appropriate conceptual language for the guardianship and financial regime, and to what extent 'decision-making capacity' is more appropriate.

- 6.8 In our preliminary submission, FACS presented the alternative position that the Commission may reconsider this term to consider:

To what extent the vocabulary and language of the guardianship and financial management system appropriately reflects the people it represents.

- 6.9 While FACS notes that the term 'disability' is broadly defined in the Guardianship Act (and captures mental illness and dementia), FACS maintains its preliminary view that the term 'disability' suggests this as an exclusive term that in decision-making regulation, ordinarily describes people with intellectual disability or cognitive impairment.

- 6.10 In its 2014-15 Annual Report, the NSW Civil and Administrative Tribunal (NCAT) highlighted that aged care, not 'disability', is the focus area of applications. The NCAT stated:

'The work of the NCAT is increasing due to the ageing population and the ability to sustain life much longer than in the past'.

- 6.11 That report captures the proportion of guardianship applications across the distinct 'disability' areas:

- 44% of applications concerned people with dementia over 55 years of age
- 16% for mental illness
- 16% for people with intellectual disability

- 13% for brain injury or neurological conditions
- 6.12 This statistical snapshot indicates that this review is an opportunity for resolving the inconsistency between the Act's emphasis on 'disability' as the 'umbrella term', and the nature of real-life applications.
- 6.13 The terminology should accurately reflect the Act's purpose to assist people, who for a broad range of reasons, require substitute decision-making in some circumstances. FACS supports the terminology of 'decision-making capacity' used in QP1 as a 'disability neutral' term which also reflects the purpose of the guardianship regime.
- 6.14 In some Australian jurisdictions, 'disability' has been replaced by alternative terminology that focuses on decision-making capacity, including:
- 'impaired decision-making capacity'(Northern Territory, *Guardianship of Adults Act 2016*)
 - 'impaired decision-making ability' (ACT, *Guardianship and Management of Property Act 1991*)
- 6.15 This review could consider this terminology as possible replacement terms for disability. Terminology that directly links to decision-making capacity best conveys the functional test for capacity and also removes the focus on the person's impairment.

Question 3.4: Acknowledging variations in capacity

Should the law acknowledge that decision-making capacity can vary over time and depend on the subject matter of the decision?

How should such acknowledgements be made?

If the definition of decision-making capacity were to include such an acknowledgement, how should it be expressed?

If capacity assessment principles were to include such an acknowledgment, how should it be expressed?

- 6.16 The primary focus of regulating when a person will be found to lack capacity should be that all people are unique and should be assessed individually, not according to a 'blanket' understanding of their disability.
- 6.17 The need for assistance with decision-making will vary among people with decision-making difficulties. Variations in capacity may be episodic, or influenced by age and/or deterioration of a person's underlying condition. The person's stage of life and influencing factors, such as their familial and interpersonal relationships, can also impact on decision-making.
- 6.18 The need for assistance will also depend upon the nature and significance (likely consequences) of the decision. A supported decision-making process may be sufficient for one decision, but inadequate for another if a deeper understanding of the issues and consequences is required. There is a difference between decisions with important financial consequences (e.g. property transactions, NDIS planning), and ordinary decisions about daily activities and preferences.
- 6.19 The law could acknowledge the variability of capacity by confirming that the application of the test is decision-specific (that is, the finding is concerned with the

particular set of circumstances which may change in the future); and acknowledging that the person may regain capacity.

Question 3.7: What should not lead to a finding that a person lacks capacity?

Should capacity assessment principles state what should not lead to a conclusion that a person lacks capacity?

If capacity assessment principles were to include such statements, how should they be expressed?

- 6.20 Capacity assessment principles should explicitly identify the types of factors that should not lead to a conclusion that a person lacks capacity. In NSW, the *Mental Health Act 2007* provides a relevant and useful model that could be considered for the decision-making context.
- 6.21 This can protect a person (including a person with disability) whose capacity is brought into question. This will be particularly relevant if the link to disability (or underlying cognitive impairment) is removed from the statutory framework.
- 6.22 This provision is also important for protecting vulnerable persons. A person (including a decision-maker, or service provider) who is not familiar with the support or communication needs of a person with intellectual disability, for example, could easily assess that person as lacking capacity because of their lack of skills or experience in working with people with disability.
- 6.23 Capacity assessment methods vary according to the nature of impairment and the support contexts in which they are applied. Identifying capacity assessment principles within the legal framework would support the interests of the person, and provide guidance to the assessor.
- 6.24 An assessment of decision making capacity should occur in consideration of these principles which could include factors such as: the person's areas of independence, current support services; availability of informal decision-makers; and whether there are any conflicts of interest in a particular decision. Consideration should also be given to any impacts across the lifespan or other areas of the individual's life. This report could then be used to determine capacity and access to alternative decision-making arrangements such as Guardianship Orders.

Question 3.8: The relevance of support and assistance to assessing capacity

Should the availability of appropriate support and assistance be relevant to assessing capacity?

If the availability of such support and assistance were to be relevant, how should this be reflected in the law?

- 6.25 Yes. Support is integral to recognising the right of persons with disabilities to equality before the law, as set out by article 12 of the CRPD. FACS endorses the view that an assessment of decision-making capacity should consider whether a person has access to appropriate support.

- 6.26 The availability of supports is an appropriate safeguard against finding that a person lacks capacity, particularly for people with deteriorating conditions or episodic conditions that cause variations in their capacity.
- 6.27 If statutory elements for demonstrating decision-making capacity are introduced into the Guardianship Act, then consideration of available support could be included as a guiding principle for applying the capacity test. The current legislative regime considers the availability of support in the context of determining guardianship. This should be expanded to capture all decision-making arrangements.

Question 3.9: Professional assistance in assessing capacity

Should special provision be made in NSW law for professional assistance to be available for those who must assess a person's decision-making capacity?

How should such a provision be framed?

- 6.28. In a support context, FACS asserts that all service providers should develop knowledge and skills sufficient to make a decision about the capacity of their client and the level of decision-making support that any particular decision demands. Referral for professional assistance will always be needed, depending on the type and consequences of the decision, the extent of worker experience and their own access to supervision and support; and the level of disagreement, if any, among third parties.
- 6.29 FACS does not currently have a position on whether the law should regulate the availability of professional assistance. However, any legal contemplation should not be overly prescriptive. In some locations, access to types of professional advice may be difficult to obtain.

7. Other preconditions that must be satisfied – the person must be 'in need' of an order and the order must be in the person's 'best interests'

Question 4.1: The need for an order

Should there be a precondition before an order is made that the Tribunal be satisfied that the person is "in need" of an order?

If such a precondition were required, how should it be expressed?

- 7.1 Yes. The 'need' for an order should express that, despite any current supports, the person has not demonstrated capacity. The need for an order should also be demonstrated by proper consideration of the availability and adequacy of the person's support; third party issues and conflicts that may impede the person's reliance on available supports; the person's wishes and preference; the person's current decision-making ability, and the nature of the decision(s) to be made.

Question 4.2: A 'best interests' precondition

Should there be a precondition before an order is made that the Tribunal be satisfied that the order is in the person's "best interests"?

- 7.2 Yes. FACS considers that the Guardianship Act should retain this precondition for substitute decision-making arrangements, and proposes that a best-interests framework should be clearly set out in the law.
- 7.3 This should require carers who are guardians, and other types of substitute decision-makers, to consider the views, wishes, or preferences of the person on whose behalf a substitute decision is being made.
- 7.4 FACS reiterates its preliminary submission that this review presents an opportunity to align a substitute decision making model (where necessary) with a rights-based approach to supporting people. A driving principle of a rights-based approach is that the person is involved in the decisions that affect them.
- 7.5 In this context, FACS also notes that the language of the CRPD's text, 'rights, will and preference' has been presented as the preferred term for regulation that impacts on people with disability. The La Trobe University Research report at **Attachment B** provides a useful starting point for considering the alternative approach to best interests in the supported decision-making paradigm:

Supported decision making is a new paradigm – a new way of thinking about how people with cognitive disability are regarded by the law and supported to make decisions. It requires new legal structures to replace or add alternatives to guardianship ... The core concepts of supported decision making are a shift from a best interests model of support and substitute decision making to a model of support based on enhancing a person's skills and experience to make decisions, to express their will and preference; and the acknowledgment that part of the supporter's role may be to interpret the individual's will and preference (page 5).

- 7.6 However, the challenge brought by this shift moves beyond the issue of whether the paradigm shift to human rights should be represented in renewed terminology, to whether the language of the Convention's 'rights, will and preferences' paradigm is the only standard that should, and can, operate in a reformed legislative context.
- 7.7 FACS affirms the position stated by the NSW Government in its submission to the model laws proposed by the ALRC that:

There will always be members of our community who are unable to express a view and whose will and preference cannot be ascertained due to the severity and long-term nature of the decision-making impairment ...and consideration be given to ensuring that the model laws do not blur the distinction between supported and substitute decision making, especially where supported decision making is used to shield what is in reality a substitute decision (available here at https://www.alrc.gov.au/sites/default/files/subs/135._org_nsw_government_submission_.pdf).

- 7.8 In its response to that review, the NSW Government also asserted:

A new decision-making framework based on a rights based approach rather than best interests would need to be explicit in terms of the appropriate considerations to

guide decision-making. For example, it may be of benefit that any model Commonwealth legislation expressly provides [a] list of 'human rights' considerations.

- 7.9. If the Commission prefers the human rights language of 'rights, will and preferences' as the replacement precondition, than FACS asserts that the review should resolve the meaning of the text 'respect for rights, will and preference' within the context and obligations set out by the CRPD.
- 7.10 The 'will and preferences model' may be more apparent for supported decision-making, however this review will need to resolve how it would operate with 'appropriate considerations to guide decision-making' where a substitute decision-maker is required.
- 7.11 FACS notes that the strong association of best-interests decision-making with disability may give rise to the claim that the Guardianship Act targets this group. This can be remedied by removing the 'disability status' approach in the Act and replacing the test for decision-making capacity with the functional capacity test. This would ensure that 'best interests' considerations apply where a person is found to lack functional capacity to make a decision, not because the person is identified as a person with disability.
- 7.12 For 'best interests' substitute decision-making to be objective and proportionate, FACS considers the Guardianship Act should set out a list of 'best interests' considerations, where the person's views are the primary consideration.
- 7.13 The UK provision on 'best interests' in the Mental Capacity Act could inform the development of such a model in NSW because it sets out mandatory considerations to be taken into account by the decision-maker. This includes the subject-person's past and present wishes and feelings, beliefs and values; and other factors likely to influence the person's decision if they had capacity. That model also stipulates the bases on which best interests decisions should not be made (for example, the person's age, or an aspect of their behaviour). This ensures that the person is not removed from the decision-making process, or that the best-interests decision is not made for illegitimate reasons.
- 7.14 A list of considerations should also be flexible to accommodate the diversity of the capacity of people, and the variety of decisions that are contemplated.
- 7.15 In this context, the review may wish to consider whether there should be a subset of best interests considerations for medical decisions. These types of may involve a dominant clinical and medical care and risk mitigation focus that is appropriate for the nature of the decision, but should, however, rate patient opinion as a legitimate view (regardless of whether the person has disability). By way of example, in the matter of *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 the court determined that 'a patient's best interests incorporate not only medical interests, but also the patient's welfare in the widest sense'.
- 7.16 The provision should also identify considerations to be applied where a person is not able to convey their views. If the person is unable to actively engage in the decision-making process or communicate/convey their wishes in any discernible way, than best interests should be determined by the opinion of the decision-maker, based on reasonably ascertainable evidence to support the opinion.
- 7.17 This should include consideration of the person's present wishes, as well as their history. A person's history should cover their prior expressed views, whether by

words or the conduct of their choices and life, or any other way that they have reasonably expressed their preferences. FACS considers that these considerations achieve a person-centred approach in complex circumstances where the decision-maker has to interpret the decision to be made on behalf of another person. FACS considers this can also be enhanced by including a broad scope of subjective considerations through terminology such as 'beliefs', 'values', 'opinion' and 'feelings'.

- 7.18 FACS also notes that the NDISA sets out duties on nominee decision-makers in the NDIS regime, when they have to make a decision in the place of the participant.

Section 80 of the NDISA provides:

80 Duties of nominees to participant etc.

- (1) It is the duty of a nominee of a participant to ascertain the wishes of the participant and to act in a manner that promotes the personal and social wellbeing of the participant.*

[...]

- (4) The National Disability Insurance Scheme rules may prescribe other duties of a nominee, including duties requiring the nominee:*

- (a) to support decision-making by the participant personally; or*
(b) to have regard to, and give appropriate weight to, the views of the participant; or
(c) to inform the CEO and the participant if the nominee has, acquires, or is likely to acquire, any interest, pecuniary or otherwise, that conflicts or could conflict with the performance of the nominee's duties.

- 7.19 In consideration of the NDIS context, FACS proposes that the future legal framework for decision-making in NSW could include explicit duties or rules on substitute decision-makers as a further safeguard for protecting the rights and interests of the vulnerable persons who require substitute decision-making arrangements. FACS anticipates providing further input on this issue in its response to *Question Paper 3: Supporters and decision-makers: appointment, powers, responsibilities and accountability (including, under current arrangements, enduring guardians, guardianship orders, persons responsible, financial managers and informal decision-making arrangements)*.

Attachment A to the Submission to NSW Law Reform Commission

Review of the Guardianship Act 1987 (NSW): Question Paper 1: Preconditions for alternative decision-making arrangements

FACS' supported decision-making programs - indicators of the preconditions for decision-making

'My Life, My Decision' – Supported Decision-Making Pilot

1. During 2012, FACS developed the Supported Decision Making Pilot in partnership with the Office of the Public Guardian and the NSW Trustee and Guardian.
2. The 'My life, my decision' evaluation report of that pilot demonstrated that 'it was possible to enhance the legal capacity of a number of people with disability to make their own decisions and deliver on the intent of article 12 of the CRPD to recognise their legal capacity'. The link to this report is available here:
https://www.adhc.nsw.gov.au/data/assets/file/0009/346194/sdm_pilot_project_evaluation_report.pdf
3. The evaluation report identified the key 'enablers' for developing decision-making capacity, including:
 - Trust between the person with disability and their supporter is critical to building decision-making capacity
 - Available assistance by facilitators of the pilot
 - One-on-one support and training of a person with disability by a trusted individual
 - Availability of supporters
 - Time available to work thoroughly through the decision-making process
 - Assistance with communication was a key enabler and highlighted the need for a proactive approach and effective aids to communication (e.g. a picture-based decision making tool was developed for a person with very limited verbal communication skills)
 - Education and training of people in the supporter role
 - Flexibility to use facilitators directly as supporters when needed
4. However, that program also highlighted that the recognition and development of decision-making capacity for persons with disabilities encounters many barriers that are not intrinsic to the specific person, but are caused by extraneous factors, including the attitudes of other people.
5. That report observed that whether a supporter was a caring person did not necessarily mean they understood that they should 'tap into' the capacity of the person to make the decisions.

Other external barriers included:

- the general life circumstances of people with disability, such as social isolation, lack of power and familiarity with making decisions
- low expectations of others

- power imbalance and conflict of interest in relationships
- the length of time required for someone to be supported to become 'decision-ready' due to their limited experience of, or exposure to, making decisions; including their inability to identify the decision to be made
- reticence in carers (both informal and formal) to support 'risky' decisions and an inflexible interpretation of their duty of care.

Support for Decision Making: A Practice Framework

6. FACS funded a recent study conducted by the Living with Disability Research Centre at La Trobe University, which released its findings in 'Support for Decision Making: A Practice Framework (January, 2016). That report cautions against removing legal capacity, based on a bifurcated view of capacity which requires that the right to decision-making is demonstrated by whether a person has, or does not have, mental capacity.
7. The research uses examples of persons with varying levels of intellectual disability to illustrate the benefit of respecting a person's capacity across a range of minor and more complex decisions.

Case example: Ellie

Minor day-to-day decision

Ellie's support worker gets out three differently coloured shirts; two are the colours Ellie usually prefers, and one is a colour she doesn't usually wear. The support worker watches Ellie's expression as he holds up each in turn, and makes a judgement that she would prefer to wear the new colour today.

Major enduring decision

Ellie has been experiencing some pain in her mouth as her wisdom teeth had come through crooked and were slowly decaying. She hated visiting the dentist but when she did it was clear there was a lot of work to be done. The dentist advised her support staff that the best option would be to go to hospital for a few days and having all her teeth out, which would save a lot of money and pain in the long run. Ellie, together with her sister and support staff, sought a second opinion. After several months, they decided together not to take this advice. Instead they have made a plan for Ellie to find a new dentist and have the necessary work done slowly over the next 12 months.

Participation in a self-generated decision with support

The support worker lays out a pair of shorts and a skirt on Ellie's bed and Ellie decides to put on the skirt.

Understanding a person's will and preferences about a decision

In terms of a decision about where to live in the future, Ellie found it hard to conceptualise living somewhere else and had no experience to draw on. Those who know her well described some of her preferences that they thought would be important in making the decision – she doesn't like being around lots of other people, she likes walking, she hates cars, she likes being with Edward now and again.

Case example: Jane

Participation in substitute or informal substitute decision-making with support

Jane's sister was concerned when she realised that Jane's savings were sharply reducing and she had signed various agreements committing her to purchasing services offered by telephone and door-to-door sales people, as well as making donations to lots of different charities who had fund raising campaigns. When they talked about it Jane didn't see this as a problem, saying she still had enough money for food and the people who rang her up or came to her door were nice to talk to. Her sister decided to seek an administration order* so they could find a way to manage Jane's money more carefully and protect Jane from being exploited. They set up direct debits for some bills, an account for everyday use with a budgeted monthly amount, and agreed to put all her other money in an account that could only be accessed jointly by Jane and her sister. Jane and her sister agreed that Jane would always check with her before signing contracts to buy items or regularly donate money.

*In Victoria, an administration order is similar to a NSW guardianship order issued by the NSW Civil and Administrative Tribunal (NCAT).

FACS' support programs for people with highly complex support needs

8. FACS also provides specific programs for people with disability who have multiple cognitive disabilities and highly complex care needs. For this client group, FACS supports the use of substitute decision-making arrangements, such as guardianship, as a legitimate safeguard for upholding their rights and interests. In FACS' view, a central aim of this review should be to ensure the continued working of a legitimate, proportionate and safeguarded system for substitute arrangements for vulnerable persons, regardless of whether they are a person with disability.
9. FACS provides the following case examples of people with complex needs who rely on a guardian and large network of supports to provide their daily life supports. These examples reveal that substitute decision-making arrangements can operate in conformity with support strategies to enhance the person's capacity and engagement.

Sean

Sean is in his twenties. He has an intellectual disability, is autistic and is non verbal. He has a guardian to manage his affairs. He has also had contact with forensic services due to an assault charge involving a worker from his previous day support provider. Risks around his reoffending remain and he is easily led and suggestible.

He is currently living in intensive support accommodation with 24 hour supervision. He used to abscond on a regular basis and much time was spent in liaising with the police, locating him and returning him to his accommodation. Over the past year, a combination of a stable staff team, few changes to his environment, and the thorough implementation of behaviour protocols have stabilised his situation. However, just recently his absconding behaviour has returned triggered by the arrival of some new staff and a new resident moving into the accommodation. Two staff members are required to supervise him effectively when he is in the community.

It is anticipated that he will be able to further improve over time with the appropriate support and as long as the capacity to provide that support is maintained. There is a large network of people involved in keeping the situation stable, including his guardian, advocates, the forensic team, and hours of emails and meetings. The risk is that as his situation further stabilises he may appear to need fewer supports than he in fact does, and for his support levels to be reduced triggering behaviours of concern.

Mathew

Mathew is in his forties. He is autistic and non verbal. He has an intellectual disability, a very short attention span and anger issues which he finds difficult to control. He can be hard to engage. His affairs are managed by the Trustee.

Mathew has 24 hour support in a shared home and attends day support three days a week. He needs assistance with most of the daily tasks but is very familiar with, and committed to, his routines. This means he likes to assist with tasks like making a cup of tea, preparing food, doing his washing or getting ready to go to day support. Some of his behaviours impact on neighbours. These include peering through their windows, touching their mail, or going through their rubbish bins. There are now a number of strategies in place to assist with his behaviours, including communication programs which are continuously developed.

He requires extensive support when any dental work is undertaken, including an anaesthetic and a trip to the hospital with support staff in attendance.

There have been transport issues. He is tall and unless he is transported in a roomy vehicle where there is plenty of leg space, he can feel crowded and behaviours can escalate. His tendency to dribble and spit in the car, and in the house, mean that there are ongoing costs for cleaning products and professional cleaners.

Recently, staff has had to implement some restrictive practices to control his obsession with food. This obsession means that he will hunt cupboards, the fridge, and rubbish bins for food, which he then eats. As well as locking the kitchen in the short term, staff has been intervening by setting up a compost heap on the site. This means that any tea bags or other suitable food he finds can be torn up and added to the heap. This has given him more control over food and his compulsions.

There have been a lot of positive changes for him in the past year and his situation is more or less stable. But this has required a multidisciplinary team and high level skills from the case manager. Some of his support team has burnt out in the process.

These case examples reveal the variation in functional capacity between people, as well as the variability within an individual in responding to any issues in daily life. The latter is clearly influenced by the availability of adequate support and the expectations of the supporters in terms of assisting the person to express a view and be included in decisions and activities that affect their lives.

Living with Disability

RESEARCH CENTRE

Supporting inclusion of people with cognitive disabilities



Support for Decision Making A Practice Framework

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Introduction and Aims

The need for good support for decision making has been highlighted through the National Disability Insurance Scheme's (NDIS) emphasis on choice and control and its imperative to generate support plans for all participants. Involvement in decision making enables people to have greater control over their own lives, improving their self-identity, psychological wellbeing and quality of life. The NDIS means that people with cognitive disability will have more opportunities to make decisions about the direction of their lives and the support they receive. A significant challenge is ensuring they have support to enable them to participate in decisions – at the preplanning, planning, implementation stage of their plans and in their day-to-day lives. This means not only understanding the processes of good support for decision making but also recognising the role of decision making supporters and developing their skills.

The right to make decisions about one's own life, particularly big decisions is regulated by the law. People with cognitive disability often have their right to make decisions removed through appointment of a guardian. However article 12 of the United Nations Convention on the Rights of Persons with Disability states that people with disability are equal before the law (acknowledged as having legal capacity and legal standing). The accompanying comment suggests that guardianship laws are contrary to this right. The UN Convention has generated debate about the concept of *supported decision making* and the need for legal reform. In 2014 the Australian Law Reform Commission proposed that **"the will, preferences and rights of persons who may require decision making support must direct decisions that affect their lives"** (ALRC, 2014, para 3).

Enabling people with cognitive disabilities to direct their own decisions will only happen if supporters have high expectations that people can participate in decision making, have strong commitments to making this happen, and have a tool box of strategies ready to be tailored to each individual and each decision. The aim of this *Support for Decision Making Practice Framework* is to lay foundations to guide practice for decision making supporters of people with cognitive disability. The framework is based on research undertaken by the authors, and their colleagues at the Living with Disability Research Centre¹ and our interpretations of the United Nations Convention on the Rights of Persons with Disabilities.

The framework can be used within existing legislation and will guide the work of the decision making facilitators employed by St Vincent de Paul Society NSW (the Society) to implement the pilot support for decision making project at Kanangra. In this project the facilitators have three key roles:

- *Working with families and staff* developing their skills and confidence as decision making supporters;
- *Helping to build a network* of supporters for people with limited family connections, and if necessary;
- *Building relationships with and acting directly* as decision making supporters for the people who have no network beyond the paid staff in the service.

The framework will also be a useful guide to others who provide support for decision making to people with cognitive disabilities, whether formally or informally, as volunteers, family members, support workers, paid decision making facilitators or guardians. It can be used in any of the various models of delivering support for decision making that are currently being piloted in Australia, and inform thinking about the practice of decision making supports for NDIS participants with cognitive disabilities.

Current Legal Context

Currently the right to make decisions is based on a person's mental capacity (decision making skills). Often, when there are doubts about mental capacity (because of difficulties understanding implications of decisions), legal capacity is overridden informally (by others such as family or staff making decisions for a person) or removed formally through guardianship (the appointment of a substitute decision maker). When this happens, those who make decisions for a person with cognitive disability are guided by an understanding of the person's preferences but also consideration of their 'best interests'. This reflects the idea of 'beneficence' where supporters' judgments

¹ Set out in the reference list

about what is good for a person with disability take precedence over their preferences. While this may not always be the case in the practice of Guardians it is the legal framework in which they work.

Examples²

Jane lives alone. When her mother died she stayed in her family home and continued to enjoy going out to the local shops, saying hello to the many people she knew, as well as cooking for herself. Her intellectual disability means she finds it difficult to manage money or plan ahead and sometimes does not see the importance of household routines. Despite a list of reminders and regular help from a support worker, the condition of her house and garden began to deteriorate. When the neighbours complained to her sister and the support worker refused to visit because of the hazards in the house, Jane's sister applied and became her guardian. Jane was keen to stay at home, but her sister decided she would be better off living somewhere else where other people could take care of her and she wouldn't have to worry about domestic tasks.

Edward loves to sit on the verandah of his new home and visits a local gym. His eyes light up when he sees the people he knows from his years in the institution who now live nearby. His friend Ellie visits once every 2 months, but she lives in a regional town so he doesn't see her around in his locality.

Edward and Ellie both have severe intellectual disability and neither use words to communicate. They used to live in an institution where everyone knew they enjoyed each other's company. This connection was visible from their changed demeanour when they were together. When plans were made to close the institution neither Edward nor Ellie understood much about the proposed move, and the government department responsible for the closure asked their families to make decisions for them. Edward's sister thought it would be a good idea for him to live in the all-male household that was set up in the suburb close to the institution. Ellie's sister thought it would be better for Ellie to live in the regional town where she herself lives.

Key concepts in the current legal framework are assessment of mental capacity, informal or formal substitute decision making that can override or remove a person's legal capacity on the grounds of mental capacity, and decisions made on behalf of a person in their best interests. Mental and legal capacity are conflated, and problems with mental capacity can lead to removal of legal capacity.

New Paradigm of Supported Decision Making

By contrast the new paradigm of *supported decision making* starts from the premise that everyone has the right to participate in decision making. It draws on a support paradigm whereby provision of sufficient and effective support is seen to compensate for difficulties with decision making. People with cognitive disabilities are enabled to participate in all decisions, through changed expectations of others, development of their skills and experience, provision of support to express their will and preferences and, at times, through the interpretation of their will and preferences. In supported decision making the person with cognitive disability is at the centre of their own decision making:

- support is made available to enable the person to participate in decision making.
- support is tailored to the person and their situation.
- support varies in type and intensity depending on the type of decision.
- supporters enable the person to exercise choice and control based on the person's will and preference (not perceived best interests).
- in the purist form a person's legal capacity is not questioned because by definition it cannot be removed.

² Through the framework we illustrate issues and points using examples from our research which are composites of people with varying levels of intellectual disability. When first mentioned, the person is described in brief; the description is not repeated when the person is mentioned in later examples.

Legal frameworks for *supported decision making* give legal standing to supporters to act together with the person to make decisions. Such frameworks include structures or schemes that set out the responsibilities of supporters, recognise their legal standing and give others the right to challenge their actions. If a person cannot express their will and preference or it cannot be ascertained through knowledge of the person, supporters are empowered to make an interpretation of their will and preference that takes account of rights.

Supported decision making is a new paradigm – a new way of thinking about how people with cognitive disability are regarded by the law and supported to make decisions. It requires new legal structures to replace or add alternatives to guardianship. These might be concepts such as micro boards, shared decision making or representation agreements found in Canada which has led the way in *supported decision making* law reform.

The core concepts of supported decision making are a shift from a best interests model of support and substitute decision making to a model of support based on enhancing a person's skills and experience to make decisions, express their will and preference and the acknowledgement that part of the supporter's role may be to interpret the individual's will and preference.

Support for Decision Making

Australia is moving towards law reform about *supported decision making* as many of its elements are not reflected in current legal frameworks. For example, there is only very limited legal recognition of decision making supporters. Concepts such as shared decision making or representation do not have legal standing, and many people continue to have guardians as substitute decision makers who are bound to act in their 'best interests' in accordance with existing legislation or supporters who act as informal substitute decision makers.

Legal reform in Australia is pending. Some elements of *supported decision making* have to wait for law reform, but others do not. We refer to *supported decision making* as something that requires a new legal framework and *support for decision making* as something that can begin within existing frameworks.

Many of the ideas within *supported decision making* are not new and much support for decision making happens informally without formal sanction of legal frameworks. The importance of supporting people with cognitive disabilities to exercise choice and control is recognised as central to the practice of disability support workers (e.g. person centered active support) and individual planning (e.g. person centered planning). Many families provide support for day-to-day decision making as a matter of course and often in collaborative relationships with support services.

Examples

Jane's support worker talked to her about the idea of moving when she realised how difficult it was for her to maintain her parent's big house on her own. Jane made it clear she was happy where she was. When the worker contacted her supervisor and Jane's sister they realised Jane had never lived anywhere else and had little sense of the other options she might have. They began to take Jane to inspections of some of the new apartments that were being built in her neighbourhood and to visit some of the people she knew from her drama group who lived in group homes or shared units. They supported Jane to stay for weekends at a small respite house, at one of her friends units and on her own in an apartment owned by the service, and began to talk about where she might be able to afford to live if she sold her parents' house. After about 12 months, Jane rented out her parent's house and began renting a flat round the corner in a small block with on call support. Three years later she and her sister decided things were going so well that Jane would sell their parents' house and buy an apartment in the same block where she had been renting.

Ellie's support worker gets out three differently coloured shirts, two are the colours Ellie usually prefers and one is a colour she doesn't usually wear. The support worker watches Ellie's expression as he holds up each in turn, and makes a judgement that she would prefer to wear the new colour today.

Participation by People with Cognitive Disabilities in Decision Making with Support

Recognising and sorting decisions

Living life means making decisions about many things. Decisions can be described in different ways – the scope, who is involved, constraining influences, time frame and consequences or outcomes. Very simply they can be sorted by scope into bigger and smaller decisions. Smaller decisions are usually day-to-day ones about things such as personal care, engagement with others or in activities. They occur in specific contexts, such as home, and may require immediate and sometimes frequent support from a small number of supporters in the immediate vicinity.

■ **Examples**

The support worker takes Edward's hand and places it on the knife. She puts her hand over his and starts to guide it over the bread spreading the peanut butter. Edward pulls his hand away. A few minutes later when the support worker takes his hand again he leaves his hand there for a short while and smiles.

Jane sees the bus coming and turns towards the support worker and says, "is this the one that goes into the city?" The support worker says "yes", and as Jane gets on the worker prompts her to get out her bus pass.

Bigger decisions are about more enduring things in a person's life, ranging from the décor of their home to where they live or what supports they receive. They are made over a longer time frame, and may occur at the interface between a number of systems or settings and involve multiple supporters. Bigger decisions often set parameters for smaller ones, making or curtailing other opportunities.

■ **Example**

Ellie has been experiencing some pain in her mouth as her wisdom teeth had come through crooked and were slowly decaying. She hated visiting the dentist but when she did it was clear she needed a lot of work to be done. The dentist advised her support staff that the best option would be to go to hospital for a few days and having all her teeth out which would save a lot of money and pain in the long run. Ellie together with her sister and support staff sought a second opinion and after several months decided together not to take this advice. Instead they have made a plan for Ellie to find a new dentist and have the necessary work done slowly over the next 12 months.

In many situations smaller decisions are the building blocks for bigger decisions, building a person's experience and confidence in decision making. Smaller decisions can also help to frame the options considered in bigger decisions.

Decisions are like Babushka (nesting) dolls embedded in each other. Bigger decisions open up opportunities for lots of other smaller decisions. They are also cumulative, decisions made in one part of a person's life will have implications in other parts, and often set parameters for smaller decisions by either making or curtailing other opportunities for decision making.

Example

When Jane decides to go to the cinema she must also decide when to go, which cinema to go to, what to see, who to go with and whether to go out for lunch beforehand.

When Edward moved to his new home, although his sister decided where it would be, there were many other decisions he could participate in such as, the colour to paint his bedroom and the living room, the type of furniture and how to arrange it, whether to have curtains or blinds and what colour they should be, and who would get the room with the door out to the garden.

Participation and support needs change with every decision

How a person participates in decision making and the support they need varies with every decision. Participation is influenced by the nature of the decision. Participation is also influenced by the person's skills, their experience of the issues bound up in the decision and the expectations of others. Support to participate in decision making must therefore be tailored to both the individual and the decision. People need different support for different decisions. The same person may participate at different times in making self-generated decisions, shared decisions and substitute decisions. Figure 1 gives a schematic overview of the ways people participate in decision making with support. At different times and depending on the decision, a person may participate in all of these ways. In this way of thinking about decision making support, some decisions will be self-generated and many decisions will be shared.

Self-generated Decisions

Supporters provide information and experience that enables the person to act on their own behalf based on their will, preferences and rights and taking account of resource constraints and consequences.

Shared Decisions

Supporters provide information and experience that enables the person to express their will and preferences and if necessary interpret these, and assist in taking account of resource constraints and consequences.

Substitute Decisions

Supporters provide information and experience and enable the person to express their will and preferences and if necessary interpret these, and assist in taking account of resource constraints and consequences.

Supporters moderate a person's will, preferences and rights if there are likely to be harmful consequences and the person does not have the ability to appreciate these.

Figure 1. Participation in Decision Making with Support

Participation in self-generated decisions with support

Sometimes a person will generate their own decision with support. For these **self-generated** decisions supporters provide opportunities for the person to access and understand information about the decision, possible constraints and consequences or widen their experiences of what might be possible. For some people and in some situations, decisions will become self-generating as their skills and experience develop.

■ **Examples**

When Jane is in the supermarket with her sister, they look at all the different brands of tea, and talk about how much more expensive the brand that Jane buys is. Her sister explains if Jane buys a cheaper brand she could afford to buy more fruit. Jane decides to buy the brand of tea she prefers even though it is more expensive than others.

The support worker lays out a pair of shorts and a skirt on Ellie's bed, and Ellie decides to put on the skirt.

The support worker helps Jane to go on the internet and view the trailers for each of the films at the cinema this week. They talk about each one and the worker supports Jane to click on the right boxes to make a booking for the one she has chosen.

Participation in shared decisions with support

In some instances decisions will be **shared** and made jointly by the person and their supporters. In these types of decision, like self-generating ones, supporters provide opportunities for the person to access and understand information or widen their experiences of what might be possible. They will also work with the person to enable them to understand the decision or some parts of it, and to express their preferences. For some people, supporters may have to interpret with others from their observations and knowledge of the person what their preferences might be. In **shared decisions** the supporter also helps the person to identify and weigh up constraints and consequences that they may not fully understand, such as availability of resources or time frames involved. The supporter works with the person to balance constraints, consequences and preferences and together they will make a decision based as best as possible on preferences.

■ **Example**

Some funds were available to support Edward to make some more social connections with people in his local community. As he had little experience of the many different activities he might participate in each week his support worker brought pictures of different activities where people did things together, such as a painting group, a yoga class, a drama group, a bike club, and the senior citizens having lunch in the RSL club. They visited some of the groups and places, and took pictures of Edward at each place. At each place the support worker observed Edwards reactions and how other people had responded to Edward, and compiled more detailed information about the costs and regularity of each group. Each week they reviewed the pictures and photos until after six months, having weighed all the different places, costs, observations of Edward and other people at the various places, they decided that Edward would enrol in the drama group for a term.

The shift to shared decision making driven by preferences rather than best interests is fundamental to a new paradigm and effective support for decision making.

Participation in substitute or informal substitute decision making with support

In yet other instances a supporter may make a substitute decision for a person. Many of the strategies used in shared decision making will also be applicable to **substitute decision making**. Similarly, supporters provide opportunities for the person to access and understand information or widen their experiences of what might be possible, work with the person to enable them to understand the decision or some parts of it, and to express their preferences, or interpret their preferences based on overall knowledge and observations of the person. Supporters will also be involved in weighing up resources or other constraints on the decision. The difference from shared decision making is that supporters take a more directive stance and may moderate a person's preferences if acting on these is likely to result in seriously harmful consequences that the person does not fully appreciate. If this is the case, preferences continue to guide a decision but are moderated to reach a less harmful decision. When supporters weigh up options to find a safer alternative they are guided by rights and finding a least restrictive alternative. They might ask for example, whether a decision would undermine rights such as respect for a person's dignity, their liberty and security, independent living, liberty of movement, and which of these is most important to the person.

Examples

When the support worker realised the car had not taken notice of the stop sign and Jane was about to step off the pavement to get onto the tram he touched her arm and said stop.

Jane's sister was concerned when she realised that Jane's savings were sharply reducing and she had signed various agreements committing her to purchasing services offered by telephone and door to door sales people, as well as making donations to lots of different charities who had fund raising campaigns. When they talked about it Jane didn't see this as a problem, saying she still had enough money for food and the people who rang her up or came to her door were nice to talk to. Her sister decided to seek an administration order so they could find a way to manage Jane's money more carefully and protect Jane from being exploited. They set up direct debits for some bills, an account for everyday use with a budgeted monthly amount, and agreed to put all her other money in an account that could only be accessed jointly by Jane and her sister. Jane and her sister agreed that Jane would always check with her before signing contracts to buy items or regularly donate money.

People participate in shared and substitute decisions through their presence and expression of preferences or through the ascertainment or interpretation of their preferences by supporters. A person's preferences would only be overridden where they cannot be realised without harm to themselves or others or breaching the law and the person does not fully understand these consequences of their preferences.

The Process of Support for Decision Making

In the following sections we set out the process of support for decision making that can be applied by supporters of people with cognitive disabilities within current legal frameworks in Australia. There are three elements:

- Steps in support for decision making;
- Principles of support for decision making;
- Strategies for practice.

Figure 2 is a schematic representation of the process of support for decision making. The real world is less ordered, for example, though separated here the steps are iterative and often occur simultaneously – principles are firmly embedded in strategies for practice.



Figure 2. Process of support for decision making

The following sections outline each of the three elements of the process. These are considered in more detail in the accompanying training materials that has been piloted at Kanangra.

Steps in Support for Decision Making

Support for decision making has seven steps shown below in Figure 3.



Figure 3. Steps in support for decision making



Step 1. Knowing the person

Support for decision making is person centred. As Figure 4 illustrates supporters need to 'know' the person well. This means knowing all aspects of the person and having a sense of the person's self-identity or self- concept (*Who I am and how I feel about myself*). This usually encompasses knowing about – their attributes and style – personal characteristics – likes, dislikes, preferences - skills, the effect on their understanding of their specific cognitive impairments – social connections - history and personal story. Part of knowing a person also means understanding the way they are seen by others in their network including the various 'experts' who have been involved in their life. Knowledge of what defines the person provides the conceptual context for understanding their will and preference.



Figure 4. Knowing the person



Step 2. Identifying and describing the decision.

It is important to identify and describe the decision that is to be made, Figure 5. The nature of the primary decision such as where to live may be clear. However, describing the decision helps to see its features in full: its scope (how much will it impact on a person's life and the other decisions that might flow from it); who should be involved in helping the person to make the decision or the formal organisations that may be involved (such as the criminal justice system or health system); the constraining factors that will help shape



Figure 5. Describing the decision

the decision, or may be taken for granted and that may need to be challenged by supporters; the time frame to make the decision, and; the potential consequences of choosing one option over another. Describing a decision helps to focus attention on the core issues and helps to guide who to involve or who has the necessary knowledge. For bigger decisions it will also identify tensions that might arise, constraining factors that if tackled early might be amenable to change and the potential flow on effects of this decision to other parts of a person's life that will have to be considered.



Step 3. Understanding a person's will and preferences about the decision

This is a 'blue sky' step in the process of decision making support. The person and their supporters think as widely as possible about the decision, all the possible options that need to be explored, the person's preferences about all the things that will be encompassed in the decision, and consequences of different options. Everyone has preferences. They stem from experiences, knowledge and available information, personal values or cultural norms. They are communicated in many ways – through words, signs, gestures, expressions, behaviour, actions or lack thereof. For some people preferences have to be interpreted by supporters based on their knowledge of the person, or garnered from the perspectives of others who know the person well or in a different context. At times there may be apparent conflict between immediate and longer term preferences that have to be weighed up. These are described by Jane Tracy (2015) who talks about her son's longer term preference for independence but his dislike of the medical treatment that might support his independence.

In this step preferences and options considered should not be constrained by parameters imposed by things such as resources or risks. This step in bigger decisions could be seen as similar to the dreaming or aspirational elements of some approaches to person centered planning but more focused on a specific decision.

Example

Where to live in the future. Ellie found it hard to conceptualise living somewhere else and had no experience to draw on. Those who knew her well described some of her preferences that they thought would be important in making the decision - she doesn't like being around lots of other people, she likes walking, she hates cars, she likes being with Edward now and again.



Step 4. Refining the decision and taking account of constraints

Nevertheless a decision is more than a dream or hopeful statement in a plan. It must be implementable. In this step preferences are prioritised, refined and shaped by constraints such as time, money, impact on other people, and safety. Ways are found to ensure the decision will be implemented, and potential constraints might be questioned or creatively managed.

Examples

Jane's decision about where to live if she sold the family home was shaped by how much she could sell the house for, the price of smaller apartments in her local area, and the amount of money she wanted to put aside to make sure she could afford a holiday every year and the maintenance on her new home. She cannot afford the newer apartments she likes unless she finds someone to share with her, but if she bought an older unit she could afford to live alone.

Ellie's decision about where she would live was shaped by her lack of money to purchase her own house and reliance on social housing. Luckily there was more social housing on the fringes of the city where she lived where there are more walking tracks. The cost of visiting old friends living in the inner city was one of the issues considered in deciding to move to the outer suburbs.



Step 5. Deciding whether a self-generated, shared or substitute decision is to be made

This step distils the knowledge gained in earlier steps about the decision, preferences, priorities, constraints and consequences. Based on the knowledge accumulated it will be clearer whether the combination of this specific decision and the person's own skills means they can be supported to make a self-generating decision or a shared decision, which may resemble an informal substitute decision, or, whether due to the anticipated harm to themselves or others they need support for a more formal process of making a substitute decision. If there is conflict about reaching a shared decision then at this stage it may be appropriate to seek a more formal decision making process such as an application for a guardian. If a person already has a guardian in place, then at this stage the decision making supporter should reach out to the guardian providing them with all the relevant information so they are in the best possible position to make a decision that reflects the person's will and preference.

Example

Jane and her sister decided together to buy an older unit in the area where Jane had always lived which would mean Jane could live on her own.



Step 6. Reaching the decision and associated decisions

At this step, the decision is made to reflect prioritised preferences as closely as possible. The many consequential decisions that will flow from a major decision will become clearer. In supporting each of these smaller decisions the support for decision making cycle loops back to step 1 and is repeated. At this step, depending on the decision, it may be formally recorded and communicated to others involved in the person's life, in a formal or informal capacity who will support its implementation.

Example

Having decided to sell the family home and buy an older unit, Jane must decide how much money to invest on making the house look less run down so she can get the maximum price, and how to go about finding a unit to buy.



Step 7. Implementing a decision and seeking out advocates if necessary

It is at this point that decision making often falters as the tasks, the power, or resources necessary to implement the decision may be beyond the scope of the supporters involved in earlier stages of the decision. Importantly, implementation may not rest with decision making supporters but with the NDIS, a case manager or service provider. At this stage, decision making supporters may seek out advocates to support implementation of the decision or others in a person's circle may shift into an advocacy role to make sure the decision is followed through. The processes of support do not stop here; as the person being supported is likely to be involved in making consequential decisions for which support might be needed and other unrelated decisions as their life unfolds. Having an advocate or a case manager to help implement a decision may not negate the need for continuing support with decision making.

■ Example

Jane will need access to expert advice and intensive support to make all the arrangements to sell the house and buy a new unit. She will also need help to navigate the legal contracts to ensure the new unit is put in her name.

Principles of Support for Decision Making

As indicated earlier in this document the values embedded in the United Nations Convention on the Rights of Persons with Disabilities underpin support for decision making. In addition, three principles inform all support for decision making, as illustrated in Figure 6.



Figure 6: Principles of support for decision making

1. Commitment

Effective support for decision making is contingent on the relationship between the person and their supporters. This means that first and foremost, supporters must have a relationship with the person and a commitment to upholding their rights. The relationship does not have to be 'excellent' or 'perfect' but it has to be underpinned by unconditional regard for the person as a human being of equal value and a holder of rights. With equality and rights as foundational beliefs, supporters are more likely to have positive expectations about the person's participation in decision making and to respect their opinions and preferences rather than subordinating them to others in the decision making space (e.g., family members, staff, experts).

Effective support relationships are characterised by trust, genuine positive regard and honest interpersonal interactions. Knowing a person is dynamic and ever changing, a supporter must be committed to continually learning about the person's changing self, often in terms of skills, preferences and circumstances.

2. Orchestration

Support for decision making is a shared task, involving a range of people from different parts of a person's life. Importantly too it will involve people who know the person in different ways, such as a friend, a sister, and perhaps more instrumentally as a client who requires intensive and costly support with everyday activities. Supporters may include immediate or extended family, direct support workers, managerial staff, and subject matter experts. A primary supporter leads and orchestrates support, drawing in other supporters, both formal and informal from various parts of the person's life, as well as mediating any differences. If such a lead person is not evident then, for some decisions, it will be necessary to find someone willing to take on that role.

3. Reflection and Review

Supporters can, consciously or unconsciously, exercise enormous influence on people with cognitive disabilities during the process of supporting decision making. Continuous reflection by supporters on their own values, their own stake in the decision and potential to influence the person they are supporting will help ensure the decision making agenda remains based on the will, preference and rights of the person they are supporting.

Reflexivity, which is *self-awareness and continuous reflection*, helps supporters to adopt a *neutral non-judgmental stance* that puts aside their own preferences and assumes a neutral view on the costs and benefits of risk taking.

These principles mean that supporters must employ a self-questioning strategy, applying *self-checks and balances* to each decision situation. Also, they must identify points in the process of support where they are particularly vulnerable to providing biased, value-laden, or constrained support. The principles of reflective practice help also to identify occasions when unchallenged implicit assumptions and worldviews are at play.

Support for decision making should be transparent and accountable, which means supporters must be both self-reflective about their support and open to review by others. Supporters should be able to articulate their reasoning processes and describe the observations, experience and knowledge they have used to inform their support and track this through to the point of decision.

Strategies for Practice

Strategies are needed for each step of support for decision making and for putting the principles into practice. As illustrated in Figure 1, very broadly strategies can be seen as providing access to information and or opportunities to widen experiences of what might be possible; enabling, ascertaining or interpreting a person's preferences and helping to understand constraints and consequences. But supporters need a wide repertoire of more nuanced strategies that can be tailored to the person they support and the decision at hand. Strategies must be person centred and will depend on timing and situational factors, the significance, scope and nature of the decision, and who else might be involved in or affected by the decision.

Here, in Figure 7, we categorise and illustrate the range of strategies that have been identified from research.



Figure 7: Strategies in support for decision making

Safeguards and Accountability of Support for Decision Making Supporters

Support for decision making rests on the commitment of supporters to furthering the rights of the person to participate in decision making and to being directed by their will and preferences. A high level of trust and responsibility is vested in supporters.

This framework for support has embedded safeguards. In summary these are:

- **Continual process of review and reflection** by supporters – requiring supporters to reflect on whether their support is driven by a supported decision making paradigm based on commitment, knowledge of the person and respect for will, preference and rights, or whether it is sliding into the old paradigm, driven by 'best interest' perspectives.
- **Accountability** – requiring supporters to be able to explain how they come to know claims about the person's preferences, the rationale for their support and give evidence about how they provide any support that lies behind shared or substitute decisions made with a person.

- **Orchestration** – requiring supporters to act in concert with others and not alone. This should mean supporters work as part of an orchestration of support with others who know the person well and are involved in their lives.
- **Person centred strategies** – requiring supporters to tailor support strategies to the person and the decision.
- **Rights and least restrictive alternatives** – requiring the values of the United Nations Convention to underpin all support for decision making, that supporters promote human rights and if they are involved in formal or informal substitute decisions that curtail rights, they do so in the least restrictive way possible.

Training Modules and Materials

Training for facilitators and supporters within this framework uses a case-based, interactive approach. Elements are identified and exemplified through the experiences of both supporters and those who they support. Training is ideally delivered through small face-to face groups but is designed to be appropriate for individual and/or distance web-based delivery with minimal modification.

Interactive, case-based methods have been adopted because these methods support deep learning and the development of critical reasoning skills, and promote motivation and enthusiasm. The cases can be presented in a variety of formats (e.g., printed or video) and serve as the stimulus for acquiring the basic knowledge needed to understand support for decision making. They also serve as the focus for developing self-awareness and reflective practice skills.

The training program includes a series of resources which act as a toolkit to provide guidance to facilitators and supporters. These resources provide systematic guides to support for decision making across the elements of the framework and are designed for broad application.

That is, they can be applied equally to provision of support for person's with high or low support needs, making small or large decisions, in differing environments (e.g., institution, family home), across varying systems (e.g., NDIS, Health) and legal jurisdictions. The resources within the toolkit take various forms to support practice and include flow charts, templates, tip sheets, checklists, practice summaries (e.g., signs and pitfalls) and practice recommendations.

The training modules designed for family members, direct care staff, appointed guardians and decision making facilitators will further exemplify support for decision making practice. Piloting and evaluating the framework at Kanangra Centre, whose residents and their families reflect one microcosm of people with cognitive disabilities, will enable it to be refined to apply more widely to other NDIS participants.