

Submission to the NSW Law Reform Commission

Review of the Guardianship Act 1987 (NSW)

Question Paper (QP) 2: Decision-making models (November 2016)

1. Publication of submission

- 1.1. The Department of Family and Community Services (FACS) welcomes the opportunity to respond to Question Paper (QP) 2: Decision-making models and consents to the publication of this submission.

2. Context of submission

- 2.1. FACS has reviewed QP2 in the context of NSW's transition to the National Disability Insurance Scheme (NDIS) with full transition to occur by 30 June 2018. Since 2011/12 and expanded further under the *Disability Inclusion Act 2014* (NSW), FACS has implemented a suite of capacity building and decision support initiatives to build the capacity of people with disability, families and carers to exercise choice and control to safeguard, empower and affirm their right to be in charge of their lives in preparation for transition to the NDIS.
- 2.2. FACS investment in consumer capacity building and supported decision making initiatives was in direct response to feedback from people with disability, their families and carers who participated in the *Living Life My Way* consultations in 2011/12. Over 4,000 people including people with disability, service providers and other stakeholders participated in these consultations which were designed to inform the policy settings for a NSW system based on self directed support and individualised funding.
- 2.3. In 2013/14, a Supported Decision Making pilot was undertaken in NSW in partnership with the NSW Trustee and Guardian and the NSW Public Guardian to commence the shift from substitute decision making.
- 2.4. The pilot received positive mention in the United Nations Committee's concluding observations on Australia's report to the Convention on the Rights of Persons with Disabilities in September 2013.
- 2.5. Building on the findings and recommendations of *My life, My decision - An independent evaluation of the Supported Decision Making Pilot*¹, a number of projects are currently underway that address the specific considerations of different cohorts of people with disability and aim to identify effective strategies to build decision making capacity (refer **Attachment A**).
- 2.6. FACS is facilitating and partnering with a range of government and non government providers to deliver these projects to facilitate embedding of supported decision making principles within the sector. As supported decision making is still an emerging concept in Australia and internationally, the projects aim to test approaches to effectively build decision making capacity of people with disability.

¹http://www.adhc.nsw.gov.au/individuals/inclusion_and_participation/supported-decision-making/sdm-projects

- 2.7. The supported decision making projects are being evaluated to ensure that evaluation findings and recommendations can contribute to the growing body of knowledge on supported decision making models and approaches and inform national directions under the National Disability Insurance Scheme (NDIS) including Information, Linkages and Capacity Building (ILC).

3. General Comments

- 3.1. In responding to QP2, FACS has drawn on its evaluation findings of the Supported Decision Making Pilot and observations from the subsequent supported decision making projects. FACS has not commented on every question asked by QP2 but has provided comments in regard to the following:
- Should NSW adopt a formal supported decision making model?
 - Should NSW retain substitute decision making?
- 3.2. It is FACS' experience that it is neither possible nor desirable to adopt a single formal supported decision making model, as a range of different supported decision making approaches may be required, depending upon the needs and support resources available to a person as discussed and highlighted in this submission. The types of support that may be required to assist people make decisions are varied and will depend on the person's individual circumstances and the type of decision.
- 3.3. Supported decision making is a process of assisting a person with disability to exercise their legal capacity to act on an equal basis with others to make their own decisions. Support for decision making is generally provided by those a person with disability trusts, and could involve assistance with communication, or providing information in accessible formats, among many other examples outlined in this submission. Importantly, the person (decision maker) is being assisted to make their own decisions; retaining their autonomy and agency to make decisions.
- 3.4. In this context supported decision making reflects the current practice for most people in the community where decision making involves engagement with and advice from others in everyday life². The extent to which this can and should be formalised in legislation requires careful consideration.
- 3.5. Instead, as previously noted in Question Paper 1, FACS considers that the review is about confirming the place of the legislative regime for substitute decision making within a human rights framework and central to this is a more robust and transparent legal framework for how capacity is determined and applied.
- 3.6. As outlined in Question Paper 1, FACS proposes that the Guardianship Act should contain an explicit presumption of capacity. This would provide a significant measure for protecting the legal capacity of vulnerable persons in the legal context providing for the appointment of alternative decision making arrangements.
- 3.7. In this regard, FACS proposes that the NSW Capacity Toolkit³ should be reviewed and adapted to support reform of NSW Guardianship law and that the legislation be strengthened to include principles for determining when a person does not have the decision making ability to make a certain decision based on the NSW Capacity Toolkit.

² Gordon RM. The Emergence of Assisted (Supported) Decision Making in the Canadian Law of Adult Guardianship and Substitute Decision making. 2000 International Journal of Law and Psychiatry, volume 23(1).

³ http://www.justice.nsw.gov.au/diversityservices/Pages/divserv/ds_capacity_tool/ds_capacity_tool.aspx

- 3.8. FACS proposes that from a legal perspective, substitute decision making should be maintained in NSW so that it can continue to make available its lawful protective functions for people who are not able to make autonomous decisions, even with appropriate support.
- 3.9. The review will also need to be cognisant of the NDIS, particularly with regard to the implementation of the new NDIS quality and safeguarding system and interactions with NSW Guardianship law. It will be important that the review takes account of any potential legislative and regulatory interoperability issues this may give rise to between State and Commonwealth systems.

4. Should NSW adopt a formal supported decision making model?

- 4.1. In a joint initiative, the NSW Department of Family and Community Services (FACS), and the NSW Trustee and Guardian and the NSW Public Guardian conducted a small scale pilot project in 2013/14 to explore what supported decision making might look like in practice in the NSW context.
- 4.2. The pilot aimed to learn:
 - how supported decision making relationships work;
 - which of the FACS tools were useful; and
 - how best to build decision making skills on a broader scale.
- 4.3. The pilot was conducted based on a Supported Decision Making Framework (2013)⁴ developed by FACS which recognises that:

The person is at the centre of decision making and each person with disability is unique and their needs for supported decision making will vary. That is why there can be 'no one size fits all' approach.

A person's need for support with decision making will depend on the complexity of the decision, previous experience, emotional and social factors, the timeframe for the decision and the preferred decision making style.
- 4.4. It is important to understand that the decision maker, the person with a disability, is the person who makes the decision, even if they are receiving support from others. Wherever possible the decision maker should drive the decision, getting the information and asking for the type of support that they desire. Supported decision making helps decision makers to learn skills to feel confident about making decisions independently.

5. Decision readiness

- 5.1. FACS found that many pilot participants required development of skills, knowledge and confidence to make decisions. Assistance with communication was a key enabler and highlighted the need for a proactive approach and effective aids to communication between people with disability and their supporters.
- 5.2. Through the pilot FACS found that, although many supporters self-assessed as decision ready, they actually had varying degrees of understanding and expertise. While all supporters were caring, they did not necessarily understand that, rather than making decisions in the 'best interest' of the person with disability, they should support

⁴ <http://www.adhc.nsw.gov.au/data/assets/file/0011/369956/SDM-Framework.pdf>

that person to make decisions. Wanting the best for a decision maker meant that some supporters tried to limit options to prevent what they perceived as ‘bad decisions’.

- 5.3. Family and friends who were supporters were highly aware of their duty of care while supporters from disability services were concerned about being labelled ‘negligent’ if the person with disability took risky decisions. Supporters could benefit from education about dignity of risk or risk enablement. This is the right of people with disability to learn from their own choices, even if they experience disappointment or make mistakes. Training must also take account of the power imbalance between decision makers and supporters and be sensitive to individuals’ and families’ needs and experiences.

Even though a decision maker and supporter considered that they already were practising SDM, facilitator feedback pointed to positive changes.

“The facilitator worked with the decision maker and her supporter on a decision to go to a shopping mall. Despite fears from the supporter over her safety, the person was able to clearly express her decision and articulate how she would get to the mall and the safeguarding measures she would take, which she later did.”

My Life, My Decision – An Independent Evaluation of the Supported Decision Making Pilot (2015)

- 5.4. Supporters must also be decision ready. This means:
- understanding supported decision making;
 - knowing their role and what it does and does not include;
 - understanding the decision maker’s rights; and
 - being aware of their own values so they do not project them onto the decision maker.

6. Time to understand and practise supported decision making

- 6.1. People with disability may need more time and support to process information. In many cases those in the pilot took a long time to identify a decision they wanted to make or even to identify the need for a decision. It became apparent that many of the pilot participants had limited experience of, and exposure to, making decisions, including smaller day to day decisions such as what to eat for breakfast, because decisions have always been made for them.
- 6.2. For supported decision making to succeed, the supporter must spend time with the decision maker to identify and discuss decisions. It takes time to research a decision and ensure the decision maker is able to make an informed decision. This may involve breaking the decision down into several components and working through the consequences and benefits of each component.

“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 – An Independent Evaluation of the Supported Decision Making Pilot (2015)

7. Changing attitudes

- 7.1. The United Nations Convention on the Rights of Persons with Disability (UNCRPD) and the *NSW Disability Inclusion Act 2014* recognise that people with disability have the right to make their own decisions. For people to exercise this right, experience from the pilot suggests that attitudes about people with disability will have to change significantly.
- 7.2. What FACS observed in the pilot was that some decision makers and supporters found it challenging to embrace the principles of supported decision making when these ran counter to long-held beliefs. Some supporters approached to join the pilot did not see the value of supported decision making, or did not think the person with disability was capable of making choices, even with support.
- 7.3. To change attitudes, pilot facilitators modelled empowering behaviour that valued the person with disability, talked to them about his or her rights and assisted with making smaller decisions to build confidence and self-belief. With some supporters pilot facilitators argued the case for supported decision making and prompted them to think about possible safeguards when decisions were potentially risky.

“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 – An Independent Evaluation of the Supported Decision Making Pilot (2015)*

8. Building trusting relationships

- 8.1. The development of respectful, trusting relationships is crucial to the success of supported decision making and to enabling people with disability to live the life they

want. There were two instances where disability support workers who were designated supporters left the pilot. The decision maker then had to build a new relationship, which was not only time consuming but adversely affected confidence in the whole process. This highlights the importance of supporters having adequate time to devote to their role and the ability and interest to continue for as long as the decision maker wants.

9. Training resources and support

- 9.1. Supported decision making requires a range of training and support for all those involved. This includes written resources, one-on-one facilitation, and group work. FACS experience in the pilot confirmed that written materials such as the Supported Decision Making Pilot Handbook for supporters have maximum impact when used one-on-one under the guidance of a facilitator. The involvement of a facilitator allowed explanation and message reinforcement through practice. Similarly, the Easy English version of the pilot handbook for decision makers proved more useful with facilitator support.
- 9.2. Both, decision makers and supporters reported that formal one-on-one training by the pilot facilitator was the most effective form of information sharing. A workshop with guest speakers was also successful, allowing attendees to share experiences and build a sense of connectedness. It demonstrated the importance of people with disability sharing their lived experience of supported decision making and how this opened up new opportunities for the participants. This had an empowering effect on other participants, some of whom described it as a “light bulb moment”. However, although group training engaged most participants, it is resource intensive. Not only does preparation take time, but people also need encouragement to attend.

10. Supporters

- 10.1. The pilot first recruited decision makers and then asked them to identify potential supporters, the vast majority of whom turned out to be carers. Not all were able to accept the role. Some potential supporters declined on the grounds of carer fatigue while others expressed the view that the person with disability was incapable of making his or her own decisions.
- 10.2. FACS found through the pilot that some participants had limited natural networks and were not able to readily identify someone to act as their supporter. In these circumstances, participants nominated a support worker or a paid advocate who was known to them and with whom they had a positive relationship.
- 10.3. Another issue to consider is potential conflicts of interest which may emerge in the supporter role. Supporters need to be aware of power dynamics and imbalances in their relationships with decision makers, including for family members acting as supporters. Supporters may inadvertently (or intentionally) make decisions for the person rather than assist the person to make their own decisions. Power dynamics underlie all relationships and can lead to conflict of interest and place limitations on a decision makers’ ability to exercise their dignity of risk.
- 10.4. The pilot facilitators acknowledged the complexities for supporters on a day to day basis and that training needs to be sensitive to individuals’ and families’ needs and past experiences.

- 10.5. The challenges for support workers also included dealing with conflicts of interest between their roles as supporter and agency employee (dignity of risk vs duty of care). Paid or voluntary disability service workers can take on supporter roles, however, they must be working in an environment that encourages and allows time for supported decision making.

“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, there was a concern that Mandy would lose the iPad. *Name changed.*

My Life, My Decision – An Independent Evaluation of the Supported Decision Making Pilot (2015)

- 10.6. NSW law, under the Guardianship Act 1987, sets out how medical practitioners should obtain informed consent from people who have a disability and do not understand the treatment being offered. If a medical practitioner assesses the person as not having capacity to understand the treatment, then substitute consent should be sought from another person who knows the patient and has a genuine interest in their welfare. There is no provision in the Act that medical practitioners should give more support to a person with disability to support the person’s understanding of the treatment. This goes to the heart of the UNCRPD and supported decision making, and of the paradigm shift that is underway from substituted to supported decision making for people with disability.

“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 – An Independent Evaluation of the Supported Decision Making Pilot (2015)

- 10.7. Following the supported decision making pilot and evaluation recommendations, FACS has funded and facilitated an additional 8 projects that aim to further test approaches to effectively build decision making capacity of people with disability (refer

Attachment A). While the projects are still underway and evaluations pending, feedback provided to date indicates that supported decision making approaches work best when tailored to the individual and their circumstances (refer **Attachment B**).

- 10.8. As noted in the FACS *Support for Decision Making: Practice Framework* (January 2016)⁵, 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 may need different support for different decisions.

- 10.9. Supported decision making is a process of assisting a person with disability to make their own decisions, so they can develop and pursue their own goals, make choices about their life and exercise some control over the things that are important to them. It is important to understand that the decision maker, the person with a disability, is the person who makes the decision, even if they are receiving support from others.
- 10.10. In this context its important that supported decision making is not overly formalised and to recognise that we all get support to make decisions about things that affect our lives. If the decision is important to us we might take longer to decide. We might ask other people for ideas or information, or to help us make up our mind by talking about the options.
- 10.11. For these reasons FACS proposes that it is not possible nor desirable to prescribe a single model of formal supported decision making, as a range of different supported decision making approaches may be required, depending upon the needs and support resources available to the decision makers as evidenced through the Supported Decision Making pilot and subsequent projects.

11. National NDIS Quality and Safeguards Framework

- 11.1. On 9 December 2016, the Council of Australian Governments (COAG) noted that all jurisdictions have agreed to a new national NDIS Quality and Safeguarding Framework to protect NDIS participants with disability, commencing from full scheme. The Commonwealth Government publicly released the NDIS Quality and Safeguarding Framework⁶ ("the Framework") on 3 February 2017 and it sets out the key parameters of the national quality and safeguards system to be implemented for full scheme NDIS.
- 11.2. The Framework is designed to ensure high quality supports and safe environments for all NDIS participants. The NDIS represents a significant reform to the way supports and services are delivered to people with disability. A nationally consistent approach to quality and safeguarding is essential to support the realisation of the NDIS vision and to support participants to make informed choices, while also ensuring there are appropriate safeguards in place to facilitate high quality support provision in a new market environment.

⁵http://www.adhc.nsw.gov.au/_data/assets/file/0011/386336/Support-for-Decision-Making-Practice-Framework.pdf

⁶ NDIS Quality and Safeguarding Framework 9 December 2016 www.dss.gov.au/ndisqualitysafeguards

- 11.3. Key safeguarding components of the new NDIS Quality and Safeguarding Framework includes the recognition of developmental and preventative safeguarding measures such as providing participants with accessible information for informed decision making and building participant's capacity to exercise choice and control.
- 11.4. Under the *National Disability Insurance Scheme (NDIS) Act 2013* (Cth) the National Disability Insurance Agency (NDIA) has a central role in safeguarding the interests of participants. This includes working with participants to assess and manage risk. The Framework affirms that supported decision making is encouraged over substitute decision making where ever possible.

Some participants will also need supported decision-making to ensure their will, preferences and rights direct the decisions that affect their lives. Supported decision-making is when one person gives another the support they need to make decisions about their own life. In the NDIS, supported decision-making will be crucial to ensure that people with communication needs, cognitive, intellectual or psychosocial disability are able to exercise genuine choice and control.

NDIS Quality and Safeguarding Framework 9 December 2016

- 11.5. The Framework outlines that where people with disability need more assistance to exercise choice and control their NDIS plan could provide access to specific supports to build their knowledge and ability to make choices, understand their plan and exercise their rights where required. If a participant needs supported decision making this can also be funded through their plan⁷.
- 11.6. Additionally, the Framework also acknowledges that the Information, Linkages and Capacity Building (ILC) stream aims to help people with disabilities better communicate their preferences and make informed and independent decisions. ILC supports will be available to both people with disabilities who have an NDIS plan and those who do not. The ILC Commissioning Framework and Program Guidelines released by the NDIA in late 2016 outline the action plan for rolling out ILC across Australia and includes as one of four key focus activity areas - funding Individual capacity building – this activity area is about making sure people with disability have the knowledge, skills and confidence they need to set and achieve their goals⁸. ILC is expected to commence in NSW in line with the transition to full scheme NDIS.
- 11.7. The Framework also recognises that the *NDIS Act 2013* makes provision for nominees to be appointed when necessary and that the NDIS operates in conjunction with existing state and territory-based safeguarding mechanisms for people with significant cognitive impairments or mental illness, such as guardianship tribunals and public advocates.
- 11.8. It will be important for the review of the *Guardianship Act 1987* (NSW) to be cognisant of the implementation of the new national NDIS quality and safeguarding system and to address any potential legislative and regulatory interoperability issues this may give rise to between State and Commonwealth systems.

⁷ *NDIS Quality and Safeguarding Framework 9 December 2016* www.dss.gov.au/ndisqualitysafeguards .

⁸ *Information, Linkages and Capacity Building Commissioning Framework November 2016*
<https://www.ndis.gov.au/community/ILCCommissioningFramework.html>

12. Should NSW retain substitute decision making?

- 12.1. As the NSW LRC notes in QP2, some commentators argue that the UNCRPD allows for substitute decision-making because this is a proper interpretation of human rights. FACS endorses this view that a rights-based framework can accommodate substitute decision making.
- 12.2. FACS recognises that in some circumstances there will be a need for formal substitute decision making such as guardianship orders as a last resort after evidence of all other supports for decision making has been exhausted. A formal substitute decision maker may be required due to multiple complex factors such as where despite support being available to a person; the severe, long term nature of their decision making impairment is such that the person is unable to express their view or their will and preferences cannot be ascertained.
- 12.3. As a service provider for diverse clients, FACS has supported people who are not capable of negotiating their way through daily life without relying on the decision-making authority of a carer or family member. Through this observation, FACS recognises that formal substitute arrangements can operate as a vital element in a person's broader support arrangements. The presence of a substitute decision maker in the life of such persons does not necessarily limit the impact of other supports and services that promote inclusion and capacity-building in the person. This point is illustrated in the following case example from the *FACS Support for Decision Making: Practice Framework* (January 2016):

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).*

- 12.4. To an extent the current *Guardianship Act 1987* (NSW) operates from the position that guardianship is a 'last resort', however there may be benefit in more explicitly stating this with respect to where evidence of all 'reasonable adjustment' has been exhausted.
- 12.5. In this respect, the Australian Law Reform Commission's Report on Equality, Capacity and Disability in Commonwealth Laws (2014) recommended the following guidelines for when a representative ("substitute decision maker") is appointed to make decisions for a person who requires decision making support:
- a) The person's will and preferences must be given effect.
 - b) When the person's current will and preferences cannot be determined, the representative must give effect to what the person would likely want, based on

- all the information available, including by consulting with family members, carers and other significant people in the person's life.
- c) If it is not possible to determine what the person would likely want, the representative must act to promote and uphold the person's human rights and act in the way that is least restrictive of those rights.
- d) A representative may override the person's will and preferences only where necessary to prevent harm.⁹
- 12.6. It is important to understand that supported decision making differs from substitute decision making (representative decision making) in two main ways:
- A substituted decision is made on behalf of a person with impaired decision making ability, whereas a supported decision means that someone has been helped to make a decision themselves.
 - A substitute decision maker is authorised to make a decision for the represented person, which is deemed the decision of the represented person. By contrast, in supported decision making arrangements, the assisted person continues to be the person authorised to make decisions, either alone (but with support).
- 12.7. As the NSW Government has previously stated:
- 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 ... [proposed] 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.*¹⁰
- 12.8. The conceptualisation of the precondition of capacity (discussed in Question Paper 1) is integral to identifying the situations in which substitute decision making is required. FACS proposes that the NSW Capacity Toolkit¹¹ should be reviewed and adapted to support reform of NSW Guardianship law and that the legislation be strengthened to include principles for determining when a person does not have the decision making ability to make a certain decision based on the NSW Capacity Toolkit. Importantly, decision making ability is assessed as having regard to appropriate support and by addressing limiting environmental factors.
- 12.9. The review should also consider that there is a distinction between people with disabilities who face, and are limited by, assumptions about their capacity; and situations involving people with immediate and significant loss of capacity that demands an immediate response, such as medical emergencies.
- 12.10. FACS considers that the review should not overturn the *Guardianship Act 1987* (NSW) current substitute decision making functions. These are purposive functions that are distinct from supported decision making which relies on the person being able to direct the decision.

⁹Equality, Capacity and Disability in Commonwealth Laws (ALRC Report 124) <http://www.alrc.gov.au/publications/equality-capacity-disability-report-124>

¹⁰ https://www.alrc.gov.au/sites/default/files/subs/135_orq_nsw_government_submission.pdf

¹¹ http://www.justice.nsw.gov.au/diversityservices/Pages/divserv/ds_capacity_tool/ds_capacity_tool.aspx

- 12.11. From a legal perspective, substitute decision making should be maintained in NSW so that it can continue to make available its lawful protective functions for people who are not able to make an autonomous decision, even with appropriate support.
- 12.12. FACS provides further comment on how substitute decision making arrangements currently operate and should work in NSW in its submission to *Question Paper 3: The role of guardians and financial managers*.

SUPPORTED DECISION MAKING PROJECTS

THE ABILITY PROJECT (TAP)

CREATE Foundation is delivering capacity building activities aimed towards building the skills of young people with disability in the Leaving Care Program (LCP), their family or carers in preparation for transition to the National Disability Insurance Scheme (NDIS). The LCP supports young people with disability in out of home care (OOHC) to transition from the parental responsibility of the Minister for Family and Community Services to live as independently as possible within the community.

TAP provides training to build the capacity of supporters or carers in using and implementing a supported decision making approach. In 2015/16, the first year of the project, CREATE delivered numerous workshops and events, and developed *Voice Your Choice* – a training video designed for anyone who is caring for, supporting or working with a young person with disability in OOHC or preparing to leave care. The training tool can be used to support in-house training on supported decision making approaches to working with people with disability or as a taster to CREATE's three-hour *Voice Your Choice* training workshop for carers, support workers or caseworkers working with young people with a disability in OOHC. The project is being independently evaluated.

FINANCIAL DECISION MAKING AND FINANCIAL LITERACY SKILL DEVELOPMENT

FACS is collaborating with the NSW Public Guardian and the NSW Trustee and Guardian to create and deliver a supported decision making program to support people make financial decisions.

The project has two parts: the training component, which is focused on enhancing sector capacity, has developed an *'Introduction to supported decision making'* full day workshop for service providers. The training is complemented by resource materials that highlight the importance of knowing the person, communication and the role of friends and family when providing support for decision making. There is also a Train-the-Trainer component for those interested in being champions of supported decision making in their workplace and beyond.

The financial decision making component of the project is working with participants and their supporters to see how the principles of SDM apply to financial decision making, by developing their capability through financial literacy training, and looking at how they can be supported to make financial decisions. The project is being independently evaluated.

SUPPORTED DECISION MAKING WORKSHOPS FOR 12-18 YEAR OLDS WITH DISABILITY, THEIR FAMILIES AND/OR CARERS PROJECT

Carers NSW and Mirri Mirri are partnering to deliver a series of workshops in key metropolitan and regional areas of NSW. The workshops will build decision making capacity in young people (12-18 years) and their families/carers. The project aims to prepare young people and their families/ carers for the NDIS, through developing age appropriate decision making and increasing their capacity to self direct. Working with families /carers will support their move away from substitute decision making.

DEVELOPING AND PILOTING A CONTINUUM APPROACH TO DECISION MAKING

The project is being undertaken in partnership with FACS, St Vincent de Paul and La Trobe University and is piloting a continuum approach to decision making supports for people with cognitive disabilities who live in FACS Large Residential Centres (LRCs). The goal is to ensure that all people are provided with the support they require to exercise optimal choice and control in decision making, regardless of their decision making capacity and existing supports as well as address some of the disadvantage experienced by people who live in LRCs, including isolation from social support, limited ability to exercise choice and restricted life experiences that can impact upon their capacity to make decisions.

The project has produced the Support for Decision Making Practice Framework which aims to lay foundations to guide practice for decision making supporters of people with cognitive disability. The framework will also be a useful resource for families, carers, support workers and guardians on how to optimise opportunities for people with cognitive disability to make decisions and have greater control over their lives. Enabling people with cognitive disability to direct their own decisions will only happen if supporters have high expectations that people can participate in decision making and have strong commitments to make this happen.

The project is midway through its implementation and is currently being independently evaluated through an action research approach.

ADVANCING SUPPORTED DECISION MAKING PROJECT

This project builds on the Supported Decision Making (SDM) Pilot by testing whether supported decision making practices can be embedded within the Ability Links and Early Links programs. The project was implemented in partnership with St Vincent de Paul Society NSW and Uniting Jaanimili by exploring a SDM practice and approach within Ability Links in Metro South Region and Early Links with their local Aboriginal communities, respectively. The project is currently being independently evaluated.

RISK ENABLEMENT TRAINING PROJECT

FACS in partnership with National Disability Services (NDS) NSW, La Trobe University and NSW Public Guardian is developing and evaluating a risk enablement training package for disability sector organisations and their staff working with people with cognitive disability.

La Trobe University is undertaking a co-design approach in the development of the training package and will include a face-to-face delivery mode and an e-learning module to promote positive risk taking for people with disability. La Trobe University is exploring the attainment of accreditation for the training as a unit of competency. The training package will be delivered by the NSW Public Guardian.

STRENGTHENING DECISION MAKING OF ABORIGINAL PEOPLE AND THEIR COMMUNITIES

A partnership between Illawarra Aboriginal Corporation, South Coast Medical Service Aboriginal Corporation and Uniting Jaanimili building on the Advancing Supported Decision Making project is exploring culturally appropriate approaches to strengthen the decision making capacity of Aboriginal people with disability, and their supporters. The project will include a co-design approach to the development of

culturally appropriate resources and approaches to supporting decisions and the development of workshops.

BOARDING HOUSE RESIDENT CAPACITY BUILDING: ELPIS PROJECT

Neami National is working with residents of Assisted Boarding Houses in NSW to support people with disability to exercise choice and control, through supported decision making approaches and to develop support networks. Neami National is also working with licensees, and managers of Boarding Houses to understand their role and develop skills to support their residents.

FACS' SUPPORTED DECISION MAKING PROJECTS – EXAMPLES OF DECISION MAKING APPROACHES

Supported Decision Making Workshops for 12-18 year olds with disability, their families and / or carers project - Carers NSW and Mirri Mirri

The process for decision-making within this workshop follows a general pattern where the facilitator:

1. Provides a situation where students are required to make a decision
2. Allows students an opportunity to process information and make a decision (if necessary, the facilitator will provide options students can choose from)
3. Gains feedback from students as to how and why they came to their decision
4. Provides students with positive reinforcement

Although seemingly simple, this approach has a number of positive outcomes. Firstly it empowers and provides a 'voice' for the students through the decision making process. Secondly, the willingness of the facilitator to listen, support and accept the students decision, significantly contributed to the positive relationships that developed between facilitator and student (within a short time frame). Finally, some teachers were able to reflect on their teaching methodologies, and highlighted a need to provide more opportunities for students to contribute to decision making within the classroom.

To date, Mirri Mirri has delivered supported decision making workshops to in excess of 300 students with a disability across NSW. These students range from 12 – 18 years and represent a diverse scope of disabilities including, but not limited to, mild intellectual disability, autism, physical disability, anxiety and mental health.

During the workshop, the vast majority of students were able to demonstrate some level of input with the decision making process. However, the student's ability to make decisions was significantly enhanced when they:

- Understood the decision making processes
- Were able to analyse information
- Learnt how to communicate positively with their supporters
- Became confident to 'speak up' and verbalise decisions they felt best suited them.

Providing ongoing educational opportunities for young people in the decision making process will ensure they are adequately skilled and capable to make decisions they feel best suit their individual needs.

Elpis Project - Neami National

Neami National is working with residents of Assisted Boarding Houses in NSW to support people with disability to exercise choice and control, through supported decision making approaches and to develop support networks.

Practice example:

The consumer attended the first Elpis session on strengths and values. During the session the consumer disclosed his inability to read. The Neami staff member spoke with him about his previous learning experiences, his desire to develop his literacy

skills, and barriers to learning. The Neami staff member was able to support the consumer to identify possible options to improve literacy in a non-threatening and supportive environment, and to overcome previous barriers to learning. The Neami staff member encouraged the consumer to learn to read telling him “it will change your life”. By the end of the conversation the consumer chose to seek further support to learn to read, and asked the Neami staff member to refer to a local service provider to coordinate classes with him. At each of the subsequent monthly sessions, the Neami staff member checked in with consumer about progress, and at the end of the project (6 months later) the consumer was able to read letters and some small words, and was still attending literacy classes.

Practice example:

The consumer attended the first Elpis session on strengths and values. The consumer spoke to a Neami staff member and said “you don’t stop and think about these things very often, but it is really good to do so”. Consumer attended all subsequent monthly sessions, and engaged with material and staff. During the duration of the project the consumer’s appearance improved significantly – both his personal hygiene and physical health - as did his confidence and engagement with staff and other consumers. By the end of the project (6 months later) he was almost unrecognisable in his appearance and demeanour. He told Neami staff that he was feeling much more independent, he was going out more and engaging in his hobbies and interests, and he attributed the change to increased confidence he had gained through participation in the project and through making better decisions for himself.

Advancing Supported Decision Making (ASDM) Project - St Vincent de Paul Society NSW

The ASDM project aims to:

- build the capacity of people with disabilities to make informed decisions, with their chosen supporter as required
- build the capacity of Linkers to assist people with disability to make their own decisions
- build capacity within Ability Links / Early Links service provider organisations to facilitate supported decision making
- develop an understanding of how supported decision making is best embedded in practice in service provider organisations
- develop an understanding of best practice approaches for using supported decision making to build people’s capacity to make their own decisions.

Practice example:

M is a man in his 50s who has been isolated from social life and social support services all his life. He has had little or no opportunity to experience the world outside a tight local circumference, and play any part in setting his own course.

M was referred to Ability Links by a case manager, to assist M to develop his interests and links in community life while some of the larger concerns about his living situation were addressed.

M was offered participation in a supported decision making project. M and his Linker spent 2 hours each week for months exploring what he would like to do and

developing M's awareness of his role in influencing what could happen in his life. During this process, M told his Linker that he liked the idea of being a stronger person and not having to rely on others so much. The Linker focussed on small decision making with M, supporting him to identify interests within his home. By building on these interests the Linker was assisting M to understand that he was making and enacting decisions.

The Linker assisted M, to see his doctor about health concerns. Historically M had been quite passive when visiting the doctor but the Linker supported M to prepare his own thoughts and questions that he wanted to ask the doctor.

Financial Decision Making and Financial Literacy Skill Development Project – NSW Public Guardian and the NSW Trustee and Guardian

Practice example: Supported decision making and capability enhancement to work towards regaining control of finances

R is a 25 year old female who lives in a regional area of NSW living with intellectual disability and episodic mental ill health. She works full time as a cleaner in supported employment and lives independently in a department of housing property. She receives formal support twice a week from two disability support workers, and a case worker and counsellor through the mental health team. She identifies one of her disability support workers as her supporter to help her make decisions about her money.

R's finances are subject to a financial management order with NSW TG appointed as her financial manager. R receives a Centrelink benefit and has money in a savings account. R acknowledges that she had a need for someone to manage her finances in the past but now wishes to take back responsibility for managing her funds. R is aware that under current legislation she needs to demonstrate that she is capable of managing her finances.

R through the project enrolled in and completed a financial literacy course to develop her skills. The project also resourced R's supporter with information on how R could be supported to seek greater control of her funds. R has been supported to make a decision to paint her flat and to spend money on materials and to request a s71(2) authority from NSW TG to manage a portion of her financial affairs – she has taken on responsibility for paying her pharmacy bills. R hopes once she demonstrates competency in this regard to take on further responsibilities as she builds evidence of her financial capability to accompany an application to NSW NCAT to have her order reviewed.

R reports that financial literacy training and having someone to support her with financial decision making has increased her confidence to talk to her financial manager about her affairs and to make decisions on how to spend her money.

R's situation demonstrates that support to develop financial skills and capability, and targeted resourcing to enhance her existing support mechanisms assisted her towards achieving her goal of greater independence.

Practice example: Supported to choose own financial safeguards

T is a 46 year old woman living in community housing in a regional town in NSW with mental illness and physical health needs. She receives primary health care for her mental illness but has no other formal support. T has regular contact with family;

she seeks support with financial decisions through a couple involved in her church.

T has a financial management order with NSWTCG as her financial manager.

T receives a Centrelink benefit and has savings in a number of bank accounts. T initially wished to seek revocation of her financial management order. After a brief episode of mental illness, T has decided that she wishes for the order to remain in place. T now feels that the order protects her from the risk that she will exhaust her savings on impulse purchases when she is mentally unwell.

The process of support with financial decision making has enabled T to determine the kind of support she wants to safeguard her finances. She was supported to explore the nature and extent of safeguards she feels she needs, while at the same time maximising her independence in other aspects of her financial decision making.

T's supporters are very risk averse. An important aspect of facilitating support for financial decision making has been to enable T to identify ways in which she can be more independent with her financial decision making, and to clarify how she wants her supporters to support her.

T's situation demonstrates that determining limits and safeguards is an important aspect of support for people with financial decisions. It enabled her to act on her will and preference, directing and owning the measures in place rather than feel them as imposed. Another option for T may have been to seek to have her financial management order revoked, but then through use of a power of attorney to make decisions about the safeguards she wishes to have in place.

Practice Example: Choosing capability development opportunities as a mechanism to demonstrate financial capability and successfully seek revocation of a financial management order

K is a 42 year old woman who lives with her partner in public housing. She has a mental illness. She receives support from the local mental health team and her partner but otherwise has no formal assistance or care. She receives a Centrelink benefit and has a small amount of savings.

K has a financial management order with NSWTCG as her financial manager. K felt that she was able to manage her financial affairs and wanted her order revoked.

K was unsure what she needed to do to take back management of her money; her need for support was in regard to her lack of knowledge of the process of seeking review of her financial management order and the importance of establishing evidence of financial capability in order to support an application for review.

The project assisted K with providing information on how to submit an application for review and gain evidence of financial capability. K completed a financial literacy course which provided supporting evidence to her successful application to resume management of her financial affairs.

K's situation demonstrates that the process to regain control of one's financial affairs can be opaque and that there is a need for readily available information and support to help people navigate the process.

Developing and Piloting a Continuum Approach to Decision Making - St Vincent de Paul, La Trobe University and FACS

The Support for Decision Making (SfDM) project is piloting support for decision

making approaches for people with complex support needs who live in FACS Large Residential Centres.

The following practice examples demonstrate how support for decision making can be used by substitute decision makers to give effect to the person's will and preferences and where necessary interpret these.

Practice example:

The SfDM project received a specific request from a substitute decision maker regarding a decision for a person who has lived in LRCs for 55 years relating to their future living arrangements. The person has a severe/profound intellectual disability and severe communication impairment as well as complex health and mental health needs. The service provider had requested an accommodation move. The substitute decision maker felt some factors may not have been fully explored; had received conflicting information and was not able to gain a sense of the person's perspective.

The SfDM facilitator worked directly with the person getting to know them (their history, attributes, likes/dislikes, experiences, skills, interaction style etc), working with the staff, identifying relationships and supports, exploring options, understanding the person's expressed will and preference, exploring constraints.

This information was collated and shared with the formal substitute decision maker who highlighted that a decision could now be made with improved evidence of the person's will and preference and more information about the options available and how constraints can be addressed.

Practice example:

In one situation a family member acted in an "informal" substitute decision maker role. Their family member has a moderate / severe intellectual disability, complex mental health history and support needs and has lived in a LRC for 45 years. The family member was concerned that although they wanted to support their family member as much as possible they identified they had a limited understanding of the person and their support needs and had not been actively or positively involved with the service.

As a result they felt they would require a formal substitute decision maker to be appointed. Through the SfDM project, a facilitator worked with the person and their family member getting to know the person, understanding the way they express their will and preference, identifying what the person would like to change in their life, what their support needs are, identifying their relationships etc.

The process also worked around some of the constraints in the person's life which existed as part of the system. This included file reviews which clarified some of the misunderstandings and beliefs which had developed around the person's mental health presentation and associated challenging behaviours. Through the process of support for decision making the family member identified that they felt more connected, had an increased understanding of the person and more able to support them with decisions going into the future.

Additionally, the process also meant that the person was able to have an increased relationship with other family members as it was highlighted she was seeking this and they felt more included and "invited in" to be part of the person's life. The supports for decision making in this situation mean that the family network has

improved capacity in supporting the person and her natural support network is stronger resulting in less reliance on paid and / or formal support needs in the future for decision making.