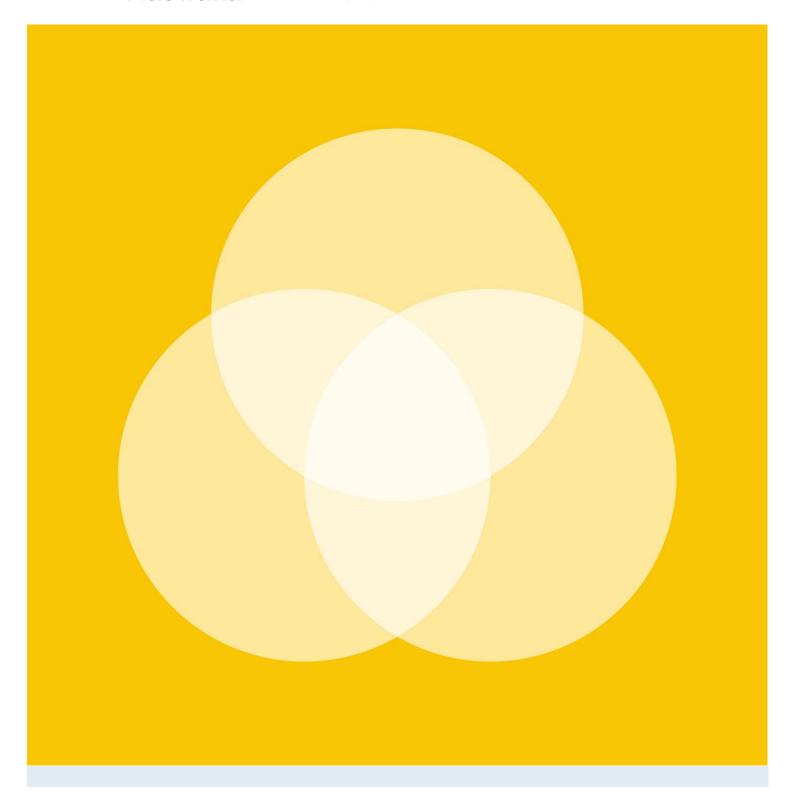# Supported Decision Making, Psychosocial Disability and the National Disability Insurance Scheme

FEBRUARY 2016

This report was commissioned and funded by the NDIS Sector Development Fund as part of a capacity building project being delivered by Mental Health Australia. The report was designed to assist in identifying the needs of the disability sector, including consumers and providers, to transition to the NDIS environment. Findings from the report form the basis of the capacity building work being undertaken by the project.

The views and recommendations expressed in the report are welcomed by the Commonwealth and have been taken into consideration as the part of policy and operational design of the transition to the full NDIS. No formal response will be provided to the report.

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About this Discussion Paper

In 2014 Mental Health Australia approached The ACT Disability, Aged and Carer Advocacy Service (ADACAS) to write a discussion paper on supported decision making (SDM) for people with psychosocial disability with reference to the National Disability Insurance Scheme (NDIS). ADACAS has completed a range of SDM projects over the past three years. These projects, undertaken by project coordinator Kate Rea, have included pilot projects developing support responses in collaboration with people with cognitive impairments, and those with cognitive and psychosocial disability. In addition, ADACAS has developed a SDM web tool and gives regular SDM training to individuals and their families, professionals and supporters. ADACAS is also a member of the National Supported Decision Making Network which is currently developing a national framework for SDM.

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Executive summary

In 2013, the Australian Government introduced the National Disability Insurance Scheme (NDIS) to offer people with disability, including psychosocial disability, more choice and control over the supports they use. The intention of the NDIS implies greater ownership of decision making by people with disability. However, some people with disability may require support in order to effectively participate in decision making.

To explore this issue, with specific reference to psychosocial disability, Mental Health Australia engaged ACT Disability, Aged and Carer Advocacy Service to develop this discussion paper on psychosocial disability, supported decision making (SDM) and the NDIS.

SDM is enshrined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which Australia signed in 2009.[1] The Office of the United Nations High Commissioner for Human Rights (OHCHR) briefly describes it as "the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters."[2]

In Australia SDM is emerging across the community in a number of forms. This diversity has made it challenging to articulate what SDM is, or how it could be used in psychosocial disability support. This paper has subsequently evolved from its original purpose, which was to stimulate discussion on SDM, psychosocial disability and the NDIS, to also include information about the evolution of SDM, and an outline of some SDM activities currently being carried out in Australia.

Although the Council of Australian Governments has agreed that NDIS should fund decision support[3] and the right to support is outlined in the NDIS rules[4]; SDM is not yet comprehensively accounted for within the NDIS. This may mean that people with impaired decision making capacity, who would like support to decide, may not currently be able to participate in the scheme on an equal basis with others.

SDM offers an opportunity for people with psychosocial disability to build skill in and experience of meaningful decision making. The NDIS offers an opportunity to develop systemically and consistently available decision support across Australia for people with psychosocial disability that would align with Australia's commitment under the UNCRPD.

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1 United Nations Enable, 2007

2 United Nations Human Rights Council, 2009, para. 45.

3 Senator the Hon Mitch Fifield, 2015

4 Australian Government, 2013

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This paper offers a range of tangible recommendations to improve access to and provision of SDM for people with psychosocial disability in the context of the NDIS. The recommendations suggest:

- establishment of national SDM principles, which take into account existing SDM principles[5] and frameworks[6]

- a range of awareness raising, education and training mechanisms specifically related to the use of SDM with people with psychosocial disability in the context of the NDIS

- a range of further research is required, including supporting people with psychosocial disability to identify how they would like to have decision supports provided.

Mental Health Australia and ADACAS stand ready to assist the National Disability Insurance Agency and the Department of Social Services in implementing these recommendations.

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5 For example ADACAS' Principles for supported decision making, available at: http://www.adacas.org.au/decision-support/AdacasprinciplesforSDM.pdf/view

6 The National Supported Decision Making Network is currently developing a national framework for supported decision making.

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1. Introduction

In 2015, Mental Health Australia engaged ACT Disability, Aged and Carer Advocacy Service (ADACAS), with support from the Australian Government Sector Development Fund, to develop this discussion paper on psychosocial disability, supported decision making (SDM) and the National Disability Insurance Scheme (NDIS).

The central premise of the NDIS is to offer people with disability more choice and control over how, when and where they purchase supports. However some people with disability may require support in order to effectively participate in decision making.

In Australia, the term 'supported decision making' refers to a very broad range of practices and concepts. What is understood by the term 'supported decision making' has been shaped across a range of sectors, including the law, health, human rights and community sectors, each with its own interests and motivations. Any discussion about 'where to next' needs to build on an understanding of this context. This introduction therefore discusses what constitutes SDM and provides some brief detail about the international and Australian context for SDM.

Chapter 2 discusses SDM practice in Australia in more detail and Chapter 3 looks specifically at support for people with psychosocial disability. In Chapters 4 and 5 the paper narrows its focus to discuss SDM in the context of the NDIS and finally in Chapter 6 the paper offers recommendations to improve access to and provision of SDM for people with psychosocial disability in the context of the NDIS.

What is supported decision making?

The United Nations Office of the High Commissioner for Human Rights (OHCHR)[7] describes SDM as "the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters."[8]

In Australia SDM is emerging across the community in a number of forms. This diversity has made it challenging to articulate what SDM is, or how it could be used in psychosocial disability support. However some Australian SDM projects have identified a range of shared steps involved in SDM, including:

- building capacity to recognise the role of decision making, the right to equality and self-determination

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7 The United Nations Office of the High Commissioner for Human Rights is a part of the United Nation's secretariat which promotes and protects human rights. See: http://www.ohchr.org/EN/Pages/WelcomePage.aspx for more information.

8 United Nations Human Rights Council, 2009, para. 45.

- learning about decision making

- recognising and expressing a decision

- identifying and establishing support

- exploring a decision

- articulating a decision for recognition by others

- advocating for the decision

- fulfilling the decision

- ongoing support for another decision.

Although this gives us some idea about what is involved in the practice of SDM, these steps also demonstrate that the supports a person uses will be decision and time specific, and will need to be adjusted according to the complexity of the decision.

Before delving too much into the complexities of defining SDM practice, it is important to first understand the international context for this emerging field.

Supported decision making and the United Nations Convention on the Rights of Persons with Disabilities

SDM is enshrined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which Australia signed in 2009.[9]

The UNCRPD says that to remove a person's right on the basis of a disability is to discriminate against them on the basis of that disability (Article 5 Non-discrimination). The UNCRPD also says people with disability have the right to enjoy legal capacity on an equal basis with others (Article 12). This means that people with disability have the right to be recognised before the law (legal personhood) and to exercise those rights (legal agency).

The United Nations Committee on the Rights of Persons with Disabilities (CRPD)[10] recognises that guardianship practices amount to discrimination on the basis of disability.[11] It calls for a new approach to people whose decision making capacity is impaired or not recognised; and for guardianship regimes to be replaced with SDM frameworks. These frameworks will recognise a person with impaired capacity can be engaged in decision making when they are supported to do so. When decision support is made available all people can retain and use their rights to be treated equally before the law.

In terms of access to support, the CRPD explicitly recognises support must be available to all. It must not hinge on mental capacity testing, nor should social isolation be a barrier to access.[12] Consistent with the UNCRPD's emphasis on full inclusion and participation, support should be provided through community and social networks.[13] It recognises governments have obligations to facilitate the creation of support in the community to

9 United Nations Enable, 2007

10 The Committee on the Rights of Persons with Disabilities is a group, which monitors implementation of the UNCRPD. See http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx for more information.

11 United Nations Committee on the Rights of Persons with Disabilities, 2014

12 Ibid.

13 Ibid.

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ensure its availability.[14] The CRPD also says that this support should enable individuals to exercise their legal capacity to the greatest extent possible and serve as a protection for all rights.[15]

As a signatory to the UNCRPD, Australia has accepted responsibly to undertake general reform to establish fully supported decision making. Australia has however, reserved the right to continue substitute decision making as last resort, with safeguards.[16] Here it is inconsistent with the UNCRPD, which does not endorse substitute decision making.

More detailed interpretation is occurring through law reform as Australia seeks to fulfil responsibilities identified in the UNCRPD. A growing body of academic work explores the UNCRPD in relation to legal capacity and decision making capacity,[17] and its implications for the practice of SDM and legal reform.[18] This work highlights the impact the UNCRPD and by extension SDM is having on human rights, mental health and guardianship laws.[19]

In Australia a number of reviews of legislation have their basis in the UNCRPD. Examples include the Victorian Law Reform Commission Review of Guardianship,[20] the Australian Law Reform Commission Inquiry into Capacity in Commonwealth Law,[21] and the review of the ACT Mental Health (Treatment and Care) Act.[22] These seek to ensure people with disability are free from discrimination, are equal before the law, have equal access to opportunity, and have real choice around how they exercise that opportunity. SDM is a tool that can support these objectives.

Clarifying supported decision making and capacity

The term capacity is used in decision making, SDM and guardianship. The term has two distinct meanings that are sometimes conflated. The distinctions are important in understanding SDM.

Decision making capacity refers to a person's cognitive capability to make a decision. In medico-legal models it might be measured according to a judgment of 'sound mind, memory and understanding'; or of a person's ability to understand and assess information, risks and outcomes of a particular decision at a particular time.[23] While there is no standard measure for capacity in Australia, and guardianship laws are steadily changing, historically, a person who is judged to have impaired decision making capacity may become subject to guardianship or other formal substitute decision making regimes.

Decision making capacity is distinct from legal capacity. Legal capacity refers to a person's right to be recognised as both a holder and user of legal rights.[24] These two parts of legal capacity are also referred to in the literature as legal personhood and legal agency. When a person becomes subject to guardianship they lose recognition of their legal capacity. So a

14 United Nations Committee on the Rights of Persons with Disabilities, op. cit.

15 Ibid.

16 United Nations Treaty Collection, 2015

17 McSherry, 2012

18 Carney and Beaupert, 2013. pp. 175 – 201.

19 For example see Gooding, 2012

20 Victorian Law Reform Commission, 2012

21 Australian Law Reform Commission, op.cit.

22 The Australian Capital Territory, Mental Health (Treatment and Care) Amendment Bill 2014 can be viewed at:
http://www.austlii.edu.au/au/legis/act/bill/mhacab2014364/

23 Australian Law Reform Commission, op.cit.

24 McSherry , 2012

person with impaired decision making capacity might lose their right to exercise their legal capacity. The intent of the UNCRPD is to acknowledge that all people have the right to enjoy legal capacity on an equal basis, and that all people are able to exercise their legal capacity when they have the right supports. SDM is a way to support a person to keep and use legal capacity if their decision making capacity is impaired.

Supported decision making and support for legal capacity as an alternative to guardianship

SDM practice models are contested.[25] There appears to be general recognition for a suite of SDM responses for people who need support to exercise their legal capacity responsive to individual circumstances, time and the decision at hand.[26] There is recognition legal reform is necessary, and access to SDM, regardless of the practice model, will need cultural and social change within the community, policy and services.[27] There is recognition decision making support needs span a continuum and will require a complementary range of supports to meet that need. These could include, for example the *Stepped Model of Supported and Substitute Decision Making*.[28]

Drawing on the conceptual links between article 12 of the UNCRPD and the developing practice of SDM, some argue that SDM is support which enables a person to exercise their legal capacity.[29] This also gets called support for legal capacity. This is distinct from support **with** decision making, defined as general support with day to day decision making.[30] Both of these enable a person to engage decision making. However, when defined as support for legal capacity, SDM is that support which is necessary for a person to undertake legally binding decisions, or for the enforcement of an individual's rights. In this case SDM is an alternative to guardianship. Formal expressions of support, such as SDM agreements (also called representation agreements) are an essential mechanism to make sure the decision maker and their supporter are recognised before the law.[31] Under article 12(c) of the UNCRPD Australia has a responsibility to ensure support for legal capacity is available to all citizens who need it. The authors note there is as yet, no identified research that explores the impact of SDM on the exercise of legal capacity and more research is needed.

Defining supported decision making through action research

The Australian experience of SDM projects gives insight into how people with a decision making disability themselves might define SDM. It suggests the wider community does not appear to recognise distinctions between legal and other decisions in relation to SDM.[32] Under these projects governments have provided funding so that SDM has a role beyond the public sphere, in people's day to day lives.[33] When presented with the opportunity for accessing decision support, people with a disability have made decisions across a very broad range of areas including, personal care, finances, relationships, home life, medication

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25 Carney and Beaupart, op.cit.

26 Browning, Bigby. and Douglas, 2014

27 Carney, 2012

28 See Victorian Law Reform Commission, 2012 and South Australian Office of the Public Advocate, 2013

29 Browning, Bigby and Douglas, op.cit.

30 Ibid, pp. 34 - 35.

31 Brayley, 2009

32 The projects, along with the processes for giving support, are summarized in section 2.

33 ADACAS Advocacy, 2013

routines and work. They have drawn on both formal and informal supports. Decisions made with support under these projects have contributed to an individual's opportunity to enjoy a range of rights that sit at the core of the UNCRPD.

The role of support for day to day decision making has demonstrated value in building experience and skill for people to engage broadly in decision making. This includes building experience to make decisions and exercise their legal capacity. It remains unclear which of these decisions would necessarily be associated with the exercise of legal capacity unless they were brought before a tribunal or court. The situation suggests a broader definition of SDM may also need to be considered when interpreting the UNCRPD and defining practice models of SDM.

More research is needed to understand the relationships between support for legal capacity and support for day to day decision making and how these distinctions may impact the decision making of people with impaired capacity. If SDM frameworks develop in Australia around support for legal capacity, how might the real and demonstrated need for more general decision support be met? If this need for general support is not met through other systems, how will this impact on support for legal capacity? Investment in community capacity building, policy and service frameworks would be required to ensure that reasonable and necessary support for day to day decision making has occurred.

Support for legal and day to day decisions for people with a psychosocial disability

While SDM has strong conceptual links to the exercise of legal capacity in the UNCRPD, the degree to which this emphasis might enable people with a psychosocial disability, and the extent to which it informs the developing Australian practice, needs further research. Support for personal decisions, while the subject of practice work done within the community, is yet to be the focus of academic work. The overarching question exploring what people with impaired decision making capacity want from SDM and from legal reform is yet to be well explored. Useful, further research, could address questions such as:

- To what degree is the emphasis on support for legal capacity useful to people with psychosocial disability?

- Are distinctions between legal and day to day decisions consistent with recovery based practices?

- Does support look different when given for day to day decisions, or legal decisions?

- How might funding bodies, decision makers and decision supporters alike make distinctions between support with and for decision making?

- Would these distinctions impact both the provision of and access to decision support for vulnerable and isolated people?

- Is there an argument for SDM models that provide seamless support for decision making, legal or otherwise?

- How do distinctions between support **for** or **with** decision making impact the fulfilment of rights to people with disability?

The voice of all people with impaired decision making capacity, including those with psychosocial disability, their families and carers need to be positioned at the centre of these debates.

2. The practice of supported decision making in Australia

While there is highly nuanced and increasingly robust debate interpreting the UNCRPD within Australia and beyond,[34] there is a developing body of work exploring how SDM might look in practice. This includes SDM as an essential element of guardianship practice as well as informal support for day to day decision making. There has been no single driver for these projects. Rather organisations have been motivated to seek funding independently to establish SDM in Australia. Funding has come from state governments, NDIS capacity building funding and philanthropic sources.

Completed supported decision making projects

Completed projects include:

South Australia Supported Decision Making Project undertaken by the Julia Farr Foundation and the South Australian Office of the Public Advocate, completed 2011. This project developed a 'freely given support model', where a supporter (chosen by the decision maker from their pool of trusted relationships) and the decision maker create a formal SDM agreement. A monitor, who acts as safeguard, mentor and coach, oversees this support relationship. This model was explored as an alternative to guardianship and is an example of formal SDM with oversight.[35]

Spectrums of Support undertaken by ADACAS, completed 2012. This project was funded by Disability ACT as part of ACT NDIS capacity building. It supported five people who may not have qualified to participate in the South Australian project, due to social isolation or lack of decision readiness. It raised questions around how support needs might be met for those who are socially isolated within the community based model, and identified the necessity of cultural change and community wide capacity building to enable participation in the first instance. It concluded that people with cognitive impairments, particularly those whose lives are currently governed by the decisions of others, may experience few of the benefits of the NDIS without access to decision support. This project explored both formal and informal decision support.

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34 For overview of key international debates see Gooding, 2015.

35 Office of the Public Advocate of South Australia, op.cit.

Self-Determination and Cultural Change Project undertaken by ADACAS, completed 2013. This project explored SDM for people with psychosocial and intellectual disability and is discussed further below.

The New South Wales Supported Decision Making Pilot was a joint project of the New South Wales Department of Ageing, Disability and Home Care, the New South Wales Trustee and Guardian and the Public Guardian in 2012. The pilot explored new ways to support people with disability to make decisions and to have more choice and control in their lives and included an alternative to guardianship stream.[36]

In 2012-13 the Australian Government provided grants through the **Practical Design Fund** to support initiatives and resources to identify practical ways to prepare people with disability, their families and carers, the disability sector and workforce for the transition to the NDIS.[37] Several of these projects related to SDM including:

- ADACAS developed tools for SDM (further information provided below)

- Disability Advocacy Network Australia developed an online tool about advocacy and the NDIS that includes information about SDM[38]

- The Endeavour Foundation developed education tools about the NDIS planning process, which include information about SDM.[39]

Current supported decision making projects

SDM projects currently underway include:

South Australian Health and Community Services Complaints Commission Supported Decision Making Project

This project works with people with cognitive impairments and physical disabilities to establish a freely given circle of support. The project supports broader cultural change toward SDM by engaging the community widely and maintaining a broad community of practice. [40]

The Supported Decision Making for People with Severe Mental Health Problems Project

This project is being undertaken by University of Melbourne, in partnership with Victorian Department of Health and Human Services, Mind Australia, Neami National, Mental Illness Fellowship Victoria, Tandem and Victorian Mental Illness Awareness Council. There is limited published information on this interdisciplinary research project, due for completion in 2016. Through narrative interviews with consumers, carers, and clinicians, the project will explore the experiences of people with severe mental health issues, their families, and carers, to identify how they would like to be supported to make decisions about their care, treatment, and service provision. It is unclear from the literature what kinds of support models will be employed. Proposed outputs include online information about what SDM is

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36 New South Wales Public Guardian, 2014

37 Information about these projects is available at: http://www.ndis.gov.au/practical-design-fund-project-descripti

38 Information about this project is available at: http://www.advokit.org.au/decision-making/supported-decision-making/

39 Information about this project is available at: http://www.endeavour.com.au/Our-Endeavour-Foundation/News/Discover-guide

40 South Australian Health and Community Services Complaints Commission, 2014

and how decision making can contribute to recovery. Online training materials will ensure supports and clinicians can contribute to this process.[41]

Project by the Victorian Office of the Public Advocate (OPA)

An ongoing project being undertaken by the OPA aims to develop a service model that matches trained volunteers within the OPA, to become decision supporters for people who are socially isolated and have a cognitive impairment.[42]

Projects producing tools for supported decision making

There are also a range of projects that have produced tools for SDM, as part of capacity building for the NDIS. These are:

- www.support-my-decision.org.au, developed by ADACAS, funded through the NDIS Practical Design Fund. This tool can be used to explore a decision, learn about decision making and give decision support.[43]

- A project undertaken by Western Australia's Individualised Services Inc. in 2014 that produced an SDM tool for use by decision supporters in the context of individualised funding. This resource is framed by person centred principles with the aim of identifying and exploring decisions.[44]

- The Department of Human Services, Victoria produced a series of booklets to support decision making. 'Making Decisions and Getting Help if you Need it'. [45]

ADACAS has also developed a set of Principles for Decision Support. Grounded in the UNCRPD and developed through the experience of giving decision support these are used by the NSW Public Guardian and a wide range of disability service providers.[46]

What can be learnt about supported decision making from the Australian project experience?

The Australian project experience begins to demonstrate what people with impaired decision making capacity want from SDM. It shows activities that might be desirable under the banner of SDM are broader than access to and communication of information. Through these projects people with disability have demonstrated there is no single way to give decision support (as outlined in the Chapter 1), shared steps for implementing for SDM have been identified.

It is evident from these projects that people who lack experience and confidence in decision making may require a broad range of decision support. This is true for both legal and day to day decision making.

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41 More information about this project is available at http://artsonline.monash.edu.au/supported-decision-making/

42 More information about this project is available at http://www.publicadvocate.vic.gov.au/advocacy-research/supported-decision-making

43 ADACAS Advocacy, 2013 op.cit

44 More information about this project is available at http://waindividualisedservices.org.au/library/resources/wais-publications-and-resources/

45 These booklets are available at http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/reports-publications/making-decisions-and-getting-help-if-you-need-it

46 ADACAS Advocacy, n.d.

While SDM has developed across a broad practice base, there is also a discernible set of shared principles.[47] These uphold the broader principle of the UNCRPD[48] including:

- promoting equality of access to participation, opportunity and experience
- upholding the dignity of risk
- recognition that the decision being made belongs to the decision maker
- acknowledgement that SDM is not disability specific, rather that decision making is interdependent for most people, most of the time.[49]

In 2014, the Australian Law Reform Commission recommended a set of national decision making principles, which included that "persons who require support in decision-making must be provided with the support necessary for them to make, communicate and participate in decisions that affect their lives".[50] Some stakeholders have recommended that in addition to this, nationally applicable SDM principles could be a key component to maintaining the quality and enhancing the reach of decision making work in Australia.[51]

For example, as mentioned above, ADACAS has developed SDM principles to assist in providing decision support".[52] In addition to this, the National Supported Decision Making Network is currently developing a national framework for SDM.

It would be important to take into account work that has already been undertaken by ADACAS and others, if a set of nationally applicable SDM principles were to be established.

Building capacity of decision makers

Projects identified above also demonstrate SDM responses need to include building capacity to:

- consider trust and vested interest
- identify relevant options
- understand how decisions may affect others
- make compromise
- consider responsibilities
- recognise skills that might be needed to make or fulfil a decision
- identify, think about and manage risk.

For people who have had little access to or expectation of decision making in their lives, building recognition of the role of decision making, and the right to equality, will be a necessary first step in embracing a role in making decisions that affect their lives.

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47 ADACAS Advocacy, n.d. op.cit.

48 Bach and Kerzner, 2010

49 Gooding, 2012, p5.

50 Australian Law Reform Commission, op. cit.

51 Discussion at Mental Health Australia Supported Decision Making and Diverse Groups working group meeting on 23 September 2015

52 ADACAS Advocacy, n.d. op.cit.

Freely given support

The dominant support paradigm for SDM is that of freely given or community based decision support. This is consistent with Article 19 of the UNCRPD which protects the right to full inclusion in community life. To fulfil this principle the CRPD states that decision support should be established from social networks and community support.[53] However, the analysis below shows some decision makers with psychosocial disability have expressed preference for independent decision support that is not freely given but purchased from a skilled expert. This approach, discussed further below is consistent with broader community expectations that advice can be purchased to help with complex decision making.

Building the capacity of decision supporters

What appears to be broadly understood as SDM seems to have extended beyond the focus on the skills of the individual decision maker, to those of their supporters and others with relationships of significance. ADACAS has undertaken SDM training with a range of professionals including guardians, clinicians and support workers who, in the lives of people with impaired capacity, are in the position to recognise and support decisions, large and small, within their professional capacity, on a day to day basis. This training may indicate the mental health sector is beginning to interpret support for decision making as a skill set or professional capability, aligned with recovery-based care.[54]

In the mental health sector clinicians are expected to be proficient in balancing dignity of risk with duty of care.[55] They have expressed interest in SDM as a framework in which consumers and clinicians alike can explore and document decisions, particularly decisions that balance dignity of risk and duty of care. In this context decision support might be made available through a clinician or equally through a peer supporter. Here SDM has a valid role promoting broader policy and practice shifts to uphold the consumer's right to self-determination. Further, the Objects and Principles of the Australian Capital Territory Mental Health (Treatment and Care) Act 2014 for example, emphasize equality and participation, and recognises the right to "support and allow for the person to make his or her own decisions."[56]

Supported decision making and cultural change

Where SDM is understood to extend beyond the individual support relationship it might also be understood as a process to stimulate broader cultural change. ADACAS has recognised that access to decision making may have less to do with a person's functional capacity to decide, than with the values and attitudes of those who share their lives. As a result, SDM responses may need to include a focus on cultural change, as well as legislative change, to ensure people are able to effectively access their right to decide.[57]

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53 Committee of the Rights of Persons with Disabilities, op.cit.

54 Department of Health, 2010

55 For example see Health Workforce Australia, 2014.

56 See the Australian Capital Territory, Mental Health (Treatment and Care) Amendment Bill 2014 (Chapter 2), which can be viewed at:
http://www.austlii.edu.au/au/legis/act/bill/mhacab2014364/

57 ADACAS Advocacy 2013

A project running through the South Australian Heath and Community Services Complaints Commission takes this further and creates decision making circles of support around people, largely with cognitive impairments with a view to embedding SDM in the broader community.[58] In the Circle of Support model, a group of people known to the decision maker come together to interpret, advocate for and give effect to an individual's decision. This process can be formalised through a micro board.[59]

Population based model for supported decision making

The projects identified above reflect there are a range of support responses that build the capacity of people to engage SDM as both decision makers and decision supporters across the community. This is consistent with the universal or population based model for SDM.[60] In this model all people have responsibility and potential to engage in SDM, as decision makers and decision supporters. Support is given through a three tiered approach. Primary interventions engage the community as a whole, to include education and stigma reduction. Providing assistance with decision making, as may be required within the disability, government, health, justice, and education sectors, is part of the secondary tier. Tertiary SDM responses include direct decision support interventions (including the development of SDM agreements), and the education and training of those involved in secondary level interventions.[61]

In summary, what SDM will look like in Australia is still evolving.[62] On one hand, SDM is being interpreted as that support which enables a person to exercise their legal capacity. Here its focus is an alternative to formal guardianship and substitute decision making. However, a more universal approach is also being explored, which places SDM on a spectrum of decision support requirements amongst the diversity of individuals and the wider community. This model encompasses SDM as support to exercise decisions that include legal capacity, as well as day to day decisions that ultimately fulfil the right of all people to self-determination.

58 South Australian Health and Community Services Complaints Commission, op. cit.

59 Vela Microboard Association, n.d.

60 Dhanda, 2007

61 South Australian Office of the Public Advocate, 2013

62 It is important to note that while this evolution is also taking place in other countries (for example the UK) the context is very different and the detail required to contrast with the Australian experience is beyond the scope of this discussion paper.

3. Supported decision making and psychosocial disability

In Australia the developing practice of SDM has been almost exclusively built around the experiences of people with a cognitive impairment such as intellectual disability. The voices, experiences, expectations, and cultural specificity of people with psychosocial disability related to mental illness are largely absent from the discussion. Upcoming research from the University of Melbourne and others on the 'Supported Decision Making for People with Severe Mental Health Problems' project will provide welcome information about how people with severe mental illness may wish to be supported in treatment and recovery. However, more research is needed to specifically examine the way people with psychosocial disability advise SDM could best be practised. Such research should be designed to ensure the developing policy and practice frameworks surrounding SDM are relevant to and useful for people with psychosocial disability, their families and carers and promote recovery.

Supported decision making and recovery

There is a strong focus in mental health research[63] and policy[64] exploring how best to support mental health consumers' personal recovery. Rather than working with a clinical definition of recovery, which might focus on alleviation of symptoms; attention is shifting to value a personal definition of recovery, which has been described as:

> *"a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of*

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63 Kings College London, Institute of Psychiatry, Psychology and Neuroscience, n.d.
64 Slade et al., 2014

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mental illness. Recovery from mental illness involves much more than recovery from the illness itself."[65]

A recovery practice orientation requires acknowledgement of the mental health consumers' expertise.[66] This approach aligns well with SDM principles, in particular:

- supporting the consumer's right to decide,

- respect for the decision maker and their decision; and

- giving only as much support as is required for the decision maker to remain active and involved in the decision.[67]

The uniqueness, value and purpose of individuals are expressed and potentially fulfilled through decision making. SDM recognises and promotes real choice through support to build on strengths, to explore and take responsibility, to the fullest extent possible. SDM also supports the dignity of risk, where support is given for the decision rather than the outcome. All SDM frameworks are grounded in rights based values of autonomy, participation and inclusion.

While SDM could be considered an important access tool for some mental health consumers to participate in personal recovery oriented practice, further research is required to explore the effectiveness of combining these approaches, particularly from the lived experience perspective.

Knowledge about supported decision making in the mental health sector

The literature suggests SDM is not yet well understood in the Australian mental health sector. In the project, *People Making Choices: The Support Needs and Preferences of People with Psychosocial Disability*, the authors found, when asked if they believed that they would need support with decision making, 68% of 41 participants believed they would not need assistance. Yet 83% of the 41 participants responded in the positive to the prospect of using decision support when it was included as an option for purchase within an individualised funding package. The authors concluded reluctance to use decision support in the first instances may have resulted because respondents associated it with the loss of autonomy and guardianship. This negative view was countered when decision support was positioned on the self-determined landscape of self-directed funding. [68] This study indicates the need for research to ascertain how SDM is perceived by people with psychosocial disability.

SDM may not yet be well understood by clinicians. Research undertaken among psychiatrists in Victoria found that, while they were open to the idea of SDM there was a

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65 Anthony, 1993, p527
66 Slade, 2014
67 ADACAS, n.d., op. cit.
68 Brophy et al., 2014, p25

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lack of consensus in what is meant by the term.[69] The St Vincent's Hospital Library Service has a resource bibliography entitled 'Supported Decision Making' although the vast majority of its entries cover shared decision making.[70] Shared decision making is distinct from SDM because participation relies on a high level of cognitive capacity and the final say may rest with the clinician.

Shared decision making emphasises participation and negotiation between a mental health consumer and a practitioner in a decision about treatment options.[71] However, SDM recognises some consumers will need support (either formal or informal) to engage and participate in decision making (including, but not necessarily about treatment) in the first place. In this way, SDM could be seen as an important access tool for some mental health consumers to effectively participate in shared decision making.

The experience of supported decision making for people with psychosocial disability in Australia

Research for this discussion paper identified just two Australian SDM projects with a specific psychosocial focus. The Supported Decision Making for People with 'Severe Mental Health Problems' project seeks to support the rights, agency and self-determination of people in the mental health system. This ARC linkage project being undertaken through the University of Melbourne and community partners, is exploring SDM through interviews with people with severe mental illness.[72] This project is in its early stages, with findings to be published in 2016, so this discussion will draw largely on the ADACAS 'Self Determination and Cultural Change' project.[73] In 2013 ADACAS undertook this small qualitative project to explore what SDM might look like in the lives of people with psychosocial and intellectual disability.

The Self-Determination and Cultural Change project supported five people who had a broad range of decision making experience, from those minimally engaged in decision making, to almost autonomous decision making. Decision makers were supported over a period of 12 months on a range of decisions including:

- healthcare
- career and work
- where they live
- food and diet
- family relationships
- supports and services.

Although it was a small project, the range of decision support experiences identified were consistent with SDM projects supporting people with cognitive impairments such as intellectual disability.[74] It was evident that decision makers wanted:

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69 Gooding, 2005

70 St Vincent's Hospital Library Service, 2014

71 Mental Health Council of Australia, 2012

72 More information about this project is available at http://artsonline.monash.edu.au/supported-decision-making/

73 Rea and May, 2014

74 Including Spectrums of Support project and the South Australian Supported decision making project.

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- to choose from a broad range of support options
- to be supported to make a decision at their own pace and at a time that suited them best
- time to develop confidence and skill
- support to advocate for their right to decide
- support to weigh and experience dignity of risk.

Participants were keen to make day to day decisions as a means to demonstrate to others that they could engage in decisions currently considered by carers or family members to be beyond their 'capacity' or to be too risky. Day to day decision making was also important for building confidence and experience. Just one of the four participants created a formal SDM agreement; the remaining three wanted less formal supports. The urgency of one decision precluded the production of a written agreement, but drew on advocacy from the decision supporter.

As well as the positive engagement and benefits for decision makers, other notable findings about the SDM preferences of people with a psychosocial disability are outlined below.

Paid vs unpaid decision supporters

ADACAS concluded that in the context of psychosocial and intellectual disability one to one support combined with capacity building initiatives, for supporters and others in the lives of decision makers, was an effective way to fulfil each person's right to decide.

However, in establishing one to one support, it is important to recognise none of the participants in the *Self-Determination and Cultural Change* project wished to draw on support from someone they already knew. One expressed concern that she already 'overburdened' friends and family and did not want to give them another role. Another did not believe she could trust anyone known to her to uphold her privacy. Decision makers perceived that those already in their lives would struggle to support dignity of risk because their relationship is marked by guardianship, or, in the words of one consumer, "because they have a habit of protecting me."[75]

This finding is supported by the *People Making Choices* project, which found 22% of people who may seek decision support would turn to family or friends or other informal support. A further 27% would turn to a case worker or other person with whom they had an established relationship. A larger group of participants, 44%, expressed preference for a person who was independent of them, such as a specialist within a field.[76] More research is needed to explore how these preferences might fit with the CRPD's preference for community support. These informal networks, it argues, are the basis for full inclusion and participation.[77]

In response to social-isolation and decision maker preferences, the *Self-Determination and Cultural Change* project introduced support through volunteer agencies and established community links including workplaces, social groups and churches. The project concluded this was a very significant time investment and project resources did not necessarily result in establishing a lasting decision support relationship. Issues that may be specific to

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75 Interviews between Kate Rea and project participants for Self Determination and Cultural Change Project.

76 Brophy, et.al. op.cit., p.26

77 United Nations Committee on the Rights of Persons with Disabilities, op,cit., para 44-45.

identifying and introducing decision support in the context of psychosocial disability included stigma around mental health; lack of understanding that people with significant mental health issues could be supported to decide; the impact of the mental health issue on readiness of the decision maker to meet new people; and the need for general volunteer programs to be able to meet the need of people with psychosocial disability, or for mental health specific programs to develop skills around SDM.[78] The issue of how community based support relationships, such as circles of support, might be able to accommodate fluctuating support needs of mental illness in the long term also needs further understanding.

Further, peer supporters spoken to within the *Self-Determination and Cultural Change* project expressed the sense they were already overburdened by the many significant roles they play in the sector. While they were enthusiastic about the idea of SDM and its potential to give consumers more control over their lives, there was reluctance among those approached to take on more unpaid work.[79]

The early findings suggest significant challenges for the model of community based decision support outlined by the CRPD which includes freely given (not paid) support. It should be noted here the general principles of the CRPD insist that social isolation must not be a barrier to support.[80] Given social isolation is a key element of the lives of many people with psychosocial disability, it is clear more work needs to be undertaken to see how the two principles of freely given support and the preference for support from family and friends can be aligned where social isolation is a factor. That is, how the characteristics of decision support relationships for socially isolated people with psychosocial disability can be identified and how these relationships can be created, resourced, safeguarded and sustained.

Education and skills development for decision supporters

The degree to which people in the lives of decision makers were interested in and benefited from building their capacity to engage in SDM was also common across the two cohorts from the *Spectrums of Support* project and the *Self-Determination and Cultural Change* project. This was true for service providers, family members, guardians and healthcare workers. For decision makers to exercise decision making, even with skilled one to one support available, those in their lives, generally, needed to build their capacity to:

- recognise the person's right to self determination

- understand and support dignity of risk

- shift from upholding best interest to supporting expressed wish

- understand how their vested interest and values impacted on the decision being made and the support they might give

78 Rea and May, op. cit. pp.9 – 10.

79 Ibid, p.10

80 United Nations Committee on the Rights of Persons with Disabilities, op.cit.

- adhere to boundaries – particularly as they related to the limiting of options they did not agree with

- be aware of the differences between a supported decision and a substitute decision.

Further, in training subsequently delivered within the Australian Capital Territory mental health sector, ADACAS identified a strong willingness on the part of professionals, to take up a role in decision support. For this to occur more broadly ADACAS recognises the necessity of promoting understanding of the spectrum of capacity/ spectrum of support paradigm across the sector to let consumers, carers and workers know that the possibility of implementing better practice around SDM exists.

The need to promote this knowledge has also been described in the *Victorian Law Reform Commission's, Guardianship: Final Report.* The report describes how decision making capacity was once understood as an absolute binary - you either have it or you do not - but is now understood to exist on a spectrum.[81] At one end of this spectrum lies autonomous decision making, at the other is substitute decision making. A spectrum of decision making capacity lies within these two extremes. Decision support can be given according to where each person is on this spectrum. This spectrum includes the understanding that while a person may have highly impaired capacity in one decision making domain, they may be supported, or indeed able to make an autonomous decision in another. For example, at a given time a person may need considerable support to make treatment decisions, but need little or no support to make a decision about care or recovery. The concept challenges embedded stigma that people with psychosocial disability are unable to make decisions, particularly when they are unwell. Promoting understanding of this concept would ensure people with psychosocial disability could retain and exercise their right to decide, as far as possible, even when they are unwell.

SDM training can enable professionals and other paid supporters to contribute more effectively to the diverse, current and emerging range of national, state and community based policy imperatives promoting self-determination, choice and control. These include the NDIS, state based legislation and recovery oriented mental health and psychosocial disability frameworks. Training and professional development in SDM needs to be made readily available if SDM is being embedded across the sector. This would be consistent with the population based model for SDM, which ensures that support is available when and where it is required.

Through training and presentations across the community ADACAS has also identified a number of challenges that will need to be addressed to embed SDM within informal support relationships. These include broader understanding amongst mental health carers about the spectrum of decision making capacity, the right to decide, the right to dignity of risk and skill in balancing competing rights. But it is also clear that this needs skill development and clear articulation to roles and expectations for all participants in a supported decision.

Outstanding questions here include:

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81 Ibid.

81 Gordon, 2000

- Within private lives and personal relationships what mechanisms might be put in place to ensure that substitute decision making is not being undertaken in the name of SDM?
- What other boundaries and hurdles might carers then face in adopting SDM practices?
- How might carers be resourced to become engaged in SDM?
- What safeguards might be needed within informal SDM relationships to protect both decision makers and decision supporters in their roles?

Specific decision support needs for people with psychosocial disability

The *Self-Determination and Cultural Change project* highlighted potential differences for people with psychosocial disability and cognitive impairments in the characteristics of the decision support relationship. Emerging largely in the disability space, SDM has focused on the experience of building decision making capacity and experience, along with establishing support that has longevity and constancy in the lives of decision makers. In the context of psychosocial disability, decision support responses need to accommodate fluctuating decision making capacity, the likelihood of more intermittent support and recovery. In the *Self-Determination and Cultural Change project* some decision makers did not wish to make an ongoing or long term, personal commitment to a freely given supporter.

> *"I just want someone to help me decide when I can't. I do not want a friend."[82]*

Decision makers, a support worker and family members wanted to be able to draw on the skill of a professional supporter, particularly one who had an understanding of the service system and how it related to a serious decision being made, in a time of crisis.[83] The preference for support to be given outside a family/friendship relationship was also expressed in the *People Making Choices Research*.[84]

The literature review identified SDM resources that generally assume support is being given in the context of cognitive impairment related to intellectual disability (for example). There is a tendency to assume that a circle of support is being set up on behalf of the decision maker, usually by family members, with the decision maker at the centre of the process contributing as much as they are able.[85] This model may not be useful where a decision maker with psychosocial disability may be independent in establishing their own supports when well, for use when they are unwell. Strategies and resources specific to the needs of people with psychosocial disability will need to be developed. The ARC linkage project may provide some useful input to this process.

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82 Rea and May, op.cit.,p 26.

83 Ibid., pp. 25-26

84 Brophy et al., op.cit. P.26

85 More information can be found at http://www.resourcingfamilies.org.au/circles-of-support/

A number of projects identified focus on online resources for decision support. It is important to recognise that, while valuable, they do not necessarily solve issues of how people who are socially isolated will establish a decision support relationship. Tools are not helpful unless there is someone to pick them up and use them. They are also not helpful for those who are socially isolated who may not recognise their right to decide, or that they can get support, as they may not look for a tool or support. Socially isolated individuals are vulnerable to having their rights not met, and not being in control of their own lives.
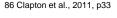
Future work in SDM must include a suite of responses, including responses that ensure people who are socially isolated, whose lives are largely controlled by the decisions of others, or who do not recognise that they have a right to decide, or a right to decision support, are able to be the decision makers in their lives. Regardless of what decision support looks like, the question of how to get it into the lives of people who are socially isolated or vulnerable to having their rights not met remains in question.

Decision support needs for specific population groups with psychosocial disability

It was not within the scope of this paper to consider the SDM preferences of particular population groups. However, it is important to acknowledge SDM practice operates in a social and cultural context and therefore decision supporters may need to adjust their practice in order to support a decision in a culturally safe and accessible manner.

For example, a report funded by the Office of the Public Advocate of Queensland on impaired decision making capacity and Indigenous Queenslanders highlighted the need for *"a broader range of decision-making alternatives to be developed for Indigenous people."* The report notes that *"alternative approaches might be designed around involving the local Indigenous community and increasing support for informal supported decision-making arrangements."*[86] However, the report also noted little research had been conducted on the cross-cultural relevance of the concept of impaired capacity.

It is therefore important that the cross cultural relevance of the concept of SDM itself be tested with Aboriginal and Torres Strait Islander Australians and by extension one could expect it is also important to test the relevance of this concept with people from culturally and linguistically diverse backgrounds.

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86 Clapton et al., 2011, p33

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4. Supported decision making and the National Disability Insurance Scheme

Launched by the Australian Government in 2013, the NDIS provides individually funded packages to people with disability and aims to provide them with more choice and control over the supports they use. It has been estimated that approximately 57,000 people with psychosocial disability (loosely equal to the estimates of people with severe and enduring mental illness across Australia) will be eligible for such a package.[87]

In addition, the NDIS also has an Information, Linkages and Capacity Building (ILC) component (previously referred to as Tier 2), which the National Disability Insurance Agency (NDIA) advises will *"establish and facilitate capacity building supports for people with disability, their families and carers that are not directly tied to a person through an Individually Funded Package. ILC should also promote collaboration and partnership with local communities and mainstream and universal services to ensure greater inclusivity and accessibility of people with a disability."[88]*

The scheme, as described, is a unique opportunity to address unmet support needs of people with psychosocial disability by providing a bridge between the social model of disability, which emphasizes how people participate and interact with community, and the medical model of disability, which treats the symptoms of psychosocial disability.[89]

Within this context, SDM can be seen as a key mechanism to ensure that people with a disability are able to exercise their full choice and control. However, no literature describing the experience of SDM within the NDIS trial sites was identified in the course of this research. Literature exploring decision making and the NDIS tends to focus on desired domains of decision making, as opposed to the specifics of how, when and where people with psychosocial disability would like to be supported to decide.[90] The extent to which SDM might become available through the NDIS is not yet well understood. Consultation undertaken on the ILC revealed stakeholders wanted to understand the kinds of decision supports available to them.[91]

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87 Productivity Commission, 2011

88 National Disability Insurance Agency, 2015

89 Bonyhady, 2014

90 Brophy et al., op.cit.

91 More information is available at http://www.ndis.gov.au/consult-info-link-capacity-building

Challenges and benefits of supported decision making for people with individually funded supports

Experience emerging from trial sites suggests that SDM has the potential to improve the experience and outcomes of the planning process for NDIS Tier 3 participants with psychosocial disability. For example, consumers and carers in the Barwon NDIS trial site have indicated that where a support person was involved, the participant had a more positive experience of the scheme (than where a support person was not involved) including securing more relevant support packages.[92]

SDM presents an opportunity to mitigate challenges around planning for participants with psychosocial disability. Some Tier 3 participants have raised the difficulty of NDIS planners assessing a person's goals and support needs within a relatively short time.[93] Indigo Daya describes this process as almost "diametrically opposed" to recovery-oriented practice.[94] Mental health consumers in the Barwon trial site reported they "can have difficulty in knowing and expressing their needs and goals".[95] SDM could be a mechanism to support mental health consumers to express their needs and goals and make choices, which are meaningful to them. It is a strengths based practice, consistent with the values of recovery. It emphasises growth and capacity building. SDM may offset some of the negative experiences identified, including the need for consumers to focus on deficits to maximise packages and the static language of 'permanence'.

ADACAS' experience giving decision support would suggest capacities built within the SDM framework, both for decision makers and carers and family members who may be acting as decision supporters, would enable participants to approach the planning process with a more developed set of support goals and the capacity to make meaningful choices. This has potential to reduce planning time and improving plan outcomes. Decision support responds to the needs and experiences of each person. In planning for the NDIS this might include support to:

- identify goals and priorities
- explore and safeguard risks
- learn from mistakes
- find personally relevant options
- understand and weigh information
- consider consequences, rights and responsibilities
- recognise skills needed to make and fulfil a plan
- make plan related decisions at a time and pace to suit participants.

The provision of decision support offers individuals the opportunity to develop experience and confidence as choice makers. It can also give support for people to consider the future and to build expectation about what that future might hold.

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92 Daya, 2015, 11

93 Ibid.

94 Ibid.

95 Psychiatric Disability Services Victoria, 2015b, 16

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Consumer advocate Isabel Collins has argued that, while choice and control are fundamental to NDIS there needs to be significant cultural change and targeted capacity building before people with psychosocial disability can truly benefit from choice. She argues consistent system failure has conditioned people with psychosocial disability to have low expectations of their own potential and the services they use. For people to make genuine and relevant choices within the NDIS they need to develop a sense of what might be possible, as well as an expectation that they are entitled to realize these possibilities.[96]

Collins' observations highlight that for many people taking control will require more than the opportunity to simply exercise choice. SDM builds skill and experience for meaningful and personally relevant decision making, hope and expectation, along with the necessary support to make decisions that turn hope into a reality. She also touches on the need for broader cultural change which could be secured through a focus on SDM in the ILC component of the NDIS.

An additional benefit for both the NDIA and participants is that supported decisions can be documented. This can act as a safeguard to choice and control. Supported decisions can record values, options, and priorities that have been explored in the preplanning process as part of a SDM agreement. This might be used by participants, family members, carers, and NDIA planners alike, to show that planning decisions fulfil the wishes of the participant, or that participants have not been subject to undue influence. Where a nominee may be deemed necessary to make decisions on behalf of the participant, SDM is an effective way to ensure that the will and preference of participants is firmly at the centre of planning decisions.

Supported decision making and the National Disability Insurance Scheme Information, Linkages and Capacity Building Framework

The aim of ILC is to create an inclusive community where people with disability are less dependent on disability specific services through improved access to social and economic participation. Capacity building among individuals and their families, communities, organisations, mainstream and disability services will be a key to improved accessibility.

For people with decision making impairments, SDM is an access tool equivalent to braille on an ATM machine for someone with a sensory disability or a wheel chair ramp for someone with a physical disability. With SDM the person with psychosocial disability is provided with all the support they need to make a decision, effectively ensuring they can truly exercise choice and control. Without SDM, people with impaired decision making capacity who would like support to decide, may not currently be able to participate in the scheme on an equal basis with others. Where SDM is universally available, so too is access by people with impaired decision making capacity.

SDM is not disability specific. The universal model for decision support suggests a role for all in creating inclusion by recognising and supporting decisions when and wherever this support is needed. This fits well within the proposed ILC framework.

SDM activities under ILC could include awareness raising, information and online resources, training for decision makers and supporters and linkages to support the establishment of

96 Collins, 2014

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SDM relationships. This could target individuals, their families and carers, healthcare, education, transport, banking, retail, employment, and the community service sector. Provision of SDM within the ILC can create access to previously unconsidered mainstream options and opportunities. Where support for decision making was made available around public transport, for example, a person may be enabled to access and understand timetables, consider risks, create contingency plans and so on, thereby reducing demand on disability specific transport within individual plans.

While SDM can increase confidence and skill, it also has the potential to reduce vulnerabilities for people with disability to engage in a range of transactions. Support to consider risks, responsibilities and vested interest can make a person less vulnerable where they might be considering, for example, a mainstream employment contract, or financial transaction. Decision support to identify options and understand and consider information outcomes can help secure the best possible outcomes for individuals and improved access. Therefore, the provision of SDM support should also be considered as a component of the NDIS Quality and Safeguarding Framework for both people accessing Tier 3 and Tier 2 support.

Supported decision making and the National Disability Insurance Scheme Quality and Safeguarding Framework

The NDIS Quality and Safeguarding Framework, which is currently under development, will ensure the NDIS provides "quality supports, choice and control and keeps people safe from harm".[97] Some of the feedback from recent consultations on the Framework related to SDM. For example Mental Health Australia recommended the NDIA establish structures and arrangements to facilitate SDM and the development of formal and informal support networks; and that the NDIA works with service providers to deliver best practice SDM.[98]

The Mental Health Australia NDIS Consumer and Carer Advisory Group supported the use of SDM in the NDIS context for people with psychosocial disability, particularly where a carer is not present or to minimise the use of restrictive practices.

The Psychiatric Disability Services of Victoria made recommendations about SDM being a key NDIS safeguarding mechanism and ensuring SDM is promoted and used wherever possible.[99]

The Mental Health Coordinating Council highlighted the importance of specific assessment for decision making capacity being built into NDIA processes and that participants are offered services that ensure SDM.[100]

The abovementioned submissions together reinforce the important place of SDM in the NDIS Quality and Safeguarding Framework.

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97 Department of Social Services, 2015, para 3
98 Mental Health Australia, 2015b
99 Psychiatric Disability Services of Victoria, 2015a
100 Mental Health Coordinating Council, 2015

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Implementation of supported decision making in the National Disability Insurance Scheme

The ILC could fund development of a suite of resources to build the capacity of people with psychosocial disability to engage in SDM. These would be tailored to accommodate fluctuating decision making capacity and a spectrum of decision making experience. These might include information sessions about decision making, SDM and establishing decision support relationships. They could highlight the role of SDM in forward planning and recovery, and share successful strategies for SDM. Workshops could be used to identify where more intensive, one off capacity building might be needed. There is a potential role for Local Area Coordinators (LACs) linking decision makers with decision supporters.

Online information resources could form a platform to support ongoing participation in SDM. Several NDIS Practical Design Fund projects focused on supporting people to develop an understanding of what constitutes choice: Speak Out 'Decisions Decisions' Video[101] and Inclusion Australia 'It's My Choice' resources[102], and www.support-my-decision.org.au, an online decision making resource for decision makers and supporters.

These projects developed useful practical tools and resources that people may use to increase their understanding of decision making and choice in preparation for the NDIS. However, a lack of ongoing funding to enable awareness raising and access to the tools has limited the community's ongoing knowledge of the availability of these resources.

More needs to be done to ensure these are broadly known in the community and to consider the extent to which they are also applicable to people living with psychosocial disability. Information resources alone are not sufficient to establish SDM in our community, and more intensive forms of capacity building and information sharing is necessary to ensure online tools are promoted and people are supported to use them.

Correspondingly the capacity of the community to act in the support role also needs to be developed. The level and type of support given will depend on the relationship the decision supporter has with the decision maker. Decision support activities undertaken by peers or family members will have different qualities than those given by a health care provider, disability service provider, transport worker or retailer. Decision support can be incidental and informal, such as that given in a shop. It might be informal but ongoing, such as that given by a peer or family member. Or support may be more formal. This would include support given in a transaction with a bank or other organisation, including the NDIS. The ILC could build capacity to engage in decision support across that spectrum.

The range of skills that need to be developed have already been touched on in this paper. At the highest level these include an understanding of the range of ways in which people with psychosocial disability can be their own decision makers and what, if any, support they may need to achieve this. These skills could be underpinned by national SDM principles, which could take into account SDM principles developed in the community sector, for example by ADACAS.[103] If such principles were well communicated and adopted by the sector, they could offer useful guidance regarding the key concepts underpinning SDM

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101 The Speak Out 'Decisions Decisions' Video is available here: https://www.youtube.com/watch?v=WmWO3E1kJT4

102 'It's My Choice' resources are available here http://www.inclusion.melbourne/wp-content/uploads/2013/06/Its_My_Choice_Vol1_web.pdf

103 ADACAS Advocacy, n.d., op.cit.

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practice and provide a useful standard against which organisations and practitioners gauge their SDM practice.

However, more also needs to be known about how people with psychosocial disability would like to be supported when developing resources. Resources that could be funded through the ILC include training tailored to organisations and business, professionals, the health sector, support workers, peers, and families.

The provision of access to decision support will be a key element of the implementation of SDM for people with psychosocial disability. The inability to secure decision support has been a consistent, demonstrated challenge to establishing SDM across SDM projects. Lack of support becomes a barrier to choice and control, inclusion and participation.

Through the ILC there is a real opportunity for the NDIS to contribute to the development of systemically and consistently available decision support across Australia, when and wherever it is needed. This could add to the quality of decision making within NDIS planning and would be consistent with the ways support for decision making is being promoted under the UNCRPD such as best practice guardianship arrangements.

5. Issues for consideration: supported decision making in the National Disability Insurance Scheme

There are significant parallels between the intent of SDM and NDIS policy. In fact, implementing SDM within the NDIS offers an excellent safeguard to ensure participants can exercise choice and control. However, there are still some issues to for further consideration relating to the planning process, the UNCRPD preference for freely given support, and how to reach those who would like more intensive decision support.

Supported decision making and planning

Limited evidence about SDM emerging from the NDIS trial sites demonstrates the role of decision supporter needs to be clearly established and have formal recognition by NDIS stakeholders, including the NDIA. The specific relationships people with psychosocial disability have with peers and support workers and their potential role in supported decisions also needs further exploration.[104]

Another key issue requiring further exploration is the relationship between decision supporter and a nominee. Within the rules of the scheme a nominee can be appointed by the participant or where necessary. Nominees have the potential to assume substitute decision making responsibilities and are charged with *"a duty to ascertain the wishes of the participant and make decisions that maximise the personal and social wellbeing of the participant."*[105] The situation would have parallels with existing guardianship relationships, where SDM has proven a useful strategy to ensure the will and preferences of an individual are recognised within substitute decision making.[106]

However, tensions may arise under the NDIS where a nominee understands 'wellbeing' to involve minimising risk. If a SDM framework was used by nominees then a nominee in the role of decision supporter could follow national SDM principles, which emphasise the right to dignity of risk and the means to balance risk with informed decision making. This would

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104 Baxter, 2015

105 National Disability Insurance Agency, n.d., para 2

106 Rea and May, op.cit.

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support real choice and control because it ensures people are able to choose from and experience a full suite of possible options, not just those which are considered to be 'safe'.

Community based support and psychosocial disability

The UNCRPD preferences decision support freely given from the community.[107] The sector as a whole should be resourced and consulted to develop frameworks to establish roles, responsibilities and safeguards for informal, community based SDM. This could create the basis for initiatives undertaken through the ILC. As a core principle, this must recognise that decision support, like decision making, is a skill that is learnt. Investment in community will be necessary to build capacity of both decision makers and decision supporters to ensure that substitute decisions are not made in the name of supported decisions.

Consumers in the Barwon NDIS trial site have frequently attributed better results through the planning process to the support provided by a worker, with whom they had already developed a trusting relationship. They have also highlighted the stress caused by being required to divulge personal information to a planner they haven't developed a trusting relationship with.[108] In the Hunter trial site, Debbie Hamilton, an NDIS participant and systemic mental health advocate explains:

> *"We [mental health consumers] are regularly locked up, sedated and isolated... I believe these unique experiences make the experience of choice and control more difficult to grasp and use. It is a factor that continues to influence our capacity to take up choice."*

This experience indicates that development of rapport and a trusting relationship underpins the effective practice of SDM in the NDIS context, particularly in the context of those who are socially isolated and do not have trusting relationships in place.

The ILC Framework states that the ILC should *"be designed and delivered in a way that recognises and responds to the diverse needs of individuals and considers under-represented and hard-to-reach groups."*[109] It acknowledges that *"these groups may require proactive outreach from ILC, to ensure that they are able to get the supports they need."*[110]

Accordingly, ILC funding could be provided to community organisations to conduct outreach and awareness raising with those who are socially isolated or to support the creation of new networks for those who do not wish to establish decision support relationships with those already known to them.

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107 Committee on the Rights of Persons with Disabilities, op. cit. para 44-45.
108 Psychiatric Disability Services of Victoria, 2015b
109 National Disability Insurance Scheme, A Framework for Information, Linkages and Capacity Building 2015, p8
110 National Disability Insurance Scheme, A Framework for Information, Linkages and Capacity Building 2015, p8

Professional decision support

While the preference for community based or freely given support was expressed by the UNCRPD, this research has shown this is not necessarily the support preference expressed by people with psychosocial disability. While there is limited practice experience to draw from, preference for professional or independent decision support has been expressed in both identified SDM projects with a psychosocial focus. This suggests there is a case for SDM to be made available to purchase support through Tier 3 packages. In the context of fluctuating mental ill-health or psychosocial disability, social isolation and other or complex issues, professional decision support may offer the required level of accessibility, expertise and anonymity that may be lacking in freely given models.

Where people face complex planning decisions, are socially isolated, or both there, is a role for NDIS planners to identify participants who may benefit from SDM, explore with them their interest in including it in their plan, and ensure it is funded in the early years of the plan, with a view to enable the participant to make more meaningful contributions to future plans.
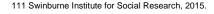
Accessibility of supported decision making resources

While there are a range of on-line tools and SDM models available, these are not universally available or accessible. Further, while on-line resources may be useful for some, there are limits to who will be able to access them or find them useful without support to use them.

People with disability are over represented within the one in five Australians who lack access to the internet.[111] Online resources may not meet the needs of those who require more intensive decision support, particularly those who do not recognise they have a right to decide, or what that right might mean in their lives if they had support to exercise it.

It has been well established in project work that one to one support is needed by some to build expectation and skill. This is also true for people whose lives are closely governed by the decisions of others. Access to decision support may mean a way to reach into people's life, past gatekeepers to extend support.

SDM could be a significant access tool for people with psychosocial disability. It would enable participants with psychosocial disability to have support for planning at a time and pace that suits them, using values and practices that are more consistent with recovery oriented frameworks and develop a more comprehensive set of planning goals. Greater recognition for SDM by NDIA planners could see them identifying those who are socially isolated or experiencing undue influence of others making recommendations for decision support.

Including a focus on SDM across all five streams of the ILC would improve access and inclusion for people with psychosocial disability by ensuring that SDM for day to day decision making is available where and whenever it is needed. More needs to be understood however, about the decision support preferences for people with psychosocial disability.

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111 Swinburne Institute for Social Research, 2015.

6. Recommendations

SDM offers an opportunity for people with psychosocial disability to build skill in and experience of meaningful decision making. The NDIS offers an opportunity to develop systemically and consistently available decision support across Australia for people with psychosocial disability that would align with Australia's commitment under the UNCRPD.

Definitions of SDM are emerging in a number of fields with no consensus about how it is practiced and with little input from people with disabilities themselves. There is a significant need to engage people with psychosocial disability and their carers to ensure that the developing practice of SDM does not adopt a one-size-fits-all approach based only on the experiences and support needs of people with other cognitive impairments such as intellectual disability.

Mental Health Australia and ADACAS recommend that awareness raising, education and training around SDM be implemented simultaneously to begin the community discourse amongst people with disabilities. This will also inform the ongoing research into how people with psychosocial disability would like to have decision supports provided. A proposal for these next steps is outlined below.

National principles for supported decision making

1. National supported decision making principles should be developed in consultation with the disability and mental health sectors. The principles should take into account existing supported decision making principles[112] and frameworks.[113]

A clear and common understanding about supported decision making

2. Further work should be undertaken to generate clear and common understandings of supported decision making, decision support terms and roles that can be used in the NDIS context for a person with psychosocial disability (and/or other disabilities). For example, Mental Health Australia and ADACAS could provide access to their networks in order to:

    »   draw together people with knowledge, expertise and/or experience of supported decision making who can develop a common set of definitions

    »   broadly disseminate agreed definitions

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112 ADACAS' Principles for supported decision making, available at: http://www.adacas.org.au/decision-support/AdacasprinciplesforSDM.pdf/view
113 The National Supported Decision Making Network is currently developing a national framework for supported decision making.

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Awareness raising, education and capacity building

3. Supported decision making tools and research should be promoted through Mental Health Australia and other appropriate networks. For example, this would include:

   » disseminating a paper on supported decision making, psychosocial disability and the NDIS as well as links to supported decision making tools (including those developed through Practical Design Fund projects) through publication on the Mental Health Australia website, via the NDIS Mental Health Network, via Mental Health Australia's CEO Update and through possible communications resulting from the National Disability Insurance Agency Operational Access Review

   » publishing a video online of a presentation on supported decision making

   » developing a fact sheet for consumers, carers and service providers in collaboration with the Mental Health Australia Supported Decision Making and Diverse Groups Working Group

4. The sector's understanding and capacity for supported decision making should be increased. For example, the ILC component of NDIS could fund:

   » supported decision making education and awareness raising activities, to familiarise mental health consumers, carers and other stakeholders with the concept of a spectrum of decision making experiences and how this fits with the intent of the UNCRPD

   » training for decision supporters (for example family carers), including how to manage fluctuating need for decision support for people with psychosocial disability.

   For example, ILC funding could be provided to local community organisations to develop and implement information sessions or workshops about supported decision making for consumers and carers and specific training for decision supporters. Local Area Coordinators could also provide referrals for people with psychosocial disability to access decision making supports.

National Disability Insurance Agency staff training

5. Training on supported decision making should be offered to agency staff. The training module should be developed in consultation with people with psychosocial disability, their carers and service providers as well as experts in supported decision making. The training could, for example, be provided as a part of broader training on psychosocial disability. Mental Health Australia stands ready to assist in designing consultations and providing access to its membership, NDIS Mental Health Consumer and Carer Advisory Group and NDIS Mental Health Network.

Decision supporter role

6. A clear role for decision supporters (both formal and informal) should be identified as a part of the NDIS planning process. This could include both paid and unpaid

support models. Mental Health Australia is available to help the NDIA consult with people with psychosocial disability, their decision supporters and experts on supported decision making to establish this role. Please note that people with other disabilities should also be included in this consultation.

Research

7. Further applied research and consultation should be conducted to explore best practice supported decision-making for NDIS participants with psychosocial disability, for example exploring:

   » how people with psychosocial disability would prefer decision support to be provided

   » the role of peers, carers and families and other decision supporters in providing decision support

   » how decision support and/or supporters should be made available to isolated individuals or those who choose not to use their family and friends for specific decisions

   » the relevance and application of supported decision making for particular population groups, such as Aboriginal and Torres Strait Islander Australians and people from culturally and linguistically diverse backgrounds; particularly focussing on informal supported decision making already occurring and issues that should be taken into account when practicing supported decision making (formal or informal) with these groups

   » the relationship between the decision supporter and the nominee in the context of the NDIS

   » whether supported decision making should be included as a specific support item under NDIS individually funded support packages.

Conclusion

It is clear from the research that SDM is being broadly interpreted by a range of stakeholders; although the voice of people with psychosocial disability, their families and carers, has not yet widely contributed to that debate.

SDM is a key element of the implementation of the UNCRPD, and thus needs to be a central part of the NDIS. This is consistent with the changes in current legal and policy reviews being undertaken to enact the UNCRPD.

There is significant need to engage people with psychosocial disability and their carers to ensure the developing practice of SDM does not adopt a one-size-fits-all approach based on the experiences and support needs of people with other cognitive impairments such as intellectual disability. It is imperative that research, education and capacity building are undertaken simultaneously so that these key stakeholders can meaningfully contribute to shaping SDM for the NDIS and in the broader conversations around reforms related to SDM in other sectors.

Further research is needed to gain deeper understanding about the specificity of decision support when given in the context of fluctuating decision making capacity. Developing SDM practices are yet to recognise the potential of peers, the role for carers, the specific quality of relationships consumers may have with service providers, nor the degree to which social isolation may impact on the take up of SDM if its availability is exclusively modelled around community based support.

Preliminary work has revealed SDM is not well understood across the sector either by consumers, carers, workers or service providers. Particularly in the mental health space, there is often broad assumption that people with psychosocial disability cannot effectively make decisions about their lives, particularly in cases where their capacity is impaired. The UNCRPD challenges this notion, but much more work needs to be done to promote the right to decide, the spectrum of decision making capacity/support requirements held across the community and what role SDM could play in the NDIS.

This work should be prioritised so people with impaired decision making capacity can exercise choice and control in the same way as all other people who access the NDIS. These experiences can go on to shape the NDIS' future development. This will include the roles of valued supporters being recognised in the planning process, and chosen supporters, be they carers, case workers or independent supporters being part of a rights based framework for giving support. Training NDIA planners in the principles of SDM would act as a safeguard against best interest decision making during planning.

Bibliography

ADACAS Advocacy, (n.d.). *Supported Decision Making: ADACAS Principles for Decision Supporters*. [PDF] Available at: http://www.adacas.org.au/decision-support/AdacasprinciplesforSDM.pdf [Accessed 27 Oct. 2015].

ADACAS Advocacy, (2013). *Spectrums of Support: A Report on a project Exploring Supported Decision Making for People with Disability in the ACT*. [PDF] Available at: http://www.adacas.org.au/decision-support/copy_of_SupportedDecisionMakingProjectFinalReport.pdf [Accessed 28 Oct. 2015].

Anthony, W. (1993). Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990s. *Psychosocial Rehabilitation Journal*, 16(4), pp.11-23.

Australian Government, (2013). *National Disability Insurance Scheme (Nominees) Rules 2013*. [online] Australian Government ComLaw website. Available at: https://www.comlaw.gov.au/Details/F2013L01062/Html/Text#_Toc357781703 [Accessed 12 Nov. 2015].

Australian Law Reform Commission, (2014). *Equality, Capacity and Disability in Commonwealth Laws*. [PDF] Available at: http://www.alrc.gov.au/sites/default/files/pdfs/publications/whole_dp81.pdf [Accessed 26 Oct. 2015].

Bach, M. and Kerzner, L. (2010). *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity*. [PDF] Available at: http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner [Accessed 27 Oct. 2015].

Baxter, B. (2015). NDIS reform: experiences of community mental health support workers. *Australian Journal on Psychosocial Rehabilitation*, [online] Summer, pp.17 - 19. Available at: http://www.vicserv.org.au/uploads/newparadigm/2015newparadigm-summer.pdf [Accessed 28 Oct. 2015].

Bonyhady, B. (2014). Tides of change: the NDIS and its journey to transform disability support. *The Australian Journal of Psychosocial Rehabilitation*, [online] Summer. Available at: http://www.vicserv.org.au/uploads/newparadigm/VICSERV%20New%20Paradigm%20Summer%202014%20-%20website.pdf [Accessed 28 Oct. 2015].

Brayley, J. (2009) *Supported Decision making in Australia.* [presentation notes]. Presented to the Victorian Office of the Public Advocate in Melbourne, Australia, 14 December 2009

Brophy, L., Bruxner, A., Wilson, E., Cocks, N., Stylianou, M. and Mitchell, P. (2014). *People making choices: the support needs and preferences of people with psychosocial disability*. [PDF] Available at: https://www.mindaustralia.org.au/assets/docs/People%20Making%20Choices.pdf [Accessed 27 Oct. 2015].

Browning, M., Bigby, C. and Douglas, J. (2014). Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice. *Research in Intellectual and Developmental Disabilities*, 1(1), pp.34 - 45.

Carney, T. (2012). Guardianship, citizenship, & theorising substitute-decision making in law. In: I. Doron and A. Soden, ed., *Beyond Elder Law: New Directions in Law and Ageing*, Berlin, Heidelburg: Springer Verlag.

Carney, T. and Beaupert, F. (2013). Public and Private Bricolage - Challenges balancing law, series and civil society in advancing CRPD supported decision–making. *University of NSW Law Journal*, 36(1), pp.175 – 201.

Clapton, J., Chenoweth, L., Clements, N., Pascoe, V., Radel, K., Cadet-James, Y., Wallace, V. and Cadet-James, D. (2011). *Impaired Decision-Making Capacity and Indigenous Queenslanders Final Report*. [PDF] Available at: http://www.justice.qld.gov.au/__data/assets/pdf_file/0011/153398/final-report-december-2011.pdf [Accessed 28 Oct. 2015].

Collins, I. (2014). What do consumers want, need and deserve from the NDIS?. *Australian Journal on Pyschosocial Rehabilitation*, [online] Summer, pp.13 - 15. Available at: http://www.vicserv.org.au/uploads/newparadigm/VICSERV%20New%20Paradigm%20Summer%202014%20-%20website.pdf [Accessed 28 Oct. 2015].

Daya, I. (2015). Raising our Voices: Emerging consumer and carer stories from the NDIS Barwon trial. *The Australian Journal on Psychosocial Rehabilitation*, [online] Summer, pp.9 - 13. Available at: http://www.vicserv.org.au/uploads/newparadigm/2015newparadigm-summer.pdf [Accessed 28 Oct. 2015].

Department of Health, (2010). *Principles of recovery oriented mental health practice*. [online] Australian Government Department of Health website. Available at: http://www.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-n-servst10-toc~mental-pubs-n-servst10-pri [Accessed 27 Oct. 2015].

Department of Social Services, (2015). *NDIS Quality and Safeguarding Framework*. [online] The Department of Social Services website. Available at: https://engage.dss.gov.au/ndis-qsf/ [Accessed 28 Oct. 2015].

Dhana, A. (2007). Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?. *Syracuse Journal of International Law & Commerce*, 429.

Gooding, P. (2005). Psychiatrists' Perceptions of Supported Decision-Making: A Victorian Empirical Study. *Psychiatry, Psychology and Law*, 12(1).

Gooding, P. (2012). Supported Decision Making: A Rights-Based Disability Concept and its implications for Mental Health Law. *Psychiatry, Psychology and Law*, 20(3), pp.431 - 451.

Gooding, P. (2015). Navigating the 'Flashing Amber Lights' of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns. *Human Rights Law Review*, 15(1), pp.45-71.

Gordon, R. (2000). The emergence of assisted (supported) decision-making in the Canadian law of adult guardianship and substitute decision-making. *International Journal of Law and Psychiatry*, 23(1), pp.61 – 77.

Health Workforce Australia, (2014). *National Mental Health Core Capabilities*. [online] Health Workforce Australia website. Available at: http://www.hwa.gov.au/publication/national-mental-health-core-capabilities [Accessed 27 Oct. 2015].

Kings College London, Institute of Psychiatry, Psychology and Neuroscience, (n.d.). *What is recovery and wellbeing?*. [online] Research into Recovery and Wellbeing website. Available at: http://www.researchintorecovery.com/what-is-recovery-and-wellbeing [Accessed 27 Oct. 2015].

Rea, K. and May, F. (2014). *Self –Determination and Cultural Change: A Report on Supported Decision Making for People Experiencing Psychosocial and Intellectual disability*. [PDF] Available at: http://www.adacas.org.au/decision-support/ADACAS_recommendations_SDM_psychosocial_and_intellectual_disabilty.pdf [Accessed 28 Oct. 2015].

McSherry, B. (2012). Legal Capacity Under the Rights of Persons with Disability. *Journal of Medicine and Law*, September 20(1), pp.22:7.

Mental Health Council of Australia, (2012). *Shared Decision Making in Mental Health Treatment: A Survey of Practitioners - 2012*.

Mental Health Australia, (2015a). *NDIS Framework for Information, Linkages and Capacity Building - Submission to the Department of Social Services*. [PDF] Available at: http://mhaustralia.org/sites/default/files/docs/mental_health_australias_submission_to_the_information_linkages_and_capacity_buiding_framework_of_the_ndis_march_2015.pdf [Accessed 28 Oct. 2015].

Mental Health Australia, (2015b). *Submission on the National Disability Insurance Scheme Quality and Safeguarding Framework*. [PDF] Available at: http://mhaustralia.org/submission/submission-national-disability-insurance-scheme-quality-and-safeguarding-framework [Accessed 28 Oct. 2015].

Mental Health Coordinating Council, (2015). *MHCC Submission in Response to Department of Social Services National Disability Insurance Scheme Quality and Safeguarding Framework.* [PDF] Available at: https://engage.dss.gov.au/wp-content/uploads/2015/05/NDIS-QS-Sub-30.04.15-v.4-F.pdf [Accessed 28 Oct. 2015].

New South Wales Public Guardian, (2014). *Public Guardian Advocacy Report 2014.* [PDF] p.12. Available at: http://www.publicguardian.justice.nsw.gov.au/Documents/advocacy%20rpt%202014final_for_web.pdf [Accessed 28 Oct. 2015].

National Disability Insurance Agency, (n.d.). *What are nominees and guardians under the NDIS?.* [online] National Disability Insurance Scheme website. Available at: http://www.ndis.gov.au/families-carers/what-are-nominees-and-guardians [Accessed 28 Oct. 2015].

National Disability Insurance Agency, (2013). *Operational Guideline - General - Conduct - Supporting Participants' Decision-Making.* [PDF] Available at: http://www.ndis.gov.au/sites/default/files/documents/operational_guideline%20_general_conduct_supporting_participants_decision_making.pdf [Accessed 26 Oct. 2015].

National Disability Insurance Agency, (2015). *Information, Linkages and Capacity Building.* [online] National Disability Insurance Scheme website. Available at: http://www.ndis.gov.au/ilc-policy [Accessed 28 Oct. 2015].

National Disability Insurance Scheme: A Framework for Information, Linkages and Capacity Building. (2015). [PDF] Available at: http://www.ndis.gov.au/sites/default/files/ILC-Policy-Framework.pdf [Accessed 28 Oct. 2015].

Productivity Commission, (2011). *Disability Care and Support: Productivity Commission Inquiry Report: Volume 2.* [PDF] Available at: http://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-volume2.pdf [Accessed 28 Oct. 2015].

Psychiatric Disability Services of Victoria, (2015a). *Submission on: NDIA: Proposal for a National Disability Insurance Scheme Quality and Safeguarding Framework.* [PDF] Available at: https://engage.dss.gov.au/wp-content/uploads/2015/05/VICSERV-Submission-on-NDIA-QS-Framework-April-20151.pdf [Accessed 28 Oct. 2015].

Psychiatric Disability Services of Victoria, (2015b). *Learn and Build in Barwon: The Impact of the National Disability Insurance Scheme on the provision of Mental Health Services in the Barwon Launch site.* [PDF] Available at: http://www.vicserv.org.au/uploads/publications/June_2015_Learn%20and%20Build%20in%20Barwon_Final.pdf [Accessed 28 Oct. 2015].

Senator the Hon Mitch Fifield, (2015). *COAG Disability Reform Council Communique.* [online] Available at: http://www.formerministers.dss.gov.au/15499/coag-disability-reform-council-communiqu/ [Accessed 26 Oct. 2015].

Slade, M. (2014). *Recovery and the CHIME Framework.* [webinar]. Presented for the University of Toronto, 25 February 2014. Available at: http://knowledgex.camh.net/researchers/areas/sami/webinars/archive/Pages/02252014.aspx [Accessed 28 October 2015]

Slade, M., Amering, M., Farkas, M., Hamilton, B., O'Hagan, M., Panther, G., Perkins, R., Shepherd, G., Tse, S. and Whitely, R. (2014). Uses and abuses of recovery: implementing recovery-oriented practices in mental health systems. *World Psychiatry*, 13(1), pp.12-20.

South Australian Health and Community Services Complaints Commission, (2014). *HCSCC Supported Decision Making: Interim Evaluation Report.* [PDF] Available at: http://www.hcscc.sa.gov.au/wp-content/uploads/2014/10/HCSCC-Interim-Evaluation-Report-Aug-2014.pdf [Accessed 27 Oct. 2015].

South Australian Office of the Public Advocate, (2013). *Annual Report 2012-13.* [PDF] pp.52-55. Available at: http://www.opa.sa.gov.au/resources/annual_report [Accessed 27 Oct. 2015].

St Vincent's Hospital Library Service, (2014). *Mental Health Update: Supported Decision Making (Primary Care edition).* [PDF] Available at: http://www.svhm.org.au/gp/Documents/Mental%20Health%20Update%202014%20PC%20No%202%20-%20shared%20decision%20making%20-%20Primary%20Care%20ed.pdf [Accessed 27 Oct. 2015].

Swinburne Institute for Social Research, (2015). Australian Digital Inclusion Index: Discussion Paper. [PDF] Available at: https://www.google.com.au/webhp?sourceid=chrome-instant&ion=1&espv=2&ie=UTF-8#q=http%2F%2Fdigitalinclusionindex.org.au%2Fwp-content%2Fuploads%2F2015%2F08%2FADII-Discussion-Paper-Final-Version2.docx [Accessed 9 Dec. 2015].

United Nations, United Nations Office of the High Commissioner for Human Rights, and Inter-Parliamentary Union, (2007). *From Exclusion to Equality: Realizing the rights of persons with disabilities: Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol.* [PDF] Available at: http://www.ipu.org/PDF/publications/disabilities-e.pdf [Accessed 28 Oct. 2015].

United Nations Committee on the Rights of Persons with Disabilities, United Nations Convention on the Rights of Persons with Disabilities: General Comment No. 1, 2014, Article 12: Equal Recognition Before the Law. U.N. Doc. CRPD/C/GC/I, 19 May 2014, at http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement

United Nations Enable, (2007). *UN Enable - Chapter Six: From provisions to practice: implementing the Convention.* [online] Available at: http://www.un.org/disabilities/default.asp?id=239 [Accessed 26 Oct. 2015].

United Nations Human Rights Council, Thematic Study by the Office of the United Nations High Commissioner for Human Rights on Enhancing Awareness and Understanding of the Convention on the Rights of Persons with Disabilities, U.N. Doc. A/HRC/10/48, 26 January 2009, at http://www.un.org/disabilities/documents/reports/ohchr/A.HRC.10.48AEV.pdf

United Nations Treaty Collection, (2015). *Chapter IV Human Rights: Convention of the Rights of Persons with Disabilities*. [online] Available at: https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en#EndDec [Accessed 27 Oct. 2015].

University of Melbourne in partnership with Victorian Department of Health and Human Services, Mind Australian , Neami National, Mental Illness Fellowship Victoria, Tandem and Victorian Mental Illness Awareness Council, Supported Decision Making for People with severe Mental Health Problems. Retrieved from http://artsonline.monash.edu.au/supported-decision-making/ 12 May 2015

Vela Microboard Association, (n.d.). *Vela*. [online] Vela. Available at: http://www.velacanada.org/ [Accessed 27 Oct. 2015].

Victorian Law Reform Commission, (2012). *Guardianship: Final Report*. [PDF] Melbourne. Available at: http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf [Accessed 26 Oct. 2015].

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