Supported Decision Making in Mental Health: A Literature Review

Developed by Consumers of Mental Health WA for the Mental Health Commission WA

Introduction

Consumers of Mental Health WA (CoMHWA) is the independent, state-wide peak body for people with lived/living experience of mental health issues. CoMWHA was commissioned by the Mental Health Commission to review the *Mental Health Act 2014* (WA) and the application and implications of supported decision-making. People with certain mental health challenges are often put in situations where a decision must be made on their behalf about their treatment, discharge or recovery, but due to their condition they are not recognised as having the necessary mental capacity to make this decision. For example, current legislation of the WA *Mental Health Act 2014* favours substitute decision-making where 'if an adult does not have the capacity to make a decision about a matter relating to himself or herself, the person who is authorised by law to do so may make the decision on the adult's behalf[1].' According to part 5, division 5, section 15, capacity is measured through the individual's ability to:

A. understand any information or advice about the decision that is required under this Act to be provided to the person
B. understand the matters involved in the decision; and
C. understand the effect of the decision
D. weigh up the factors referred to in paragraphs (a), (b) and (c) for the purpose of making the decision
E. communicate the decision in some way.

The State legislation in its current form does not prioritise the rights of the individual being involved in their own treatment and the above criteria – which places value on the individual's capacity for logic, reflection and understanding – and reflects a paternalistic

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[1] *Mental Health Act 2014* (WA).

attitude to decision-making where the individual is judged on their capacity to make the ‘right’ decision. According to Pathare and Shields:

> The bias in this approach lies in the fact that it assumes [people with mental illness] must make ‘right’ and reasonable decisions to be considered to have capacity, and it does not afford PWMI [people with mental illness] the right to make mistakes or wrong decisions (and to subsequently learn from experience) like others in society[2].

This position is counter to the United Nations Convention for the Rights of People with Disabilities (UN CRPD) which emphasises the legal capacity of all individuals to make decisions, and that equity in this field requires that people have access to the support they need in order to make decisions. In the Australian context, Victoria is at present the only state to demonstrate a legislative commitment to the principles of supported decision-making in mental health. Victoria’s *Mental Health Act 2014* lists among its core principles (Part 2, section 11, 1.c, d) that:

- Persons receiving mental health services should be involved in all decisions about their assessment, treatment and recovery and be supported to make, or participate in, those decisions, and their views and preferences should be respected.
- Persons receiving mental health services should be allowed to make decisions about their assessment, treatment and recovery that involve a degree of risk.[3]

Other international jurisdictions including Canada (with varying degrees of provincial participation), Sweden, Scotland and Northern Ireland among others acknowledge supported decision-making as a human right for people with disability, including psychosocial disability.

The aim of this literature review is to provide a comprehensive yet focused overview of relevant literature in order to identify best practice of shared/supported decision-making for consideration in the amendment of WA’s *Mental Health Act 2014*. While this document defines and explores both shared and supported decision-making, we acknowledge the

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[2] Pathare and Shields (2012).

[3] *Mental Health Act 2014* (VIC).

weight of the UN CRPD and its emphasis for supported decision-making as the dominant framework for decision-making for people with disabilities including psychosocial disabilities. The literature review aims to address the following questions:

- What are the distinctions between supported decision-making and shared decision-making, and what are the implications of both in a mental health context?
- What promotes the practice of shared/supported decision-making in jurisdictions where SDM is a regular part of mental health care?
- How does legislation inform/promote the practice of SDM in other jurisdictions?
- What works to change culture from substituted (best-interest) decision-making to supported/shared decision-making in mental health?

Methodology

The researchers undertaking the review agreed on a set of terms as part of their search including supported decision-making; shared decision-making; mental capacity and legal capacity; decision aids; supported decision-making and implementation; UN CRPD and mental health; mental health and person-centred medicine; mental health and treatment adherence. The following databases were searched including Web of Science; Scopus; Medline; SocIndex; and PsychInfo. Additionally, consumer-based websites were searched to access so-called ‘grey’ literature, which despite being non-academic provides crucial grassroots consumer-led perspectives that can offer more democratic ideas. Their inclusion and exclusion criteria included the following: international and national literature; policy briefs; case studies; and consumer based resources. In total 30 pieces of literature were reviewed and included in this paper.

The literature review begins with an overview and description of supported/shared decision-making including from where it originates and what it may look like according to primary and secondary studies of its practice. The distinction between supported and shared decision-making is explained and its implications are discussed. The current context of supported decision-making is discussed including Australia and other jurisdictions, and the review identifies best practice methods of implementing supported decision-making.

What is supported decision-making?

Supported and shared decision-making refer to a framework of decision-making and legal capacity that prioritises involving consumers more equitably in their treatment, care and recovery. Supported and shared decision-making emerge as an alternative to the well-established practice of substitute decision-making or guardianship[4], where consumers are assumed to not have mental or legal capacity because of their mental health issues and decisions are made on their behalf in their 'best interest'[5]. People First Scotland argue that academic literature constructs a distinction between 'best interest' decisions made about people on their behalf, and decisions made by the individual that are instead ruled by their own 'will and preferences'[6]. The group contests that this is a 'false distinction', proposing that:

> When any person makes a decision, it is not true that they decide things which are not in their best interests. For most decisions, all human beings will take account of what they believe will make them happier, will suit them and, in the main, be good for themselves even when they know there may well be more logical or healthier or more prudent options that they have not chosen.[7]

From this argument, People First Scotland assert the right of people with disability and mental illness to decide what constitutes their best interests and make decisions based on those concepts.

According to Shepherd et al[8] the current literature regards decisions made by a substitute in 'best interest' as 'being complicated by difficulties involved in the clinician gathering all relevant information relating to the decision to be made'. By contrast, supported decision-making (and shared decision-making, to an extent, which will be explored later in this review) adopts a more nuanced, rights-based and person-centred approach to capacity that recognises that all people deserve to be involved directly in making decisions that impact their lives[9], and that, according to Chartres and Brayley, 'no person should have another person appointed to make a decision on their behalf, if they could make the

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[4] Pathare & Shields (2012).

[5] *A Journey Towards Autonomy? Supported Decision-Making in Theory and Practice* (2014).

[6] People First Scotland (2016).

[7] *Ibid*.

[8] Shepherd, Shorthouse and Gask (2014).

[9] Simmons & Gooding (2017).

decision themselves with assistance and support[10]'. Further, Bach and Kerzner[11] argue that the central question should no longer be, 'does this person have the capacity to make that decision?' but, rather, 'what supports are needed to ensure that this person can best exercise their rights?'[12]

Supported decision-making in the context of mental health has historically been more complex and contradictory than in other areas of disability such as physical disability because of the role mental health issues can play in affecting mental capacity; that is, while a person with diabetes is not assumed to have reduced mental capacity to make decisions about their treatment, recovery or their lives in general because they have diabetes, people diagnosed with Serious Mental Illness (also known as SMI, referring to a group of severe disorders including schizophrenia, bipolar disorder, major depressive disorder and schizoaffective disorder) are often assumed to be incapable because of this diagnosis[13]. Zisman-Ilani et al argue that this attitude is a major barrier to the implementation of supported or shared decision-making among individuals with SMI, as is the role self-stigma plays in undervaluing the mental capacity of the individual.

Supported decision-making emerged from the disability rights movement and was bolstered by the UN CRPD. During the Convention negotiations, psychosocial disability groups argued that the notion of capacity is socially constructed and has historically been used to exclude marginalised groups. Further, because the definition assesses *cognitive* capabilities, individuals who make decisions on an *emotive* or *intuitive* basis are framed as lacking capacity[14]. Article 12 of the Convention states that:

- States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
- States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.[15]

Article 12 (sections 2 & 3) asserts the inherent legal capacity that must be assumed about all people with disabilities. While concepts of mental capacity refer to whether someone is

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[10] Chartres & Brayley (2011).
[11] Bach and Kerzner (2010).
[12] *Ibid*.
[13] Zisman-Ilani et al (2021).
[14] Chesterman and Carter (2009)
[15] *Convention on the Rights of Persons with Disabilities* (2006).

intellectually or emotionally capable of understanding, weighing, remembering and communicating all aspects of a decision[16], legal capacity maintains that everyone has the right to make decisions about their own lives. ‘Capacity’ remains a contested term in the literature of supported and/or shared decision-making because of the weight and shifting role of ‘mental capacity’ in assessing ability to make decisions. McSherry[17] identifies two components of capacity: a person’s ‘“legal standing” in the sense of being viewed as a person before the law’, and ‘“legal agency” or what is sometimes referred to as “active legal capacity”’. Mental capacity, conversely, is decided by a clinician or clinicians as to whether the person is mentally competent. Gooding[18] proposes that article 12 does not identify mental capacity and legal capacity as exclusive terms, meaning that a person retains their legal capacity even if they are deemed to lack mental capacity through failing a mental capacity test. This contests the tendency to conflate mental and legal capacity, where it is assumed that if someone is determined to lack mental capacity, they too are unable to hold legal capacity[19]. Davidson et al argue for the use of the term ‘decision-making ability’ as a preferred alternative to ‘capacity’ to avoid this confusion.

The UN CRPD has been ratified by 185 States and contains reservations made by Australia, Canada, Georgia, Ireland, the Netherlands, Norway and other countries[20], where Article 12 has been interpreted to grant the right for the use of substitute decision-making only as a last resort in cases where emergency treatment is required, and the individual is deemed to lack mental capacity to make their own decision[21]. Bach and Kerzner argue that these interpretations take ‘the position that, while not prohibiting substitute decision making regimes, Article 12 places emphasis on the importance of supported decision-making’[22]. Elsewhere, human rights activists such as Webb have argued that any consideration for substitute decision-making undermines Article 12 because it conflicts with the central principle that all people, whether they are deemed capable or incapable, have the right to make decisions about their own lives[23].

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[16] Roper et al (2019).
[17] McSherry (2014).
[18] Gooding (2013).
[19] *Ibid*.
[20] *Convention on the Rights of Persons with Disabilities* (2006).
[21] Stainton (2016).
[22] Coughlan (2016).
[23] Webb (2007).

What does it look like?

In Victoria where supported decision-making has been implemented, a key document titled 'Guidelines for Supported Decision-Making in Mental Health Services[24]' outlines four key enablers of supported decision-making. These are: legal mechanisms including advance care directives which will be discussed further below; interpersonal skills and relationship building; the empowerment of people experiencing mental health challenges; and management and leadership. Other legal mechanisms mentioned include nominated persons, and utilising secondary psychiatric opinions or advocacy services such as Legal Aid. Interpersonal skills and relationship building include providing practical support, peer support and continuity of care. Consumers are empowered and engaged in their own care when practitioners communicate treatment in an accessible and positive way, and where practitioners challenge their own beliefs about mental health issues. Management and leadership centres around the need for senior management to adopt and model supported decision-making in their own practice for all team members to see[25].

Chartres and Brayley also suggest the following range of supported decision-making services which need to be provided[26]. These include informal assistance of family and friends; the range of approaches to communication; supported decision-making representatives/networks; support to the other people involved; practice guidelines; information, education and awareness campaigns; advocacy; community support systems; and practical assistance[27].

Advance care directives

Advance care directives are mentioned across the literature as one of the primary measures for consumers of mental health to plan their treatment if they are unable to independently make a decision for themselves. Advance care planning refers to a process of making decisions when you can do so, for a time in the future when your ability may be impaired[28]. Although there is great benefit to advance care planning, Papageorgiou et al. found that it is not useful for everyone and that an individual's preferences and

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[24] Brophy et al (2018).
[25] Kokanovic et al (2017).
[26] Chartres and Brayley (2011).
[27] Davidson et al (2015).
[28] *Ibid.*

circumstances need to be considered when all forms of supported decision-making are being provided[29].

What kinds of decisions are made?

Much of the literature on both shared and supported decision-making revolves around decisions to do with the consumer's medical treatment and recovery journey. A dominant theme among shared decision-making studies is how shared decision-making can be used as a way of ensuring compliance (or adherence, which is the consumer-preferred term) to taking medication[30][31][32]. Deegan and Drake argue that a shared decision-making approach can resist paternalistic frameworks of compliance, instead moving towards an understanding that: 'using medication is an active process that involves complex decision-making and a chance to work through decisional conflicts[33]'.

Risks and Challenges

Davidson et al found that there are challenges in ensuring good practice is consistently provided across all settings if there is no legal framework or Code of Conduct to adhere to[34], which is supported in activist groups' calls for national supported decision-making frameworks[35].

One of the key barriers to implementation of supported decision-making from the clinicians' perspective is the factor of risk and liability for the clinician, which is a major priority in psychiatric training. Kokanovic et al[36] found that psychiatrists expressed a range of concerns about supported decision-making including: the challenges associated with administering advance care statements, where there was potential disagreement between the clinicians and family members supporting the consumer; and the added time, skills and resources that may be required to administer care statements. However, it was found that psychiatrists who prioritise the autonomy of patients are more likely to utilise advance

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[29] Papageorgiou et al (2002).
[30] Deegan and Drake (2006).
[31] Ashoorian and Davidson (2021).
[32] Kaminskiy et al (2021).
[33] Deegan and Drake (2006).
[34] Davidson et al (2015)
[35] *Calling for a National Supported Decision Making Framework* (2016).
[36] Kokanovic et al (2017).

statements and could 'champion' or assist to develop education or training programs and support decision-making mechanisms for other psychiatrists'[37].

The tendency towards risk-avoidance in clinical practice has implications for how shared and/or supported decision-making has been implemented and observed. Many primary studies dominantly trial supported or shared decision-making with voluntary inpatients or outpatients of public and private services[38], meaning there is little data or research on how SDM can be implemented among involuntary patients, for whom a significant decision has already been made in their 'best interest' by a clinical authority. Burnout, patient load and limited appointment time are other barriers that contribute to the barriers of SDM, and it is often perceived by psychiatrists that SDM for voluntary consumers is already placing high demands on time and resources[39][40]. This imbalance suggests that SDM is seen as an option only for consumers of a predetermined level of wellness, insight and capacity, meaning the binary of having capacity or lacking capacity remains largely unchallenged[41]. Guerrier et al[42], however, argue that it is possible to follow clinical practice guidelines and implement shared decision-making, although this study relates to physical health (specifically acute respiratory tract infections) and therefore has limitations in extrapolating to mental health contexts. The Australian Supported Decision-Making Network, in their 2016 report *Calling for a National Supported Decision Making Framework* acknowledges the importance of balancing duty of care with dignity and risk, and suggests the aim for supported decision-making should refer to 'maximising the person's decision making potential and autonomy while keeping risk to an acceptable level[43].' Similarly, the NHS Department of Health 2007 report recommends following a person-centred approach to care, where, 'Ultimately, the local authority has a statutory duty of care and a responsibility not to agree to support a care plan if there are serious concerns that it will not meet an individual's needs or if it places an individual in a dangerous situation[44].' At present, the articulated balance between duty of care and dignity of risk needs to be more distinct to be offered as a model of implementing SDM.

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[37] Kokanovic et al (2017).
[38] Légaré and Thompson-Leduc (2014).
[39] Zisman-Ilani et al (2021).
[40] Shepherd, Shorthouse and Gask (2014).
[41] *Ibid.*
[42] Guerrier et al (2013).
[43] *Calling for a National Supported Decision Making Framework* (2016).
[44] Department of Health (2007).

Zisman-Ilani et al call for a perspective shift on shared decision-making as 'shared risk-taking'[45] in clinical practice to reframe SDM as an opportunity for consumers and clinicians to share the 'dignity of risk and the right to failure[46]', rather than prioritising the elimination of risk. Dignity of risk refers to the equitable chance to make choices according to one's will and preferences that may, from certain perspectives, seem unsafe or unwise. Zisman-Ilani et al argue that this reframing could bridge the gap between calls to implement SDM and its limited use in practice.

Ways Forward

Collaboration with Providers

People experiencing severe mental health issues, families and other informal supporters, and mental health practitioners emphasised the importance of developing enduring relationships with mental health practitioners and other health service providers (such as General Practitioners) that are based on safety, trust, choice, collaboration and empowerment.

Involvement of Family

Involvement of family in the supported decision-making process is arguably a complex one. For some individuals having the support of their family will be crucial in the process of their treatment and recovery, while for others their families may be the contributors to their challenges. Some of the literature indicates the importance of involving families and other informal supporters in decision-making, recognising their expertise and the need to engage them as key supports for people's treatment decision-making.

Shared versus supported decision-making: key distinctions

Shared and supported decision-making, while semantically similar, place different emphasis on the importance of who makes the decision and how the decision is made. Shared decision-making describes a process where two 'experts' (the clinician, expert of evidence-based research and the consumer, expert of their own experience and preferences) come together to mutually arrive at a decision with which both parties are

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[45] Zisman-Ilani et al (2021).

[46] Deegan (1992).

satisfied. Activists have pointed out[47] that it is difficult to state with certainty whether this relationship can ever be truly ‘equal’, given the power always-already granted to psychiatrists and other clinicians to make decisions that override those made by the consumer, especially if they are deemed to be making the ‘wrong’ decision.

Where shared decision-making is often described as a *model* related to a specific decision, usually related to treatment, care or discharge (for example, clinician and patient come together to discuss the patient’s options for medication they do or do not want to take), supported decision-making is an *ethos*[48]. That is, where shared decision-making can be followed like a formula or flow chart through steps of the decision-making process, supported decision-making focuses not on the outcome of decision but that the person most deeply involved in making the decision is the person who will be affected most by the impact of the choice. Primary studies of shared decision-making implementation tend to focus on medication adherence, specifically around antipsychotic prescribing, and concur several barriers and enablers to ‘successful’ use in clinical settings. Deegan and Drake[49] outline some of the principles behind shared decision-making including the importance of person-centred medicine, which places the individual at the nexus of their own decision-making; the partnership between two experts (clinician and consumer); and a mutual agreement to find what ‘works’, both from a clinical perspective in terms of evidence-based support and from the consumer’s perspective of how medication allows them to best access their strategies of ‘personal medicine’ (that is, the non-clinical activities that give life purpose, build self-esteem and promote accomplishment).

While shared decision-making is shown through primary studies to be more easily implemented and better aligned with the existing culture of current mental health systems[50][51], it is less oriented towards human rights perspectives and can at any time be incorporated back into the dominant model of substitute decision-making when the individual is determined to be making the ‘wrong’ choice or is deemed to lack mental capacity, especially if the individual is an involuntary patient.

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[47] Roper et al (2019).
[48] Simmons and Gooding (2017).
[49] Deegan and Drake (2006).
[50] Hamann et al (2009).
[51] Kaminskiy et al (2021).

In conclusion, key distinctions between shared and supported decision-making, for the purpose of this review, relate to whose perspective is prioritised. This has implications for which practice is more clearly supported by evidence-based literature. While much of the literature for shared decision-making offers concrete, qualitative and quantitative primary studies showing the enablers and barriers to implementation, a large majority of the literature on supported decision-making is ‘grey’, not peer-reviewed and often originates from grassroots, human rights, consumer-led perspectives rather than scientific research. This is telling for how shared decision-making may be already more aligned with current biomedical models of mental health and therefore may be more invested in upholding dominant power relations, but this also implies there are more cultural barriers to implementing supported decision-making, which is a framework that is less compatible with current medical frameworks. Another key distinction between the two models of decision-making relates to what kinds of decisions are made. While the literature on shared decision-making is overwhelmingly focused on medical, legal or occasionally financial issues, the purview of supported decision-making is much broader and can involve much more informal kinds of support.

The current context

Researchers have begun to agree that while shared decision-making models can and have been tested through randomised control trials and have evidence to support their use, it is more difficult or even paradoxical to gather or produce evidence measuring the effectiveness of *supported* decision-making[52]. This is because the goal of implementing supported decision-making is to recognise the rights of all individuals to be involved in decisions about their own lives, and can therefore not be adequately measured through medical discourse that understands effectiveness through medical outcomes or financial relief to the disease burden. *A journey towards autonomy? Supported decision-making in theory and practice* report from the Office of the Public Advocate, Brisbane, notes that literature discussing supported decision-making uses evaluation processes to determine ‘the alignment of supported decision-making as a concept with principles of autonomy and self-determination as well as the principles underpinning the UN CRPD’[53].

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[52] Chesterman and Carter (2009).

[53] *A journey towards autonomy? Supported decision-making in theory and practice* (2014).

Conversely, the goal of shared decision-making is dominantly focused on a series of health outcomes, such as staying out of hospital, adhering to medication plans and decreasing chances of relapse[54][55][56][57][58]. Pathare and Shields, in their review of literature about supported decision-making, argue that while previous reviews place emphasis on Randomised Control Trials of SDM, ‘restricting inclusion to a particular study design could substantially limit relevant data included in the evidence base[59]’, especially given that much of supported decision-making is evaluated through other methodologies including quasi-experimental studies and qualitative studies. Academic articles such as those by Pathare and Shields[60], Simmons and Gooding[61], Davidson et al[62], Stainton[63], and Gooding[64], for example, present comprehensive literature reviews using a range of methodologies that map dominant themes, histories and trajectories emerging in academic, legal and medical discussions of supported decision-making.

There are emerging pilot studies that describe and evaluate supported decision-making both internationally and nationally. These will be discussed below.

Australia

Australia signed the UN CRPD on the 30th of March, 2007, and ratified the document on the 17th July, 2008 reserving their interpretation of Article 12 in the following way:

> Australia recognizes that persons with disability enjoy legal capacity on an equal basis with others in all aspects of life. Australia declares its understanding that the Convention allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person,

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[54] Hamann et al (2009).
[55] *Health Policy Brief: Patient Engagement* (2013).
[56] Légaré and Thompson-Leduc (2014).
[57] Ashoorian and Davidson (2021).
[58] Chmielowska et al (2021).
[59] Pathare and Shields (2012).
[60] *Ibid*.
[61] Simmons and Gooding (2017).
[62] Davidson et al (2015).
[63] Stainton (2016).
[64] Gooding (2013).

> only where such arrangements are necessary, as a last resort and subject to safeguards[65].

Under this interpretation, Australia reserves the right to implement substitute decision-making ‘as a last resort and subject to safeguards’, meaning the priority should always be to include the consumer in any decision made about their lives; however, the reservation does not specifically describe under which conditions such arrangements may be ‘necessary’, which leaves room for clinicians and institutions to exercise discretionary power when identifying how and when substitute decision-making is appropriate. It is notable that the Human Rights Commission of Australia, in a submission to the UN Committee on the Rights of Persons with Disabilities, encourages the Australian Government to ‘withdraw its interpretative declaration to the CRPD’ concerning article 12, because it is ‘inconsistent with the Committee’s jurisprudence and prevent effective implementation of the CRPD[66].’ The same submission also recommends that the Australian Government ‘implement a nationally consistent supported decision-making framework’ as recommended in the Australian Law Reform Commission’s 2014 report *Equality, Capacity and Disability in Commonwealth Laws.*

In Australia, only Victoria has supported decision-making written into the rights of people with mental illness under the *Mental Health Act 2014*, which states that:

- Persons receiving mental health services should be involved in all decisions about their assessment, treatment and recovery and be supported to make, or participate in, those decisions, and their views and preferences should be respected.
- Persons receiving mental health services should be allowed to make decisions about their assessment, treatment and recovery that involve a degree of risk.[67]

Under the Victorian *Mental Health Act 2014*, individuals can make advance statements as to preferred treatment options, based on their values and preferences, and nominate

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[65] *Convention on the Rights of Persons with Disabilities* (2006).

[66] *Information concerning Australia’s compliance with the Convention on the Rights of Persons with Disabilities* (2019).

[67] *Mental Health Act 2014* (VIC).

others to support them. This may be particularly valuable in the event they become subject to compulsory treatment or to help avoid compulsory treatment[68].

The Office of the Public Advocate Document[69] has identified some examples of SDM in practice in Australia which include:

- Supported decision-making may also involve a written agreement between designated support people, written plans and documented decisions. The closest example in Australia is the Citizen Advocacy model.
- In Victoria, work on supported decision-making has been undertaken by Jo Watson from Scope Victoria over several years. Her work is particularly valuable, in that it explores the nature of the assistance that can be provided as well as the framework and paradigm.

- Supported decision-making has also been considered by the NDIS who opened up a consultation process for consumers to feedback into demonstrating that this is being considered at a Federal level also[70].

My Medicines and Me

An example of supported decision-making being implemented is the My Medicines and Me Questionnaire project designed and led by Dr Deena Ashoorian at the University of Western Australia and in partnership with CoMHWA. The project centres around a consumer centred communication tool – the M3Q – which supports people to confidently take part in shared decision-making with clinicians regarding their medication treatments. Most mental health or psychiatric medications have side effects. Studies show the experience of medication of side effects influences people’s beliefs and behaviours towards taking medications as they have been prescribed, such as the 2017 report commissioned by the National Mental Health Consumer and Carer Forum entitled *A Critical Literature Review of the Direct, Adverse Effects of Neuroleptics[71].* Other studies recognise the benefits to improving health outcomes and decreasing health costs by engaging consumers in decision-making. Elements of the project involve elements of shared decision-making and supported decision-making process which leads to positive outcomes for patients and their management of medication. The project improved their

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[68] Kokanovic et al (2017).
[69] Chesterman and Carter (2009).
[70] NDIS (2021).
[71] Dorozenko and Martin (2017).

confidence and knowledge to effectively take part in the management of their medications[72].

Other leading jurisdictions

Canada

Canada has a range of formalised and semi-formalised supported decision-making arrangements. These vary according to the guardianship law in the particular jurisdiction and to whether legislation refers to supported (assisted) decision-making. In some jurisdictions, supported decision-making is based in policy rather than in legislation[73]. Gooding writes that in Canada, ‘representation agreements and supported decision-making legislation were never intended for use during emergencies but rather, prior to problems and conflicts developing’[74]. Legislation in British Columbia, for example, allows for a representation agreement where the supported person appoints their own representative[75].

United Kingdom

In the United Kingdom the Mental Capacity Act 2005 provides a legislative framework for those who for whatever reason are not able to make a decision independently. ‘A Court of Protection may appoint a deputy for a person unable to make their own decisions[76].’ The Act provides Independent Mental Capacity Advocates for people who do not have family or friends and are facing serious life or health decisions. These advocates are based in community organisations.

Sweden

Sweden has instituted a range of legal supports for people with disabilities. Mentorship is the preferred form whereby the civil rights of the individual remain intact and the mentor acts only with the consent of the person. Mentors are appointed by a court and paid by the state and application for a mentor can be made by the person, a relative or the public trustees. Where mentorship is inadequate because of the person’s disability or

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[72] Ashoorian and Davidson (2021).
[73] Chesterman and Carter (2009).
[74] Gooding (2013).
[75] *Ibid*.
[76] Chesterman and Carter (2009).

circumstances, an administrator or trustee can be appointed to make substitute decisions to protect the person[77].

Conclusion

Supported and/or shared decision-making is well-theorised from academic, policy and activist perspectives but the logistics of its implementation, both in legislation and in practice, remains under-researched. People experiencing mental health challenges have a right to be directly involved in decisions made about their lives, to be allowed the dignity of risk and to have their legal capacity presumed rather than tested on a binary scale of having mental capacity or not. This review has sought to illustrate principles, practice and effects of SDM in the context of mental health. A dominant narrative in the literature on SDM supports a shift from substitute decision-making, or even shared decision-making where the psychiatrist or other medical authority is granted ultimate power over the outcome of a decision, towards the human rights principles of supported decision-making. While there is some academic literature specifically in favour of supported decision-making, some of the strongest proponents of supported decision-making emerge from a disability rights activist space, or policy documents from advocacy organisations.

What was clear from the literature available is that a move towards a human rights centred approach of mental health treatment and recovery is the way forward for this sector. Progress towards a recovery and human rights focus in the mental health sector has contributed to policies and law aimed at ensuring individuals with lived experience of mental health issues will have their views and preferences respected.

> Mental health laws, policies and practice are moving towards a stronger focus on personal recovery and human rights. The personal recovery model values autonomy and the right of people experiencing severe mental health problems to have choice and control over important decisions.[78]

Further, recovery-oriented practice shifts the focus in mental health care from simply alleviating symptoms to working with strengths, capacities and opportunities for personal recovery.[79] Supported decision-making can help facilitate this process and is recognised

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[77] *Ibid.*

[78] Kokanovic et al (2017).

[79] *Ibid*.

by the United Nations Convention for the Rights of People with Disabilities (UN CRPD) as the most valuable framework for decision-making for people with disabilities including psychosocial disabilities.

Glossary of terms and acronyms

Best interest: a term used in the definition of how decisions are made on the behalf of another person. Best interest tends to refer to how the individual’s basic and most important needs can be met, at the cost of some measure of autonomy and risk.

Decision-making ability: The ability to understand, measure, and make decisions.

Guardianship: A legal process by which a nominated person is recognised as the legal guardian of another and who is authorised (by an external authority) to make decisions in the ‘best interest’ of the individual.

Legal capacity: The extent to which an individual is recognised and represented as equal under the law, and their ability to act in this standing.

Mental capacity: An assessed state of mental competence/cognitive ability that grants individuals access to make decisions about their own lives.

Paternalism: A culturally dominant practice/approach to medical care informed by a sense of duty toward the patient that positions the clinician in a role of power above the consumer, and the consumer as a ward of the clinician.

Person-centred medicine: an alternative approach to medicine that prioritises the will and preferences of the consumer

PWD/people with disability: those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others

PWMI/People with mental illness: people diagnosed with mental illness, as well as those who identify as mental health consumers, survivors of psychiatry, ‘mad’ and so on.

RCT/randomised control trials: A form of scientific experiment where participants are assigned randomly to one of two groups: the experimental group receiving the intervention being tested, and the control group receiving conventional treatment.

SDM/supported or shared decision-making: Two distinct models of decision-making that together pose an alternative to substitute decision-making. Supported decision-making centres the rights of the person involved to make decisions about their lives, with varying degrees of support that they might need, and shared decision-making constructs an ‘equal’ relationship between clinician and patient coming together as experts to make a decision together.

SMI/Serious/severe mental illness: a mental, behavioural, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities.

Substitute decision-making: a process by which another person is appointed to make decisions about the life of another in the case that the person is found to lack mental capacity to make their own decisions.

UN CRPD/United Nations Convention for the Rights of Persons with Disability: a United Nations document that outlines central tenets of human rights for people with disability.

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