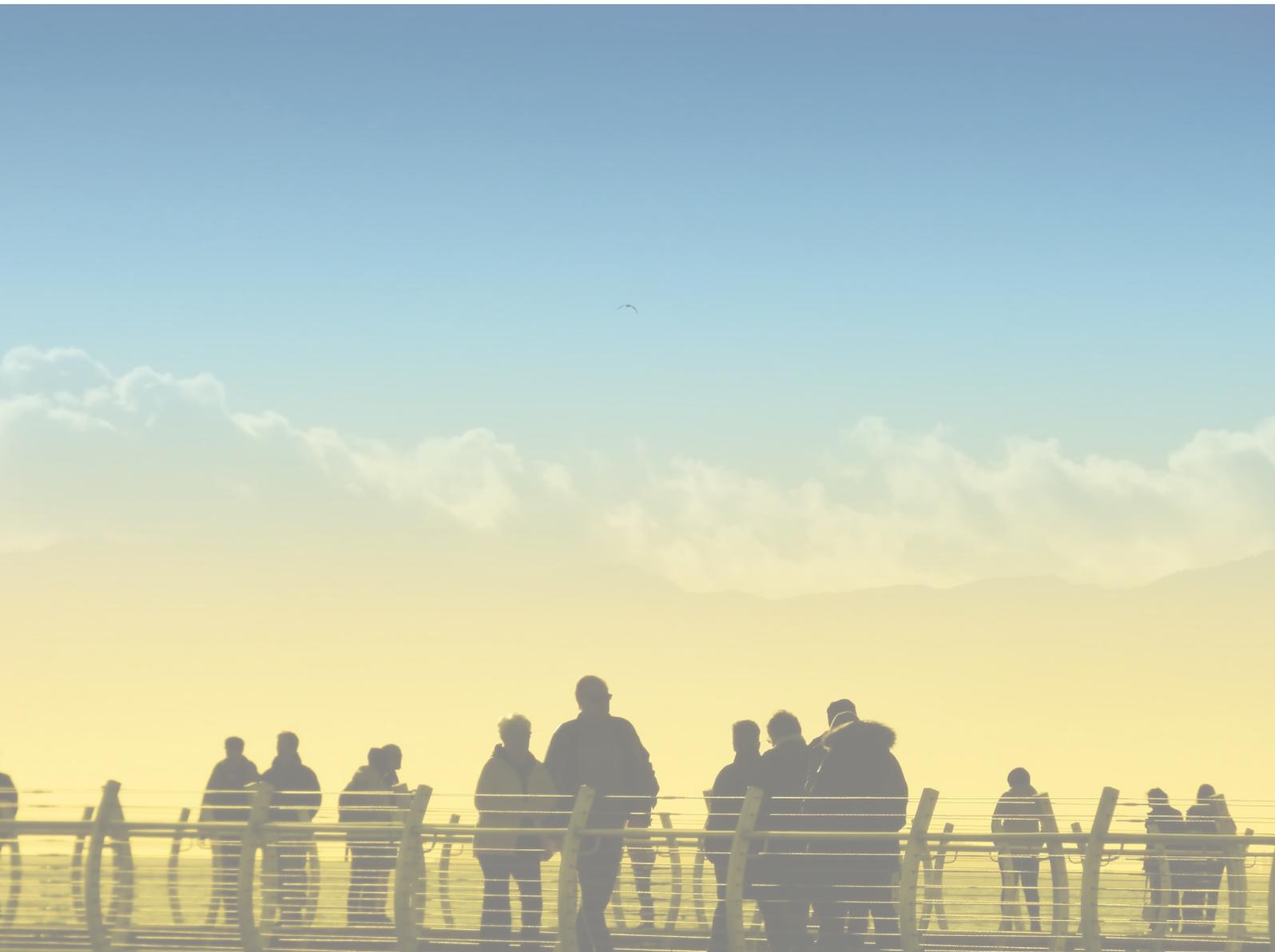




Guidelines for Supported Decision-Making in Mental Health Services



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These Guidelines are part of a series of resources designed to inform and improve practices that enable supported decision-making for people who experience mental health challenges and to assist families and other supporters participate in supported decision-making. These resources can be used individually, as an aid to policy development, and in training.

See also:

- What Is Supported Decision-Making? Fact Sheet
- Supported Decision-Making Legal Mechanisms Fact Sheet
- Practices To Improve Supported Decision-Making In Mental Health Services Fact Sheet
- Introduction To Supported Decision-Making For People Experiencing Mental Health Challenges And Their Families And Other Supporters
- Resources To Assist With Supported Decision-Making Fact Sheet
- Report – Options For Supported Decision-Making To Enhance The Recovery Of People Experiencing Severe Mental Health Problems
- Online resources: <http://research.healthtalkaustralia.org/supported-decision-making/support-in-treatment-decisions> and <http://research.healthtalkaustralia.org/carers/carers-and-supported-decision-making-mechanisms>

Overview and Scope

These Guidelines provide suggestions on how to implement supported decision-making in mental health services, including clinical and non-government or community support services. The Guidelines are based on reviews of the literature on supported decision-making and on the findings of the Australian Research Council supported decision-making research project which gathered the perspectives of people experiencing mental health challenges, families and other supporters and mental health practitioners, including psychiatrists.

Mental health practitioners are encouraged to incorporate supported decision-making into their practice to meet their clinical, ethical and legal obligations. This relates to national mental health policy, state based legislation and international human rights law, as well as professional codes of practice.

The United Nations Convention on the Rights of Persons with Disabilities [1] (CRPD) which Australia has ratified, sets out as its first guiding principle, “[r]espect for inherent dignity, individual autonomy including the freedom to make one’s own choices” (Article 3). The CRPD applies to those with “mental impairments” as well as intellectual, sensory and physical impairments (Article 1).

This notion of supporting people to make or participate in decision-making stems from one interpretation of Article 12 of the CRPD which deals with equal recognition before the law. Article 12(3) states:

States Parties [that is, countries that have ratified the CRPD] shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

The Committee on the Rights of Persons with Disabilities has stated that taking away a person’s legal capacity because she or he is thought to have impaired decision-making skills is discriminatory. [2] Hence, Article 12 of the CRPD requires support to be provided so that persons with disabilities can exercise their legal capacity, enabling their autonomy and citizenship.

Supported decision-making

Supported decision-making may be defined as the process whereby individuals are assisted to make decisions through being provided with the support they need. [3] It recognises that the person supported is at the

centre of the decision-making process. The process involves individuals receiving support from others to consider, weigh up alternatives and make specific decisions. Supported decision-making may include formal mechanisms such as through advance statements and nominated persons schemes, as well as through informal mechanisms such as help from peers, families and other supporters.

Supported, substituted and shared decision-making

Supported decision-making differs from substituted decision-making where specific persons, such as guardians or administrators, are granted responsibility to make decisions for those considered to be unable to make decisions themselves. It also differs from shared decision-making which describes person-centred approaches in health care settings where patients and health practitioners make decisions together about treatment. [4] Shared decision-making has also been linked to recovery oriented practice and is well supported internationally, with clinical and ethical justifications for involving clinical expertise with lived-experience expertise to achieve the best outcomes for people. [5]

Evidence for the impact of supported decision-making interventions

A review of the evidence concerning supported decision-making was conducted [6] and support was found for the effectiveness of advance statements on reducing the risk of compulsory admission to hospital for treatment of mental health problems. [7] However other studies that focus on simple outcomes such as admissions to hospital or number of days in hospital have not shown effectiveness, [8, 9] leading to calls for further trials. [10] There is emerging evidence that advance statements can be useful as part of a suite of strategies to reduce the use of restraint and seclusion in psychiatric wards. [11, 12]

Qualitative evidence suggests that there is an unmet need for involvement in psychiatric treatment decision-making among people experiencing mental health challenges. Current institutional practices may inhibit the efforts of mental health practitioners to incorporate that involvement into their practice, by focusing on risk and the accountability of practitioners for the actions of consumers or service users.

These Guidelines are based on the best available evidence at this time as well as findings from our project. Ideally, users of these Guidelines will incorporate evaluations of their implementation programs to help develop the evidence for supported decision-making in practice.

Embedding supported decision-making in practice

There are a number of key areas in which supported decision-making initiatives can be promoted. Staff training is needed to improve communication and negotiation with mental health service users (consumers) and with families supporting people experiencing mental health challenges so that supported decision-making processes are carried out.

Psychiatrists express a range of concerns about supported decision-making that must be addressed, as these concerns may deter psychiatrists and other mental health practitioners from following requests in advance statements, particularly during times of crisis or acute episodes of mental ill-health. These concerns include the potential difficulties associated with administering advance statements, including the potential for conflict (for example, between the practitioners and family members supporting the consumer) and the added time, skills and resources that may be required. However, those psychiatrists who prioritise the autonomy of patients are more likely to utilise advance statements and could 'champion' or assist to develop education or training programs and support decision-making mechanisms for other psychiatrists. [13]

People experiencing mental health challenges have a range of ideas about how they want to be involved in decision-making and support should be tailored to that preference. They are likely to want to be central to the decision-making about their treatment and care, but they may have had previous experiences of requests in advance statements being ignored or rejected, or otherwise feeling disempowered in decision-making and may be wary of the utility of future involvement. [14]

Mental health practitioners can facilitate autonomy and supported decision-making by utilising the recommendations found in these Guidelines.

Objectives

These Guidelines aim to provide evidence-based information to leaders and managers of mental health services, mental health practitioners,¹ people experiencing mental health challenges and families and other supporters regarding optimal supported decision-making practices in mental health treatment and support services. Supported decision-making

1 Mental health practitioners include psychiatrists, psychologists and other allied health professionals working in the mental health system, mental health nurses, and staff working in mental health community support services.

practices may reduce compulsory admissions and the use of seclusion and restraint in in-patient settings. Supported decision-making practices will assist services to fulfil their legal and ethical requirements under the CRPD and, if implemented, could aid the personal recovery of people experiencing mental health challenges.

These Guidelines are designed for mental health treatment and support services and the people who access them. [15, 16]

These Guidelines have been developed in accordance with the Appraisal of Guidelines Research and Evaluation requirements. [17]

Consumer and other stakeholder involvement

These Guidelines were developed as part of the supported decision-making research project. [6] This project involved collaboration with researchers based at RMIT University, Monash University and the University of Melbourne. Partner Investigators were based at the Victorian Department of Health and Human Services (DHHS) and five major non-governmental organisations (NGOs) supporting mental health service and delivery in Victoria: Neami National, Tandem, Victorian Mental Illness Awareness Council (VMIAC), Wellways and Mind Australia Limited (Mind).

The project was guided by an Advisory Board comprising of people experiencing mental health challenges, family carers, an interdisciplinary group of academic researchers, health services and non-government mental health services representatives and relevant policy makers. It aimed to better understand the experiences of people living with psychiatric diagnoses including bipolar disorder, psychosis and schizophrenia. The Advisory Board contributed to quality assurance of the material produced for the online resources, and the dissemination of project findings.

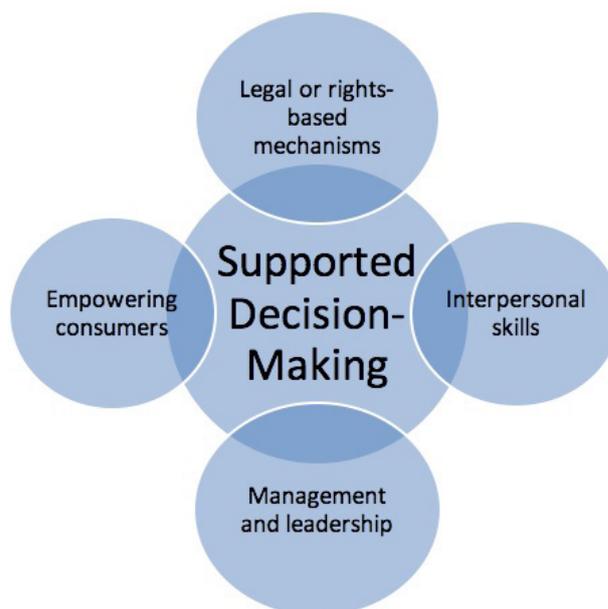
The project was funded by the Australian Research Council Linkage projects scheme (LP130100557).

Method

These Guidelines are based on:

- a) research conducted by the supported decision-making project research team; and
- b) a systematic review of the academic legal, health and welfare literature on mental health decision-making between 2000 and 2016 conducted from July 2015 to August 2016.

Recommendations for facilitating supported decision-making in mental health treatment and support



Four key enablers of supported decision-making have been identified. [6] They are: legal mechanisms, interpersonal skills and relationship building, the empowerment of people experiencing mental health challenges and management and leadership. These enablers were identified in interviews conducted for this project with participants with experience of mental health challenges, families and other supporters and mental health practitioners. Each of these enablers is described below with reference to the interviews.

1. Legal or rights-based mechanisms

In [my role] I've become incredibly passionate about advance statements and trying to, to push those within ... our service and it's, it's slow ... slowly, slowly starting to see change, which we expected. But you know, every so often you know, I'm starting to hear really good stories. (Mental Health Nurse)

Legal or rights-based mechanisms are one of the most direct facilitators of supported decision-making and are generally incorporated into contemporary mental health legislation. These include:

Advance statements

In Victoria, an advance statement sets out a person's treatment preferences in case they become unwell and need compulsory mental health treatment. Much of the current research has focused on advance directives (which are sometimes also called a "living will") and joint crisis plans, but there are similarities and differences in these approaches to advanced care planning. [18]

Advance statements provide people experiencing mental health challenges with an opportunity to express their views and preferences about treatment and guide those providing treatment and care in how to respect their wishes. There is some evidence that appropriate use of advance directives or statements leads to clinically significant reductions in compulsory admissions. [7] People experiencing mental health challenges want to use advance statements to ensure their preferences are incorporated into treatment decisions. [19] With the aid of a peer supporter or other advocate, people experiencing mental health challenges can complete advance statements while in hospital and this may assist in the reduction of seclusion and restraint. [11] When they experience their preferences not being carried out, this can affect their confidence and active involvement in future care, so it is important that advance statements are implemented in a way that maximises their relevance and influence on practice. [20]

Nominated persons

A person may be able to nominate another person to support him or her and help represent his or her interests about their mental health treatment. For example, in Victoria, a nominated person must be consulted about treatment (*Mental Health Act 2014* (Vic), section 23(c)), but cannot make decisions on behalf of the person being treated. Treating clinicians are required to make reasonable efforts to notify the nominated person

when significant changes are made to a person's treatment conditions. More about the nominated person scheme can be found at: <https://www2.health.vic.gov.au/mental-health/practice-and-service-quality/mental-health-act-2014-handbook/recovery-and-supported-decision-making/nominated-persons>

Second psychiatric opinions

Second psychiatric opinions may enable people to participate in decisions about their treatment by promoting discussion between the authorised psychiatrist, the treating team, the person, carers and family about the person's treatment. Information about the rights and responsibilities associated with second opinions in Victoria can be found at: <https://www2.health.vic.gov.au/mental-health/practice-and-service-quality/mental-health-act-2014-handbook/recovery-and-supported-decision-making/second-psychiatric-opinions>

Advocacy services

Mental health advocacy provided by the Health Consumer Council (an advocacy service operating in Western Australia) has been linked to increases in empowerment and wellbeing of people experiencing mental health challenges. [21] In Victoria, independent advocacy is provided by Victoria Legal Aid (<http://www.legalaid.vic.gov.au/>) and by the Independent Mental Health Advocacy (IMHA) service (<https://www.imha.vic.gov.au/>).

For more information, see the Resources Fact Sheet and online resources to hear people experiencing mental health challenges talk about supported decision-making (<http://research.healthtalkaustralia.org/supported-decision-making/how-to-increase-participation-in-decision-making>), along with families and other supporters' views (<http://research.healthtalkaustralia.org/carers/carers-and-supported-decision-making-mechanisms>).

Participants identified many opportunities and benefits in supported decision-making including the opportunity to empower people, to show them greater respect, and to expand their potential to have, and make, choices. For example:

I think the advance statements are a really great start ... because they allow the consumer to put down on paper their preferences and what they've learnt from their own experiences. I think it is absolute, or it should be absolutely mandatory for carers or whoever the primary support person is to be involved in the decision-making, if the consumer consents to that. (Family member)

2. Interpersonal strategies

Participants talked about the importance of connecting with the person and their values and working with the person's construction of the mental health issue, or what they think has happened to them. This relates to valuing listening and problem solving. Providing practical support, peer support and continuity of care are all valuable strategies for building trust and sometimes intensive support may be required to enable supported decision-making.

Peer support groups are the most well attended groups on the in-patient unit ... I think that people can relate to the person's experiences more and they can share their own experiences. And the peer support worker that we have ... offers information about ... things that he had to think about when he was writing his advance statement and things that he had to think about ... when he was ... choosing a nominated person. (Occupational Therapist)

Recommendations from the supported decision-making research project focus on the importance of developing relationships between staff and consumers and families and other supporters that are based on safety, trust, choice, collaboration and empowerment. Interpersonal strategies are particularly important in working with people who have experienced trauma. [21]

Supported decision-making aligns with commonly appreciated strategies for 'good practice' in person-centred approaches to mental health care including information sharing, collaboration, continuity of care, listening and problem solving and taking a 'strengths-based' approach. Supported decision-making also aligns with taking a personal recovery-oriented approach. [22]

According to families and other supporters, acknowledging the extensive information and expertise that families and other supporters have, contributes to better decision-making. Therefore, actively including families and other supporters in the information sharing process is preferred over just being informed about treatment decisions.

In research conducted by the supported decision-making research project, [6] mental health practitioners identified interpersonal strategies as important for embedding supported decision-making into practice. These

strategies are important to ensuring that people's views and preferences about their treatment and care are heard and respected.

Yeah, I spoke to a staff member from [mental health organisation] who was really good and helped me in what to say to the psychiatrist. Because even though you know I'm an articulate person and I've studied a university degree and worked in the public service, it's very hard to know what to say to the psychiatrist. (Consumer)

Early intervention is valuable in ensuring people are always encouraged to express their treatment preferences as well as providing education and understanding. This work needs a positive environment as well as skilled workers. Sensitivity to cultural and linguistic issues and being prepared to work with people and their families are other components of the interpersonal skills to enable supported decision-making.

3. Empowering people experiencing mental health challenges

People in contact with mental health services can feel that legal or administrative procedures take priority over care and good communication. [20] An accumulation of these experiences can result in feelings of disempowerment and hopelessness that undermines supported decision-making. [23]

Participants experiencing mental health challenges described how feeling empowered by their General Practitioner (GP) or mental health practitioner helped restore their confidence to make decisions. For example, on the website, Joseph has this to say about his GP:

He's been a fantastic advocate ... He's been really with me every step of the way ... He's been a really, really empowering part of the process in what otherwise could have been totally disempowering. (Consumer)

Psychiatrists and other practitioners also emphasised the value of practices and attitudes that communicated belief in the person's capacity to make decisions. [6]

It's around people ... being supported to be human and take chances, make choices, learn from them and be part of the community in that way. (Mental Health Service Manager)

Responsibility, choice and self-efficacy

Mental health practitioners acknowledged that many factors can undermine decision-making in people experiencing mental health challenges. [6] Helpful interventions include retaining a focus on the person's strengths, rather than on limiting factors, and tailoring interventions to be focused on enhancing capacity:

People experiencing the most severe illness, the most treatment resistant ongoing symptoms, difficulties in their day-to-day function, perhaps some cognitive difficulties as well, maybe substance abuse getting in the way of their understanding. All those things could come into play and - um - you might think, on the face of it, oh well, how can they participate in making complex, sophisticated decisions? But the point is: everyone can to some extent, you've just got to find and support the maximum extent that everyone can and that definitely takes skill, time, inclination, and a belief that it's possible. (Psychiatrist)

Other useful attitudes, skills and strategies for empowering people experiencing mental health challenges include:

- Encouraging empowerment and hope in order to challenge stigma and discrimination;
- Assisting people to gain access to internet-based information and tools that are credible and help to provide people with a range of information and resources;
- Providing opportunities for comparison of people's experiences and normalising people's experiences, especially through linking people with peer support; and
- Encouraging people to engage in self advocacy. This may require coaching so that people develop the confidence to express their own views, will and preferences.

4. Management and leadership

As a consultant, it's about leading it [supported decision-making], demonstrating it, modelling it, starting the work and laying out a plan for your team members. (Psychiatrist)

Participants in the supported decision-making research project were aware that it was important for senior leaders and managers in organisations to lead change and support and motivate staff to embed supported

decision-making into practice. Mental health services should promote the thorough implementation of supported decision-making through:

- Ensuring that all staff have the **supervision and support** they need to guide them through the change in practice, and build the **organisational culture** required by the shift to supported decision-making. This requires a greater focus on consumer responsibility, choice and self-efficacy in practice;
- Using the project's **Fact Sheets and websites** in regular **training and staff development** activities. Include supported decision-making training and professional development as part of mandatory requirements;
- Encouraging staff to engage in **reflective practice** using group or individual supervision and mentoring that will enable greater self-awareness and '**knowing yourself as a worker**'; and
- Acknowledging good practice through awards, newsletters and other forms of public acknowledgement. **This will recognise and support change and 'pockets of excellence'**.

Other strategies for embedding supported decision-making include:

- Education through a range of information sharing options, including social media and online;
- Ensuring that all staff have access to specific supported decision-making resources;
- Placing supported decision-making Fact Sheets and posters in prominent places in mental health services; and
- Appointing supported decision-making 'champions' and allocating time in their positions to locate and distribute supported decision-making information to other staff and demonstrate practice that facilitates supported decision-making.

Addressing obstacles to supported decision-making

While there was considerable agreement about the enablers for supported decision-making described above, participants were also aware of some significant challenges that need to be recognised, understood and acted upon in order to implement supported decision-making. Overarching themes include:

Risk and duty of care

The following explains the concerns many staff have regarding the ongoing pressure they may experience to manage risk even if these incidents are rare:

So it gets confusing ... I mean none of it, when we let somebody go out and they, if the mistake is, is not life threatening and not, you know, homicidal or suicidal ... we can get away with it sometimes, but the minute that there's a death ... what were they thinking? What were these people doing? (Mental Health Nurse)

Assisting staff to manage risk and respect the decision-making of people experiencing mental health challenges is important to supported decision-making. In her work on the “dignity of risk” and the “right to failure”, Patricia Deegan has suggested that it is necessary “to distinguish between a person making a dumb or self-defeating choice, and the person who is truly at risk”. [23] The law of negligence recognises that there are limits to the duty of care.

Courts have focused on the importance of autonomy and liberty in mental health care as defining principles when apportioning responsibility for adverse outcomes. [24] There is thus a difference between a duty of care in law and what some mental health practitioners may think of as a duty to care. [24] Ultimately, supported decision-making recognises that the person supported is at the centre of the decision-making process.

Stigma and discrimination

Addressing the underlying beliefs that people experiencing mental health challenges are unable to process the information required to make decisions is another overarching challenge. Leadership and training are key strategies to discouraging this and building a more respectful environment.

So we say it's about risk but I still think it's about prejudice and discrimination. That we think that people with low prevalence disorders for some reason can't cope with information. (Mental Health Nurse)

Features of the mental health system that prevent supported decision-making

Addressing those characteristics of the service that prevent supported decision-making in practice requires system transformation. This requires tailoring strategies to relevant location and service types to ensure that

changes are implemented. For example, services for older and younger people in the research project were both found to have particular challenges in respecting autonomy in decision-making. Strategies for engaging families and other supporters in enabling supported decision-making are particularly important in these services.

Services in rural areas may have particular difficulties in offering real choice to people so that their preferences for treatment can be respected. This may require greater attention to options such as gaining access to online resources. Related to the issue of choice is the degree to which services offer psychosocial interventions that may provide a greater range of treatment and support options.

Continuity of care, flexibility and personalisation in service delivery are likely to be essential elements in practice that facilitates supported decision-making. It is important that supported decision-making is not sidelined as soon as there is a crisis or that only continuing care parts of the service adopt supported decision-making.

We're not educating people yet ... So you've got, you know, somebody who's - um - who's got a severe mental illness; they're at home all day, you know, they've - no social supports. Services turn up at six o'clock on the dot to, to give them their medication. How do people know about that? [option of having medication later] Because really we'd - our service would have to be the one informing them about it and if we don't see it's an issue how are they going to know about it? (Mental Health Nurse)

Conclusion

These Guidelines were developed by the supported decision-making project research team following interviews with ninety people experiencing mental health challenges, families and other supporters and mental health practitioners, including psychiatrists.

These Guidelines are linked to the Fact Sheets, report and online resources at <http://research.healthtalkaustralia.org/supported-decision-making/overview>.

The project identified four enablers of supported decision-making:

1. Legal and rights-based mechanisms, including advance statements, nominated persons, second opinions and advocacy services;
2. Interpersonal strategies, including communication skills;
3. Empowering consumers, including through encouraging choice and self-efficacy; and
4. Management and leadership, including through staff support and development and recognising good practice.

Challenges that may prevent supported decision-making include emphasising risk prevention at the expense of supported decision-making, stigma and discrimination and the need for system transformation.

The move toward a personal recovery and human rights focus in the mental health sector has contributed to policies and laws aimed at ensuring people experiencing mental health challenges, some of whom may receive compulsory treatment, have their voices heard. Ultimately, supported decision-making aligns with personal recovery principles and practices that focus on self-determination. In addition, in ratifying the Convention on the Rights of Persons with Disabilities, Australia has agreed to ensuring people experiencing mental health challenges are supported to exercise their legal capacity. This includes being supported to make decisions about their treatment and care.

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