Supported Decision-Making for Persons with Mental Illness: A Review

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ABSTRACT

Persons with mental illness (PWMI) are often not afforded the same opportunity to make decisions on a par with others in society. Article 12 of the International Convention on the Rights of Persons with Disabilities (CRPD) states that persons with disabilities should have equal recognition before the law and the right to exercise their legal capacity. Exercising legal capacity can mean making decisions about employment, medical or psychosocial treatment, property, finances, family, and participation in community activities. The aim of this paper is to comprehensively review the evidence on supported decision making for PWMI, both in legislation and research globally, with a focus on low- and middle-income countries (LMICs). Results reveal only a few countries have provisions for supported decision-making for PWMI, with a particular shortage of such provisions in legislation in LMICs There is also a general paucity of research evidence for supported decision-making, with the majority of research focusing on shared decision-making for treatment decisions. This review highlights the need for additional research in this area to better guide models, which can be utilised in domestic legislation, particularly in LMICs, to better implement the ideals of Article 12 of the CRPD.

Key Words: Supported decision-making, mental illness, human rights, CRPD, legal capacity

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INTRODUCTION

Making decisions is central to a person's autonomy and the essence of what is regarded as personhood, and is a crucial component in enabling an individual to have control over their life and engage with society.[1] Without the ability to make decisions for ourselves, we are seen as non-persons before the law and our actions and decisions no longer have any legal force.[1] In such circumstances, third parties often make decisions on behalf of persons who are deemed to lack legal capacity and guardianship is often appointed, either informally (i.e., a relative) or formally (i.e., court appointed representative). People with disabilities are thus at risk of being stripped of their decision-making abilities and rights to self-determination by having others take on the authority to make decisions for them.[2,3] In particular, the presence of a mental illness is often equated with a lack of decision-making capacity.[2,4-6] Society has historically restricted choice to persons with mental illness (PWMI) due to an assumption of incapacity.[7] As a result, institutions "took care" of many choices for PWMI, removing autonomy, responsibility, and self direction.[7,8] For PWMI, having a substitute decision-making or guardianship system in place can abolish rights to self-determination and take away the opportunity to enter into transactions or contracts autonomously.

The Convention on the Rights of Persons with Disabilities (CRPD) came into force in 2008 and has created an impetus for change in disability laws (including mental health laws). The CRPD demands a paradigm shift in the disability sphere, moving from a substitute decision-making model to a supported decision-making model.[4-6,9-14] Article 12 has been called the core of the CRPD and states that all persons with disabilities (PWD) should have equal recognition before the law.[14-16] It declares that PWD should have both the recognition of their rights, legal capacity and the right to exercise this legal capacity.[6,17,18] In practical terms, exercising legal capacity means making decisions for oneself in all areas of life including medical treatment, housing, employment, relationships, finances, children, family planning, and property. The CRPD recognizes that there are times when PWD may require support in making decisions and that depending on the course of the disability or illness, varying levels of support may be needed.[6,18] Accessing support, regardless of its form, is central to the recognition of being equal and full citizens before the law.[3] Countries are expected to take measures to support PWD to exercise their legal capacity, which are tailor-made to the person's circumstances and preferences; apply for the shortest amount of time possible; provide safeguards to prevent abuse; and are regularly reviewed by a legal authority.[19]

In most countries, mental health legislation does not include provisions for PWMI to exercise legal capacity. A number of laws still adopt a paternalistic approach with the stated purpose of protecting the individual and society from harm.[5,20] This protection has been linked to the historical view that PWMI are dangerous to others[21] or violent,[22] leading the state to adopt a protective role. Early laws concerned with mental health were often penalizing and concerned with taking the individual away from society,[21] frequently prescribing institutionalised treatment and guardianship as the solution and as a means of protection.[5,6] Fortunately, mental health reform in a number of countries has led to new mental health legislation that better promotes treatment in the community and inclusion of PWMI in society. Despite mental health reform, however, guardianship and substituted decision-making systems are still the prevailing norm in many countries and jurisdictions for PWMI.

Terminology used to describe decision-making capacity as it relates to mental illness differs substantially across jurisdictions, countries and even between disciplines of law and health. Decisions can be made in a number of ways in both law and health. Decisions can be made autonomously or by electing powers of attorney or writing advance directives, or by having court-appointed mentors or legal representatives or by having other supports (e.g., information aids, decision aids, peer support) or by having a *substitute decision-maker*. For the purposes of this review, we consider *guardianship* as a form of *substituted decision-making* where a decision maker is appointed to make decisions on behalf of a person believed to lack mental capacity.6 Guardianship can vary in its levels of decision-making power; for example, guardianship can be limited, partial or full (also known as plenary). While limited and partial guardianship are not ideal for realising legal capacity and autonomy, they allow an individual to retain some decision-making abilities in other areas of life, thus these levels of guardianship are preferred over full guardianship.[6]

The concepts of mental and legal capacity differ and hold different meanings. *Legal capacity* can be viewed as a person's capacity to have rights and exercise these rights without discrimination.[3,15,23] In contrast, *mental capacity* can be seen as the ability to understand incoming information, considering the harms and benefits of making or abstaining from a decision, and the ability to communicate the decision to others.[23,24] The correlation between the two definitions is that the cognitive requirements for mental capacity are also needed to exercise legal capacity.[23] Frequently, health or law professionals decide on both legal and mental capacity and it is often established prior to involvement from the legal system.[24] However, even an individual unable to go through this decision-making process should

still have the right to retain full legal capacity, instead accessing support where necessary to be able to reach the same decision autonomously.[23]

Research on decision-making for PWMI has been largely restricted to the medical domain, focusing primarily on treatment decisions. There is limited research outside this sphere, which test or evaluate supported decision-making models and assess legal outcomes as related to mental illness. Research has predominantly focused on *shared decision-making*. Shared decision-making has not been precisely defined in the literature,[25,26] although it has been extensively researched[27-34] (for review see[26,34-41]). In an attempt to clarify the concept of shared decision-making, Makoul and colleagues[42] posited that for a decision to be shared, it must involve at least two participants, have shared information and the decision must be made and agreed upon by all parties. Montori and colleagues[43] subsequently added to this conceptual definition of shared decision-making by stating (specific to decision making in health care) that a decision is only shared if there is an ongoing partnership and collaboration between the health care worker and patient. Adams and colleagues[44] emphasise the patient participation angle of shared decision-making, highlighting that patients should have accessible information, enabling them to participate in an active and meaningful way.

Shared decision-making enables an individual to exercise partial autonomy over decisions and has been positioned as an intermediate option between paternalistic models and informed choice models[35] and has been associated with improvements in patient satisfaction, treatment adherence, and improved health outcomes (e.g., reduction of severity of symptoms).[34,45-48] Conversely, *supported decision-making* is broader, and can consist of organisations, networks, provisions or agreements with the aim of supporting and assisting an individual with a mental illness to make and communicate decisions.[6,23] In supported decision-making, the individual is always the primary decision maker, but it is acknowledged that autonomy can be communicated in a number of ways, thus provision of support in different forms and intervals can assist in the expression of autonomous decisions. Supported decision-making enables the individual to retain legal capacity regardless of the level of support needed.[3] Forms of supported decision-making can therefore include advance directives, enduring powers of attorney, health care proxies, arrangements for financial decisions (e.g., payee regimes, banking systems), nominated representatives, and/or personal ombudsmen. These forms of support are more formal and offer less autonomy to PWMI on the support spectrum than less formal forms of support.[6] Less formal but equally important forms of support can consist of support networks of family and friends and peer support.

Research has extensively focused on *advance directives* which are defined as a supportive tool that specify a person's wishes and preferences for treatment decisions for the future when he or she loses decision-making capacity.[49-51] In advance directives, the wishes of the client are expressed and based only on circumstances wherein the client loses decision-making capacity.[49,51] Advance directives, while a valid support tool and a form of supported decision-making, offer less autonomy and can transition into a form of substituted decision-making depending on the authority of the other person involved in the decision-making process. Furthermore, these tools are often not offered to persons with severe mental illness as they are seen by professionals to lack capacity.[3]

Despite the CRPD's exhortation for supported decision-making, there has been resistance, primarily due to the assumption that PWMI are unable to make the right decision and are not aware of their best interests. This is based on the "outcomes" approach to legal capacity, which infers one's capacity from the outcomes of decisions they make. This means that there are "right" and "wrong" decisions, and someone only has capacity if they can demonstrate that they can make "right" or reasonable decisions.[2] The bias in this approach lies in the fact that it assumes PWMI must make "right" and reasonable decisions to be considered to have capacity, and it does not afford PWMI the right to make mistakes or wrong decisions (and to subsequently learn from experience) like others in society.[2] Furthermore, persons without disabilities also solicit advice from family and professionals prior to making a decision—particularly health care decisions. In this sense, the concept of supported decision-making for people with disabilities only re-emphasises the norm of seeking advice and input when making an important decision.

As no countries have fully implemented Article 12 of the CRPD,[1,52] there is a need to review what progress has been made to date, particularly in low- and middle-income countries (LMICs) where constrained resources required to shift legal and social sectors to a model of supported decision-making may be problematic. Reviewing the evidence and legislation will assist in guiding the research findings, delineate crucial areas for future research, and draw on the efficacy of support aids for PWMI within legislative frameworks to make the "paradigm shift" of the CRPD a reality in practice. Therefore, the aim of this paper is to review the literature on supported decision-making processes in light of Article 12 of the CRPD, examine best practices in supported decision-making internationally and point towards how components of supported decision-making can be implemented.

METHODS

Study selection

As this review focuses on supported decision-making as it relates to mental illness and legal capacity, we review shared decision-making only briefly and synthesise the evidence in a way that might inform supported decision-making models. Studies in decision-making are not always conducted as randomized controlled trials (RCTs), and restricting inclusion to a particular study design could substantially limit relevant data included in the evidence base. We therefore included RCTs, quasi-experimental studies, and qualitative studies. We also included grey literature (policy documents, legislation, unpublished presentations, reports) for the portion of the review identifying legislation for supported decision-making. We included all studies as long as at least 50 percent of the sample population had a mental illness and the intervention or research aim focused on decision-making for this population. We excluded studies if they focused on support tools which were not fully defined to be "supportive" (i.e., advance directives, nominated representatives, powers of attorney, health care proxies); populations with mental retardation, intellectual disabilities, Alzheimer's, dementia or cognitive impairment, or focused on patients with health conditions other than mental health problems. There were no language restrictions for this review. Outcomes of interest for this review included patient satisfaction, health care outcomes (e.g., hospitalization rates post-intervention, severity of symptoms, medication adherence), effective supported decision-making models, legislation including provisions on supported decision-making (for grey literature). Relevant settings for the review of the research literature were community, primary, secondary, tertiary health care and social care settings (including inpatient psychiatric facilities).

Search Strategy

In order to maximize the number of possible retrieved studies from the searches, we conducted searches incorporating a number of terms related to decision-making for PWMI. All search terms were combined with AND "mental health" OR "mental illness". We conducted the search using the following terms: "assisted decision-making," "shared decision-making", "facilitated decision-making" and "supported decision-making." We broadened these search terms as we recognized that searching only for shared decision-making would focus primarily on medical treatment decisions, and although relevant, we wanted to additionally include articles focusing

on other circumstances beyond medical decisions. For the legislative component of the review, we reviewed laws from any country regardless of its income level, as long as it incorporated provisions for supported decision-making for PWMI or included alternatives to guardianship and substituted decision-making systems. We searched in the following databases: PubMed, MEDLINE, PsycINFO, and Cochrane Library. References were searched from 1950 up until 2012. We also searched through reference lists of included studies to identify any additional references for potential inclusion that our searches might have missed. These additional references were searched in Google Scholar.

Data collection

From each study, we extracted the study design, setting, participant information, interventions (where appropriate), results, and limitations of the study. Both authors looked through the reference lists of included studies to identify any additional references that may have been missed by the searches. If relevant for inclusion, we obtained the abstract from the reference, and if relevant, obtained the full-text of the reference for review.

Results

Our initial search yielded 8,041 references in total. Of these, we assessed those based on titles and abstracts, which yielded 511 potentially relevant studies, of which we obtained the full-text. After applying our inclusion criteria, we included 26 studies (13 studies for the research review and 12 for the legislation review). From the reference lists of the included studies, we identified an additional 134 potentially relevant studies, of which 30 were included in both the legislative and research review. A flow chart of the sifting strategy is shown in Figure 1. Common reasons for exclusion of studies include: the intervention was beyond the scope of this review (e.g., end-of life decision-making interventions, decision-making interventions aimed at physical health problems like diabetes or cancer); topic of paper focused on legislation outside of decision-making and legal capacity (e.g., on treatment orders or discharge from treatment); the population of focus in the paper was beyond the scope of this review (e.g., focused on patients with Alzheimer's or dementia or mental retardation). In total, we reviewed 25 research studies and 30 papers providing information on legislation in 16 countries.

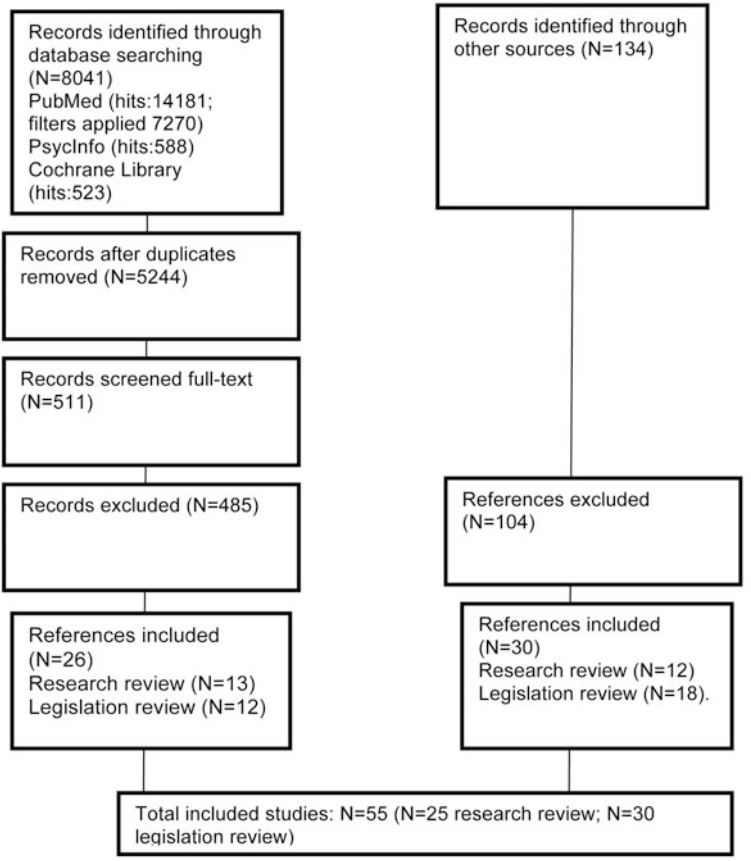

Fig. 1. Flow chart of study selection.

LEGISLATION REVIEW

A number of countries, all upper middle- or high-income, include provisions for supported decision-making in national legislation (see Table 1). One result emerging is that advocacy services and/or community organisations (e.g., the Canadian Association for Community Living) are influential in assisting PWMI in arranging supported decision-making agreements. In the United States, there is strong support for psychiatric advance directives (PADs) to PWMI in 25 states, however our search did not identify any state legislation referring to supported decision-making beyond provisions for PADs. In Canada, five provinces (British Columbia, Yukon Territories,

Table 1

Supported decision-making legislation internationally

Country/Region [Income Level]	Provisions/Progress towards Supported Decision-Making	Associated legislation
Austria [HIC][92,93]	• Guardians appointed either for one reason (e.g., financial management) or several fields (limited guardianship) or all fields (full guardianship). • Review of guardianship regime: every 5 years, revoking guardianship is possible if no longer needed (e.g., health status improves), otherwise guardianship duration is infinite. • Family friends most likely appointed as guardians. • In absence of social network, NGOs lawyers, notaries or social workers can be appointed. • An enduring power of attorney (POA) removes the need for guardianship when there is a lack of capacity. • Forms of support offered: Life planning supports; independent advocacy; communication and interpretation support; representatives; relationship-building supports (groups and networks).	Austrian Civil Law; Austrian Guardianship Law
Australia [HIC][53,94-99]	• Legislation varies by state and territories. • Usually limited guardianship, plenary guardianship offered, but rare. • Presence of mental illness associated with whole or partial incapacity for managing personal affairs/making decisions. • Guardianship orders usually time limited (3-5 years) and review possible. • Guardians: make least restrictive decisions on behalf of client and in best interests. • Victoria's Draft Exposure Bill: supported decision-making model and enables compulsory patients to make own decisions about mental health treatment/care. Assumes that PWMI have capacity to make decisions unless determined otherwise. Introduces statutory mechanisms to support people to participate in decisions about treatment/care, and makes provisions for nominated person scheme, and substituted decision-making is a last resort. • New South Wales (NSW) considering amendments to legal capacity legislation. NSW has no formalized support arrangements but may transfer ideas from financial decision-making capacities with trustee and financial manager to other areas. NSW submitted a proposal to conduct a research trial on supported decision-making. • South Australia: Completed phase 1 of research trial on supported decision-making; considering amending legislation to facilitate supported decision-making.	Victoria's Mental Health Act;

Table 1 Contd.

Country/Region [Income Level]	Provisions/Progress towards Supported Decision-Making	Associated legislation
Canada [HIC][3,6,57,100-104]		
Alberta	• Supported decision-making offered to mild disabilities; for more significant impairment: co-decision makers, guardians, or trustees. • Co-decision makers (court-appointed) collaborate together with the individual. The individual still can make decisions but with support (retains legal capacity). • Guardians (court-appointed) take legal responsibility on behalf of the individual who lacks capacity. • Trustees make financial decisions for the individual who lacks capacity. • Co-decision makers, supported decision makers, and specific decision makers cannot make mental health treatment decisions for formal patients or patients who have a community treatment order if they lack mental capacity. • A health care provider can choose a relative to make decisions based on a ranked list if no guardian or advance directive is available for treatment decisions. • Tools available for support are advance directives, enduring POA's, and supported decision authorizations.	Guardianship and Trustee-ship Act & Personal Directives Act
British Columbia	• Representation agreements (RA's) cover personal, health and financial affairs. • A representative (usually multiple representatives to cover different areas, and with an external monitor to ensure representatives are fulfilling duties as a safeguard to protect from abuse) helps the individual to make their own decisions, and/or makes substituted decisions. There must be a clear desire for a representative agreement and a trusting relationship between the individual and representative(s). • The individual must have capacity to make a RA (depending on whether it is section 7 or 9 agreement). RA's can be amended and revoked; thus less restrictive than guardianship. • RA's involve elements of supported and substituted decision-making and presume everybody has capacity until proven otherwise. • RA's enable the individual to remain in control and retain decision-making rights.	Representation Agreement Adult Guardianship and Planning Statutes Amendment Act, 2007

Table 1 Contd.

Country/Region [Income Level]	Provisions/Progress towards Supported Decision-Making	Associated legislation
Manitoba	• Acknowledges support networks, exercising decision-making rights, implements safeguards to prevent abuse and neglect and keeps substituted decision-making as a last resort. Only available for persons with intellectual disabilities, not for PWMI.	Vulnerable Persons Living with a Mental Disability Act
Quebec	• Curators and tutors (court-appointed) available for PWMI. Curator assignment implies that incapacity of the individual is total and permanent and tutorship implies incapacity is temporary. • Advisorship is also available and is least intrusive, pertains to administration of the individuals' property; decision-making power is retained in all other aspects of life. Advisors are imposed on the individual, so the person is unable to refuse support. • Support tools (mandates) such as advance directives are also available.	Civil Code of Quebec
Saskatchewan	• Hybrid between supported and substituted decision-making. • Guardians: court ordered, courts choose who guardian will be, supports imposed by order (rather than by choice). • Co-decision makers: available to assist in making decisions jointly with the individual. • Temporary guardians are also available for emergency situations. • Decision-making orders can be assigned for areas of life that an individual has particular difficulty in reaching decisions in (so capacity is intact to make autonomous decisions in other aspects of life). • Individuals can also refuse support, as long as they have the capacity to communicate that decision.	Adult Guardianship and Co-decision-making Act
Yukon Territories	• Full spectrum of varying support options (supported decision-making agreements, representation agreements, substituted decision-making for health care decisions, guardianship) based on needs of the individual. • Supported decision-making agreements possible if person has capacity at time of requesting agreement. If the client loses capacity, the agreement is terminated. • The supported decision-making agreement involves the consent and formalization of two (or more) adults to enter into a support relationship.	Adult Decision Making and Protection Act (Yukon)

Table 1 Contd.

Country/Region [Income Level]	Provisions/Progress towards Supported Decision-Making	Associated legislation
Colombia [LMIC][105]	• Efforts to make changes to Law 1306, which defines legal capacity by clinical diagnosis. Colombia has instituted a multidisciplinary advocacy group (La Mesa) bringing together stakeholders (universities, CSOs, lawyers, Ministry of Social Welfare and National Council on Disability) to lobby for legal reform recognising legal capacity for PWMI and PWD.	None yet; but reform of Law 1306
Czech Republic [HIC][54]	• New law introduces supported decision-making as an alternative to guardianship, recognises legal capacity, implemented safeguards to prevent abuse. • Restriction of legal capacity as last resort. • Support mechanisms such as representatives and advance directives available.	Czech Civil Code
Denmark [HIC][106,107]	• Guardians/representatives do not imply loss of legal capacity; belief that person with limited legal capacity should retain as much of their right to exercise legal capacity as possible. • Guardianship can only be used under legal circumstances (contractual agreements and financial decisions). • Other decisions (accommodation, participation and personal affairs) administered and supported by advocates/assistants who support the client rather than act as guardians.	Guardianship Act
England and Wales [HIC][106,108,109]	• The MCA (2005) is centralised around the individual and their decision-making process; supports involvement of the individual and their social network in decisions. • Everybody has capacity until determined otherwise; incapacity in one area means still retaining decision-making abilities in other areas. • Capacity assessments conducted on a decision-specific basis rather than globally applied to all decisions. • If guardians assigned, must take best interests approach, and are reviewed/supervised by the Office of the Public Guardian. • Support places emphasis on family, friends and professionals coupled with legislation safeguards (rather than on court-appointed support). • If no support from social network, independent mental capacity advocates (working for CSO's) can offer support for decision-making.	Mental Capacity Act (2005)

Table 1 Contd.

Country/Region [Income Level]	Provisions/Progress towards Supported Decision-Making	Associated legislation
Germany [HIC][92]	• No plenary guardianship and strong focus on supported decision-making. Limited guardianship (temporary orders up to 6 months, maximum orders 7 years) can be granted for court-specified duties (i.e., for financial affairs) but an individual retains full legal capacity.	German Guardianship Law; German Civil Code
Hungary [HIC][55,56,92]	• Planned reform for Civil Code in 2010, Hungarian Constitutional Court has blocked the reform from being enforced. • Reform was to shift from plenary guardianship to join decision-making arrangements between client and guardian. • Anticipated that these reforms will be re-considered after active lobbying. • Current system: plenary guardianship, limited options for reviewing or revoking a guardianship regime.	Hungarian Civil Code
India [LMIC][110]	• New draft bill acknowledges legal capacity and capacity to make mental health treatment or care decisions. A number of tools can be provided if a person is unable to make a decision autonomously (advance directives and nominated representatives).	Mental Health Care Bill 2012
Netherlands [HIC][106,107,111]	• Mentors and protective trusts. • Protective trusts: only financial decisions, so legal capacity is retained in all other areas. • Mentors: limited to nonfinancial interests pertaining to care and treatment guidance. Mentors advise, update, and regularly inform clients of actions taken in all non-financial matters. • For medical care, automatic decision-making given to the partner or close relative when the individual is incapacitated. • Advocacy services available to assist with supported decision-making. An advocacy representative can offer support (via information provision, representation, etc.) to help the individual express own views. • For admission to a psychiatric hospital, obligatory for the treatment plan to be drawn up collaboratively between the patient and clinician, and if the patient lacks capacity at that time, the person drawing up the agreement must discuss the treatment and hospitalisation plan with either a legal representative, a named representative, a spouse, or relative.	Netherlands Civil Code; Medical Treatment Act (WGBO)

Table 1 Contd.

Country/Region [Income Level]	Provisions/Progress towards Supported Decision-Making	Associated legislation
Norway [HIC][106,107]	• Advocates support adults with decision-making (particularly financial affairs) so legal capacity is not lost. • Legislation provides 2 levels of decision-making interventions: Assistance representative or support person. • Assistance representative only compromises legal capacity when necessary and their decisions prevail over the individuals only in extenuating circumstances. • Support person assists with helping client to express interests/wishes.	
New Zealand [HIC][92]	• Welfare guardians (usually a family member) appointed to make or communicate decisions around personal care and welfare (if this is the only option available for the client). • Temporary orders can be made for 3-6 months, longer orders up to 3 years. • Welfare guardians should: promote best interests and welfare of the individual, encourage exercising legal capacity for the individual to make autonomous decisions, encourage individual to act on own behalf to furthest extent possible (and consult with the individual as much as possible), and assist in community integration of the individual.	The Protection of Personal and Property Rights Act 1988
Scotland [HIC][2,5,92,97]	• Scotland's system provides free access to independent advocacy (obligated responsibility of each Health Service/Board). • Less legal approach to determining decision-making capacity; acknowledges times where decision-making capacity is retained and other times where it may be compromised due to a mental illness. • There can be no personal appointment to position of guardian (only a POA). Having a POA in place for a PWMI removes the need for guardianship. • A "named" person can be nominated by the client to attend hearings and provide information for the client. PWMI have access to advance directives, particularly in treatment decisions. If a PWMI cannot consent to treatment or refuses to, a clinician is obligated to consider (and record in writing) the reason for not consenting; the views of the involuntary patient and a nominated person together with any advanced statement; and how efficacious the treatment is.	Mental Health (Care and Treatment Act) 2003; Adults with Incapacity (Scotland) Act 2000

Table 1 Contd.

Country/Region [Income Level]	Provisions/Progress towards Supported Decision-Making	Associated legislation
Sweden [HIC][5,52,92,107,111,112]	• No plenary guardianship but a partial guardianship as last resort. Instead, have a system of support for PWD and PWMI. • Two options: mentor or "god man" (court appointed; usually consisting of family members or community members, who acts with consent of the individual) or trustee "forvaltare" (more similar to guardians, has authority in designated matters over the incapacitated individual). • Trustee can make decisions in financial/personal welfare areas, and must approach decisions using the best interests principle. Trusteeship still incorporates elements of full guardianship and does not fully emphasize individual rights/preferences. • Personal ombudsmen (PO) for PWMI available: accessible (anyone can request PO); supports the client in personal, financial and legal affairs, no alliance with social services, authorities or carers, trained in developing rapport.	Swedish Law/ Parental Code
Switzerland [HIC][92,113,114]	• Federal Council tends to amend Swiss Civil code support the right to choose and acknowledge legal capacity via introduction of advance directives and developing/tailoring a support package for a person who lacks capacity. The authorities tailoring the support package will conduct a needs assessment for the person concerned, to identify tasks/roles needing to be completed by official assistance.	Swiss Civil Code reform
United States [HIC][115,116]	• 25 states offer provisions in legislation for psychiatric advance directives (PAD's) • States without legislation for PADs often have provisions for advance care planning for mental health care via the Health Care Power of Attorney (HCPA) statutes.	HCPA Statutes, state specific PAD statutes

Alberta, Saskatchewan, Quebec and Manitoba) have legislation providing for varying forms of supported decision-making.[6] Canada and Australia, although having signed and ratified the CRPD and having provisions for varying forms of support for exercising legal capacity, have both entered a reservation on Article 12 of the CPRD, interpreting compulsory treatment and fully-supported or substituted decision-making as permissible under the CRPD, but only as a last resort.[53] Scotland's progressive Mental Health Act and the United Kingdom's Mental Capacity Act have both developed a Code of Practice to assist service users and carers on interpreting these Acts, which is particularly useful when it comes to outlining decision-making capabilities.[2,5] In 2012, The Czech Republic enacted a new civil code introducing supported decision-making and stating that restrictions of legal capacity are a last resort.[6,54] Germany has also made use of supported decision-making agreements in various forms for PWMI.[6] The introduction of a "friend" or "mentor" appointed by the court has become common in a number of European countries, such as Germany, Finland, Sweden and Austria. Friends/mentors are appointed to an individual after a capacity assessment finds the individual to lack capacity. The friend/mentor has authority to make substitute decisions, is expected to elicit the preferences of the client, and can also allow for the individual to make autonomous decisions in certain areas of life.[52]This arrangement has been viewed as a middle ground between autonomous and substituted decision-making.[3]

ON THE WAY TO REFORM

Advocacy measures to implement Article 12 of the CRPD are strong, though legal reform has yet to take place.[52] Guardianship law reform is occurring in the Czech Republic, Hungary, France, Ireland, Portugal, Slovakia and Slovenia. Several South American countries like Colombia also offer either plenary guardianship or assistance to make decisions, where the individuals' decision is taken into account along with a third party. The Hungarian Government, after plans in 2009 to abolish plenary guardianship and offer supported decision-making as an alternative, declined to enact the new reforms in 2010.[55,56] Norway and Germany have mixed systems, offering both support and substitution decision-making.[57] Sweden has abolished plenary guardianship and offers a system of support services in favour of the support paradigm ranging from mentors to trustees allocated to support PWD. Mentors can be family members, members of the community or professionals who act only with consent of the person receiving support. Trustees, however, are similar to guardians but the individual retains the right to vote.[52,58]

RESEARCH REVIEW

Supported decision-making in high-income countries (HICs)

Few studies have assessed supported decision-making beyond treatment decisions, such as how supported decision-making impacts legal capacity and other life decisions. One study looked at having choice about housing and receiving support to autonomously decide about housing in the community. Srebnik et al. found that perceived autonomy to decide about housing had a substantial impact on psychological well-being.[8] Other authors have discussed financial capacity in persons with schizophrenia, recommending the use of advance directives to outline preferences and processes with regards to financial matters during periods of both capacity and incapacity.[59] Another study in Australia[60] looked at the impact of supported decision-making. Results revealed that out of 22 adults, eight (36%) wanted to receive support in several areas of their life (e.g., choosing services, housing, medical procedures). Social exclusion was identified as a barrier to supported decision-making, as three of 22 participants had nobody they could nominate in their life as a supporter, though they were keen to have support.[60,61] Participants believed that an advocate or multidisciplinary team would be best to provide support for mental health care decisions, a solicitor for legal decisions, and a friend or relative for day-to-day matters. Another study conducted by Amnesty International in Ireland[62,63] revealed that after interviewing eight clients, all were unanimously in favour of writing advance directives and expressed strong ideas in favour of supported-decision making. Participants acknowledged that emotional distress can impact decision-making capacity, and capacity can be further reduced by social and environmental factors, such as lack of available treatment options, lack of trust in an information provider, and inaccessible information. The participants also articulated that incapacity as it relates to mental illness is a partial rather than a total phenomenon. They stressed that assessments of capacity need to take into account how much the individual at that particular time is able to contribute to their own decision-making rather than making assumptions that they are incapable due to mental illness or relying on past episodes to infer current capacity. The findings from Australia and Ireland highlight the need for a strengths-based approach in accord with a social model of disability to build up the decision-making confidence of the individual.

Shared decision making in mental health care

While a number of reviews have assessed shared decision-making we chose to review primary studies and not conduct a review of reviews. Despite the extensive research on shared decision-making, we were unable to identify any studies focusing on shared decision-making interventions in LMICs; therefore our review is limited to studies conducted in HICs (Table 2).

Shared decision-making interventions have shown mixed results. Some authors have found that shared decision-making interventions had some impact on reducing the severity of substance-related and/or psychiatric problems but did not impact quality of life.[64,65] Another study found shared decision-making to have a significant impact for clients with a mental illness even when deciding on secondary decisions like lifestyle behaviours.[66] Mahone (2008) found that participation in shared decision-making was associated with better medication adherence rates,[65,67] while a recent study found that a computerized shared decision-making tool had no impact on medication adherence in community outpatient settings.[68]

Preferences in decision-making

Common across the majority of the studies is the finding that PWMI have a higher desire for treatment decision-making than other groups within general medicine.[39,69-71] In addition, participants in a number of studies declared that they had a clear desire for greater participation in decision regarding their psychiatric care compared to the current care they were receiving.[39,65,67,70] To illustrate, in one study, 82 percent of participants preferred a collaborative relationship with their health care provider, however only 70 percent experienced this collaboration.[65] Interestingly, participants articulated a clear idea of how and when to prioritise autonomy in decision-making and when to consult or defer the decision to health care professionals. One study[72] interviewed participants who endorsed a two-step process of decision-making; first prioritising autonomy and if autonomy was not possible, case managers were consulted to help make a decision.. The desired autonomy for decision-making varied by type of decision: for example, with medication choices, 77 percent prefer either autonomous or shared roles regarding their choices.[44] Preferences for decision-making also vary when it comes to who patients prefer to make health care decisions for them. Participants in one study[70] wished for collaborative decision-making with health care professionals for medication decisions, autonomous decision-making for psychosocial treatment and a passive role in decision-making with their general health care providers.

Table 2.

Supported and shared decision-making included study characteristics

Study ID/Country/Setting	Characteristics
Amnesty International, 2009[62] McDaid and Delaney, 2011[63] **Country**: Ireland **Setting**: Public locations	**N=8** clients with direct experience of mental health in Ireland **Method**: Qualitative; semi-structured interview **Sampling**: Snowballing
Campbell et al., 2007[75] **Country**: UK **Setting**: Home-based	**N=16** **Method**: Qualitative interviews **Sampling**: Purposive
Deegan, 2010[86] **Country**: US	**Method**: Intervention design/description
Hamann et al., 2007[83] **Country**: Germany **Setting**: Inpatients	**N=107** **Method**: Cluster RCT pilot study **Intervention**: Decision making intervention (decision aid, planning consultation) vs. usual care
Hamann et al., 2011[67] **Country**: Germany **Setting**: Inpatients	**N=61**; Shared decision-making training (N=32) or cognitive training (N=29) **Method**: RCT **Interventions**: Shared decision-making training (intervention) or cognitive training (control)
Hamera et al., 2010[66] **Country**: US **Setting**: Outpatient clinics	**N=98** **Method**: Secondary analysis of 98 audiotaped interviews (between practitioners and patients) **Intervention**: Computer program in a decision support centre run by peers.

Table 2 Contd.

Study ID/Country/Setting	Characteristics
Jonikas et al., 2011[85] **Country**: US **Setting**: Public outpatient/peer support community services	**N=555** adults (N=276 in experimental, N=270 in control) **Method**: RCT **Intervention**: 8 (2.5 hrs each) sessions delivered peer-instructors in recovery in groups of participants vs. control (wait list + usual care)
Joosten et al., 2009[64] **Country**: Netherlands **Setting**: In/outpatient addiction centres	**N=220** **Method**: Randomized quasi experimental (non-blinded) **Intervention**: Shared decision-making, brief intervention added to inpatient treatment vs. treatment as usual
Kumar et al., 2012[87] **Country**: India **Setting**: Urban outpatient	**N=122** patients; cross-sectional writing advance directives **Method**: Cross-sectional pilot study (observational)
Lester et al., 2006[77] **Country**: UK **Setting**: Primary care	**N=18** focus groups (N=45 patients, N=39 general practitioners, N=8 practice nurses in 6 primary care trusts) **Method**: Qualitative focus groups **Sampling**: Convenience
Loh et al., 2006[82] **Country**: Germany **Setting**: Primary Care	**N=20** **Method**: Observational (audiotape recordings of consultations) **Sampling**: Convenience
Loh et al., 2007[78] **Country**: Germany **Setting**: Primary care	**N=405** clients (N=263 intervention; N=142 control); N=30 physicians (N=20 intervention physicians, N=10 control physicians) **Method**: Cluster RCT **Comparison**: Physician training and patient centred-decision aid vs. treatment as usual

Table 2 Contd.

Study ID/Country/Setting	Characteristics
Mahone, 2008[65] **Country**: US **Setting**: Community MH centres	**N=84** with serious mental illness **Method**: Cross sectional correlational study **Sampling**: Convenience
Mahone et al., 2011[76] **Country**: US **Setting**: Public outpatient MH	**N=7** focus groups (consumers, family members, prescribers, MH clinicians & rural providers); **N=44** participants in 7 focus groups **Method**: Qualitative focus group
McMullen, 2012[80] **Country**: Canada **Setting**: Primary care	**N=11** physicians **Method**: Qualitative in-depth interviews **Sampling**: Convenience sample
O'Neal et al., 2008[70] **Country**: US **Setting**: Outpatient; residential facility	**N=65** (N=33 older adults over 50 (OD); N=32 younger adults (YD) **Method**: Cross-sectional pilot study (observational) **Sampling**: Convenience
Office of the Public Advocate, 2010[60,61] **Country**: Australia **Setting**: Community	**N=22** referred to project, 8 had signed agreements **Method**: Evaluation study to test applicability of supported decision-making **Intervention/Project**: Supported decision-making for PWMI
Patel and Bakken, 2010[71] **Country**: US **Setting**: Outpatient	**N=60** **Method**: Survey **Sampling**: Convenience
Simon et al., 2006[74] **Country**: Germany **Setting**: Inpatient, outpatient, self-help	**N=40** patients with depression (45% severe) **Method**: Qualitative; Semi-structured interviews **Sampling**: Convenience

Table 2 Contd.

Study ID/Country/Setting	Characteristics
Srebnik et al.,1995[7] **Country**: US **Setting**: Supported housing project	**N=115** **Method**: Qualitative interviews; Quasi-experimental **Intervention**: Program offering MH and community support services with obtaining/maintaining housing
Stacey et al., 2008[73] **Country**: Canada **Setting**: Outpatient and community hospital	**N=9** **Method**: Semi-structured interviews **Sampling**: Non-randomized convenience sample
Stein et al., 2012[68] **Country**: US **Setting**: Community mental health clinics	**N=1122** **Method**: Non-randomized computer intervention **Intervention**: Computerized decision support program vs. treatment as usual
Woltmann and Whitley 2010[72] **Country**: US **Setting**: Public community MH services	**N=16** living with severe mental illness **Method**: Qualitative, structured interviews **Sampling**: Purposive; Sample taken from a previous RCT comparing usual care vs. electronic decision support program
Woltmann et al., 2011[84] **Country**: US **Setting**: Urban community MH services	Case mangers (EDSS, N=10) and control N=10; clients (EDSS N=40; control N=40) **Method**: Cluster RCT **Comparisons**: Supported planning group vs. usual care planning group
Young et al.,2008[81] **Country**: US **Setting**: Outpatient	**N=298** interactions between 18 “clients” and 152 physicians **Method**: Secondary analysis from an RCT; Coded 287 audio recorded interactions between physicians + patients assess shared decision-making behaviours

Similarly, Stacey and colleagues found that 52 percent of individuals with depression preferred to make treatment decisions alone, 38 percent collaboratively with the health practitioner, and eight percent wanted the practitioner to make the decision.[73] In another study, the majority preferred to make their treatment decision alone and have an active role in decision-making, followed by sharing the decision with their health care provider, and lastly, very few wanted someone to make a substituted decision on their behalf (even if the substitute decision maker was a family member).[71,73]

More difficult decisions will elicit a need for validation from health care professionals, like hospitalisation. Simon et al. found that participants noticed decision-making took longer when difficult topics arose and when clients were uncertain about the benefits of a decision exceeding the harms (e.g., with medication).[74] In this particular study, 75 percent of patients reported ambivalence towards decision-making, and judged that when symptoms became too great, decision-making should be placed in the hands of professionals. More difficult personal circumstances of the client (e.g., severity of symptoms at the moment, perceived self-competency, experiences with health care professionals) also play a role in determining whether a client relinquishes decision-making control to the health care professional.[75]

One factor potentially influencing results is treatment setting, that is, whether participants interviewed in these studies were formal or informal patients, outpatients or inpatients. This could influence the results as formal or inpatients may feel they have less options and less autonomy to make decisions, as well as perceived reduced decisional capacity compared to when they voluntarily seek treatment or when receiving care in the community.

The extent to which decision-making will be utilised by patients depends on a number of cognitive and affective factors such as individual preferences regarding involvement in the decision-making process.[45] It is not the case that all individuals want to make autonomous decisions, however the central idea is that all individuals should have access to supported decision-making should they need and want it, and all individuals should have the opportunity to exercise their legal capacity.[2]

Barriers to decision-making

Barriers at the individual level

First, not being informed and the perceived feeling of not being supported appeared as one barrier in decision-making in mental health care in the literature. Stacey and colleagues found that of 94 participants, 67 were

uncertain about their decisions regarding medication and treatment, and the uncertain group (compared to those displaying more certainty) felt less informed, less supported and less clear about how to value the benefits and risk of options.[73] These participants required guidance in acquiring information, clarifying values, and support to reach a decision. Second, some also expressed fear about their own level of competency and were reluctant to breach the topic of shared decision-making with their health providers often relating back to traumatic experiences from the past with health care providers. Another study identified that clients felt particularly uncertain about decision-making when they were perceived to not be competent due to their mental illness.[76] Third, cultural factors in help-seeking behaviour and decision-making also impact the willingness to share decision-making with health care providers. Patel and Bakken found that Hispanics preferred more passive decision-making in mental health care compared to non-Hispanics who preferred a more active decision-making role.[71] Fourth, social exclusion has also been cited as a barrier to decision-making.[60] If clients have someone to discuss decisions with (peers, families, community members) this often contributes to mobilising a large proportion of support needed to reach a decision.

Lastly, decisional conflict was cited as a barrier leading to increased treatment discontinuation and treatment refusal. Supported decision-making would contribute to addressing factors that influence decisional conflict such as being uninformed, having unclear values, feeling unsupported, and having low motivation. Another barrier to a more active role for PWMI in treatment decision-making is the fear and anxiety that they are "difficult" patients and challenging their health care provider and this will lead to reduced access to much needed care.[67,77] Psychoeducation, having peer-staff listen and inform clients, or providing information prior to consultations with health practitioners could alleviating some of this anxiety, fear and insecurity when considering participation in mental health care.

Barriers at the professional level

For health care workers, a number of barriers to employing a shared decision-making approach have been mentioned in the literature. In line with the patient perception of being perceived as difficult if engaging in shared decision-making behaviours, a trial comparing a shared decision-making intervention and treatment as usual by Hamann and colleagues (2011)[67] found that even at six months post-intervention, although patients in the shared decision-making group had modified their behaviour compared to baseline (more motivated, held different attitudes towards participation

and decision-making), the treating psychiatrists perceived the shared decision-making group to be more difficult to treat (in terms of stress levels for the psychiatrist) compared to control group patients. Other barriers mentioned have been difficulty in ascertaining how to respond when it comes to mental health crises, lack of system support, and additional time required for shared decision-making.[56,58] Although other studies, have found that shared decision-making does not require additional time.[78,79] McMullen found that physicians she interviewed often did not make used of shared decision-making principles, but rather persuaded clients to decide on empirically supported treatments which physicians themselves had some control over (e.g., therapy in their office, pharmacotherapy as administered via their prescription pad).[80] Two other studies found that most physicians did not try to involve patients in shared decision-making and that physicians failed to fully participate in shared decision-making in consultations.[81,82]

Peer support and support systems

Two RCTs conducted in Germany revealed that shared decision-making interventions had a marginal increase in patient satisfaction and demonstrated some evidence that shared decision-making also increased doctor facilitation of patient involvement in decision-making, and did not increase doctor consultation time. Neither of the trials found any positive effect of shared decision-making on clinical outcomes, hospital readmission, or patient compliance with treatment.[78,79,83] A more recent RCT found that an electronic decision support system did not increase patient satisfaction, however clients became more involved in treatment plans and case managers became more aware of clients concerns and needs, potentially facilitating a more collaborative and supportive relationship in the future.[84] Another study had peer-educator led training for people with mental illness, which emphasised informed decision-making, wellbeing, and self-management.[85] These long-term training sessions resulted in a greater inclination to engage in self-advocacy behaviours and these effects continued after six months post-intervention as well as across settings and cultures. Advanced directives have also been seen as a way to support the client in reaching a decision and facilitate collaborative partnership between doctors and patients, particularly due to the fact that it takes into account that mental capacity may fluctuate over the course of mental illness. Deegan (2010) found that even within a short 15-minute consultation, peer support and technology could be utilised to enhance psychiatric medication visits and make them more efficient for both patients and clinicians.[86] The drawback to this system is the cost of developing and implementing such a system.

Supported decision-making in LMICs

While the literature in HICs is limited, research in LMICs on supported decision-making is even sparser. Poor understanding of patient rights, limited education, and limited medical and legal resources have been reported as reasons for the lack of research.[87] An opinion piece on advanced directives points towards several implementation barriers in LMICs.[50] The authors take the view that the service delivery context in a country like India make implementation of supported decision-making tools problematic, as such tools are designed to be implemented in a more accessible, equitable, and organized system.[50] Another barrier is the limited resource availability for monitoring and evaluating these legislative frameworks leading to potential abuse of such progressive tools deisgned to aid in decision-making and promote autonomy.[50] Lastly, limited resources means that dedicated legal aid services are scarce, and make implementation of advanced directives in an affordable and accessible manner difficult.[50] One study countering these opinions was the first study on PADs in India which demonstrated that persons with a chronic mental illness (even with active symptoms) can make use of supportive tools in a resource-poor setting.[87] While advance directives are not a supportive tool allowing for full autonomous decision-making (although it does fall along the spectrum of support in a supported decision-making framework), this trial is a step in the right direction for shifting to more supportive decision-making models in India.

DISCUSSION

This review aimed to assess progress made in both research and legal domains on supported decision-making models for PWMI. PWMI have a right, like those without a mental illness, to exercise their legal capacity and make decisions in all areas of their lives. The debate surrounding decision-making, mental illness, and the right to exercise legal capacity brings up a number of ethical and legal considerations. Part of the complex debate regarding decision-making for PWMI stems from the attribution that PWMI lack mental capacity to make decisions. Indeed, there are periods of time when PWMI may lose capacity to make decisions. Under these circumstances, support measures must be in place to provide all information and guidance necessary to support that person to make an autonomous decision. Support can take on various forms and be directed towards a number of decisions in life, ranging from the mundane to the profound. There is inherently an element of risk for people taking decisions about their own lives[88]; however a supported decision-making paradigm requires

that choice and risk of making these choices is transparent in order to enable fair appraisal of the decision-making process.[88]

Our findings indicate a disconnect between international conventions (CRPD) and domestic legislation. We found very limited evidence on supported decision-making, and even less evidence on interventions assessing autonomy and decision-making outside treatment decisions. We found that the models of decision-making tested in the research arena are often very narrow and controlled and do not reflect the dynamic relations between health care professionals, legal professionals, clients, and carers that occur in practice. The findings from the research, predominantly on shared decision-making, indicated that common to the majority of PWMI, there is a desire for autonomy in decision-making and support for decisions involving complex life issues, particularly when the person is uncertain about the pros and cons of the decision, or uncertain about their competence.[76]

Some health care providers have expressed concerns about managing capacity and treatment decisions in crises, additional time, resources and infrastructure required, and difficulty in seeing clients as equals; all perceived as barriers to collaborating on decisions.[56,58] However, supported decision-making should not be seen as an impediment to accessing care, but rather a facilitator of better quality care. Supported decision-making as well as shared decision-making for treatment decisions both point towards a model of inclusion, wherein if a person has difficulty in expressing and communicating his or her wishes, the solution is not coercive and involuntary treatment or assignation of guardianship. Instead these methods allow a relationship to develop in ways that make it possible for an individual to communicate what he or she wants in certain aspects of their lives.[52] It is also important to recognise that there is no "ideal" for supported decision-making either at the professional, state, or national level; but rather a set of components, which, depending on the resources, training and cultural values of the country, can be utilised to promote legal capacity and autonomous decision-making.

From a legal point of view, countries that have ratified the CRPD have a particular impetus to modify or update their mental health legislation in light of the Convention, particularly when it comes to provisions enabling people to exercise their legal capacity. The CRPD requires mental health legislation to be framed in such a way that presumes all PWMI have legal capacity until proven otherwise, and even with a lack of decisional capacity, they should be offered supports and accommodations to reach an autonomous decision.

The lack of legislative frameworks and research evidence suggest that health care professionals, governments, legal systems, and guardians do not always make decisions in accordance with the best interests principle.[6]

This provides further impetus to shift from a paternalistic way of viewing PWMI to a more inclusive and supportive system embracing decisions made by PWMI. There is an expectation from the CRPD that governments have a responsibility to change their existing legislation on substitute decision-making and supplant it with a more supportive model encouraging supported decision-making.[89] Policies and programmes should accordingly be designed to implement such legislation. This depends on how countries interpret Article 12 and interpret support for PWMI. Their interpretations and reaction to these interpretations ultimately shape practices and legislation.[6] It is therefore important that research be conducted to inform examples of how Article 12 of the CRPD can be implemented, and additionally, governments must liaise with user organisations, peer support networks, carers, and the social sector to ensure that support aids are used in practice when appropriate.[89] From a practical legislation perspective, instituting a law-based system of supported decision-making should focus on main decisions of legal relevance impacting PWMI, such as finances, who they live with, employment, medical decisions, community participation and choice of appropriate support services.[11] The key for legislation is to make provisions which enable support to individuals in a way that encourages them to utilise existing support networks and access support when they feel it is necessary to reach a decision.[11]

ADAPTING SUPPORT MODELS TO LMICs

Several countries discussed in this paper, such as the UK, Canada, Sweden and Australia, are leading the way towards inclusion of supported decision-making in their legislation and other countries could look to these examples to identify applicable components to their own context and legal systems. LMICs particularly need research and applicable models in supported decision-making. To illustrate, a review of shared decision-making training programs globally found no evidence of programs in LMICs to train health professionals in shared decision-making.[90] The question remains as to how supported decision-making models can be feasible for clinicians and clients, and adapted to suit the legal and medical context in LMICs.

The first issue for LMICs is re-conceptualising decision-making capacity for PWMI. For example, in a number of African countries, decision-making capacity is viewed as an all or nothing phenomenon. This means that PWMI when stripped of decision-making powers, lose the ability to make decisions in all areas of their lives and rarely have an opportunity for re-assessment of capacity to change this status.[91] Another issue is the potential for abusing

supported decision-making efforts, as a person providing support may use their influence over the PWMI in a way that may not be in accordance with the best interests of the PWMI.[70] In LMICs, there is limited availability of monitoring systems in place to pose a safeguard against such abuse, however, non-profit organisations could perhaps enlist a guardian monitoring service. An additional consideration is, in resource-constrained settings (especially in LMICs) how and from whom can support be provided in the absence of family and friends? This is particularly the case, in both HICs and LMICs, for PWMI who have been institutionalised for a significant period of time in psychiatric hospitals and have limited community support. How can supported decision-making tools be extended to this population? The Australian supported decision-making study found that a number of people wanted support in making decisions but did not have the network to do so. Gordon discusses how community advocacy organisations have previously experimented with the development of support networks for people without family and friends who are willing or able to provide support and how the organizations can continue to do so. While this is a very positive initiative, Gordon expresses concern as to how sustainable it is to expect that non-profit organizations can handle large incoming caseloads of PWMI requiring support.[57]

The second issue when adapting models from HICs is the limited financial resources in LMICs. A personal ombudsman model like in Sweden may not be feasible in a LMIC due to the high implementation costs. Family support is crucial in LMICs and can provide a unique opportunity when considering appropriate supported decision-making models. However, despite the limited financial resources, there are ways that LMICs can provide support for people to exercise their legal capacity. It is plausible that placing emphasis on the role of families and support networks in decision-making, similar to the UK, could be beneficial in LMICs, both from a cultural and financial standpoint. Involving independent advocates, where financially feasible (perhaps from voluntary organizations in LMICs) could potentially alleviate the barrier of social exclusion that limits support for PWMI who do not have a carer or support network. This is an effective model that works in the UK.[88] It would also be necessary for the legal system or for an independent body to monitor this informal support to ensure that the client is making autonomous decisions and that their human rights are respected.

Brayley proposes a model of supported decision-making based on a spectrum of increasing or decreasing state intervention and autonomy.[57] The model "steps up" options for care and intervention offered by the state, depending on need. The highest state intervention involves the appointment

of a state official as a guardian of last resort, whereas the step with the lowest state intervention is autonomous decision-making. Steps in between involve: a support team assisting with decision-making; single one-off decisions being made by a tribunal (wherein the client retains decision-making power for all other matters with the exception of this one-off decision); enduring guardianship, which the client sets out prior to losing capacity; guardianship by a family or friend with government support or overview. This is similar to a sliding scale of support, which would be beneficial in LMICs but also in HICs. Offering a number of support mechanisms on a spectrum based on need, and based on existing resources of the state or country and which build upon the values of the given society would be most effective to accommodate diverse needs of people with disabilities. In addition, particularly in LMICs, but not exclusively, people turn to informal support networks when they realise they need support.[11] As a result, peers and social networks can be invaluable in providing accommodations and support to those who would like to reach a decision while also utilising existing resources in a country and when the addition of legal advocates and representatives might be costly, particularly in resource-constrained settings. This could entail training people on the path to recovery from mental illness in peer-support training who can provide support or resources to those who require it to make decisions. This would indeed translate action to implementation of Article 12 of the CRPD by strengthening and extending informal networks rather than substituting them with professional legal and medical services.[11]

There is no single best practice for supporting people with disabilities to reach decisions, as systemic factors impact the provisions of these accommodations (resources, legal system, implementation of legislative frameworks, availability of support networks) as well as individual factors (level of need of the individual, accessibility to support networks and services, capacity at the time of need). Furthermore, the decision-making process in mental illness is complex (largely due to the chronicity and course of illness) and dependent on circumstances and context. However, certain components from successful models that embody the support paradigm, as well as a social model of disability, could be extracted and utilised in systems and settings wishing to shift away from a guardianship model. It is therefore important that research pinpoints components of supported decision-making which facilitate exercising legal capacity but which could be used in different countries, and then tailored to reflect the context. Research is therefore urgently needed in light of the fact that guidelines, policies and international conventions like the CPRD advocate for supported decision-making, with little evidence of effect.[26]

LIMITATIONS

There are of course limitations of this paper that need to be addressed. Perhaps most importantly, the terminology of decision-making is highly heterogeneous and loosely defined, impacting the results of our review with regards to the numbers of included studies. It is possible we may have missed a number of studies due to our search terms. For example, we did not look at patient participation in mental health care as a search term, which could have yielded some studies focusing on shared decision-making. Our hand search identified a number of more relevant studies than did our database searches, potentially due to the grey literature, which we included in the legislative review. In addition, the reviewed literature was primarily observational or pilot studies with a small, narrowly focused sample size, which is not generalizable to the wider population.

There is a substantial gap between supported decision-making models and actual practice; actual decision-making process rarely fits any of these idealised models.[80] Similarly, while there is no problem in understanding the ideals of Article 12 of the CPRD, truly shifting from substitute decision-making to a more supportive mode is an entirely different problem.[6] Selection of a decision-making model depends on the circumstances of the decision that is being made, the preferences of the clients, other relevant parties, and based on available information. An illustrative example is a consumer health survey which found that although a large majority of respondents did not endorse health care professionals to solely make decisions; general practitioners conversely believed that their task was to relieve patient anxiety and comply with patient expectations rather than involve them in the decision-making process.[80] Third, in many settings, to provide supported decision-making options for clients, it is necessary that there is a paradigm shift to approach disability from a social model,[62,63] involving the assumption that people with disabilities have the capacity to make their own decisions.

CONCLUSION

The paucity of research in supported decision-making models for PWMI highlights the need for tested models, not only in HICs, but also in LMICs. Furthermore, we note that in order for the ability to exercise legal capacity to become a lived reality for PWMI, there is a need for more research assessing which components of supported decision-making could be used in legislation and in practice. A disconnect still exists between national and/

or state legislation and the CRPD provisions. While a government may be in favour of the idea of supported decision-making, their mental health and/or guardianship legislation is often not conducive to exercising legal capacity. It is important that mental health laws be updated to reflect CRPD provisions, as mental health legislation can shape, empower, and regulate the entire mental health system, including services, policies, and relationships between professionals and end users.[5]

Acronyms List:
CRPD = The Convention on the Rights of Persons with Disabilities
HICs = high-income countries
LMICs = low- and middle-income countries
PADs = psychiatric advance directives
PWD = persons with disabilities
PWMI = persons with mental illness
RCT = randomized control trial

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