

Manual on Supported Decision-making



– for Service Providers



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India Mental Health Observatory

The India Mental Health Observatory (IMHO) is an initiative of CMHLP. The IMHO is a repository of data and information on mental health to promote evidence-based policy making and bridge systemic gaps for advancing mental health in India. The IMHO's mission is to improve mental health outcomes by facilitating equitable, accessible, affordable, quality and rights-based mental healthcare in India. The IMHO is supported by the Thakur Family Foundation.

Centre for Mental Health Law and Policy

Founded in 2007, the Centre for Mental Health Law & Policy (CMHLP) is based in Pune at the Indian Law Society (ILS) a public charitable trust founded in 1924. CMHLP aims to protect and promote the rights of persons with psychosocial disabilities using a rights-based approach to mental health. We work with different stakeholders including people with lived experience, caregivers, mental health professionals, policymakers, civil society organisations and researchers. We work nationally and internationally with a specific focus on vulnerable and marginalised populations in low- and middle-income countries (LMICs).

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Why this Guide?

This guide is meant to assist mental health professionals in incorporating supported decision-making strategies into everyday mental healthcare and engagement with persons with psychosocial disabilities (“PwPD”). Supported decision-making (“SDM”) means making autonomous choices or decisions regarding one’s own life with varying levels of support or help – something that all people do in a variety of everyday life situations.

In many parts of the world, including India, SDM is not practically implemented, particularly in the case of persons with disabilities, more specifically, PwPD. Instead, most countries use the substitute decision-making approach, whereby the parent, caregiver, service provider, or legal guardian makes decisions on behalf of the PwPD, often without the person being given an opportunity to participate in the decision-making processes. These include both very simple decisions, such as what to wear and more complex ones, such as choosing whether or not to receive a particular a mental health treatment, for example electroconvulsive therapy (“ECT”).

Furthermore, mental health professionals, service providers & caregivers often wrongly stereotype PwPD as being irrational, unreasonable, or lacking the decision-making abilities to make their own decisions – with or without support. It is falsely presumed that persons with severe mental health problems cannot make decisions about their own life due to their condition. As a consequence, PwPD are denied the right to exercise their freedom to make their own decisions and have control over their own lives. This is seen as a violation of a basic human right to exercise one’s own autonomy and free will.

While substitute decision-making is used with the best of intentions – including protection of persons with disabilities from abuse and neglect – often family members, caregivers, and service providers take decisions keeping in mind what they think is in the best interests of the PwPD. In doing so the will and preferences of the PwPD are not taken into consideration, instead the decision is made for them based on what is perceived by another person as ‘best’ for them.

For persons with disabilities, SDM helps ensure they retain their independence and legal capacity. For countries, SDM helps them fulfil their human rights obligations, by viewing decision-making as a right and by eliminating schemes of substitute decision-making, such as guardianships.

SDM is mandated by the United Nations Convention on the Rights of Persons with Disabilities (“CRPD”) & India’s Mental Healthcare Act (2017). The guiding principles of the CRPD include the right to autonomy and independence, dignity and non-discrimination, participation and inclusion in society, and equality and appreciation for human diversity. SDM is one of the many ways of incorporating these principles in decision-making processes related to persons with disabilities and is derived primarily from Article 12 of the CRPD, which requires equal recognition before the law and ensures that persons with disabilities retain their legal capacity on an equal basis with others. The Committee on the Rights of Persons with Disabilities, the treaty body responsible for monitoring state compliance with the Convention, has interpreted the text of Article 12 to require SDM in all areas of life for persons with disabilities, including health care and treatment-related decisions.

According to the Mental Healthcare Act (2017), all mental health professionals and service providers in India are obligated to ensure SDM for PwPD while providing mental healthcare and treatment. However, since SDM is not commonly practiced in India, this guide aims to help mental health professionals and service-providers understand what SDM means in the context of mental healthcare and equip them with strategies to support autonomous decision-making by PwPD.

SUMMARY

Supported decision-making is making autonomous choices or decisions with varying levels of support or help— something we all do every day.

SDM is currently not the norm in India for persons with mental health problems, despite the fact it is mandated by international and domestic law.

This guide will help service providers understand SDM and propose strategies they can use in their everyday practice to support PwPD.

Important Terms

- **Persons with psychosocial disability (PwPD):** a person with mental illness or mental health problems who due to various barriers in their

environment is unable to participate in daily life activities in the same manner as others.

- **Decision-making:** the process of becoming informed, understanding consequences, and expressing one's preferences or making a choice.
- **Capacity:** the ability to make decisions about things that affect one's life. Capacity includes three different abilities: (i) ability to understand information needed to make a decision (ii) ability to understand the reasonable consequences of a potential decision and (iii) ability to communicate one's decision to others.
- **Legal capacity:** one's legal status to hold rights and the right to exercise such rights or make legal decisions.
- **Personhood:** recognition as an individual person with thoughts, feelings, goals, dreams, and free will.
- **Substitute decision-making:** decision-making model whereby a person makes decisions on behalf of another person who is presumed to lack decision making abilities.
- **Guardianship:** traditional form of substitute decision-making whereby a parent, guardian, or a court-appointed person makes decisions on behalf of someone else, usually on behalf of persons with psychosocial or intellectual disabilities.
- **Supported Decision-Making:** making choices or decisions about one's own life with varying levels of support or help – something we normally do in a variety of everyday and normal situations. In the mental health context, such support or help can take the form of a trusted support person, special technology, or legal tools that help PwPD express their preferences at times when they are unable to make decisions.
- **Advance Directive:** a personalized treatment plan made in preparation for a future event. Advance directives can be used by PwPD to express treatment preferences in the event that they experience a mental health problem and are unable to make decisions on their own.
- **Nominated Representative:** anyone (parent, spouse, sibling, friend, or

professional) that the PwPD trusts and chooses to represent them in matters of mental healthcare and treatment or to support them to make decisions.

What is Decision-Making?

What is Decision-Making?

Though we make decisions all the time, most of us never stop and think about how we make a decision. Decision-making seems very simple – we make hundreds of decisions every day without thinking about the process that led

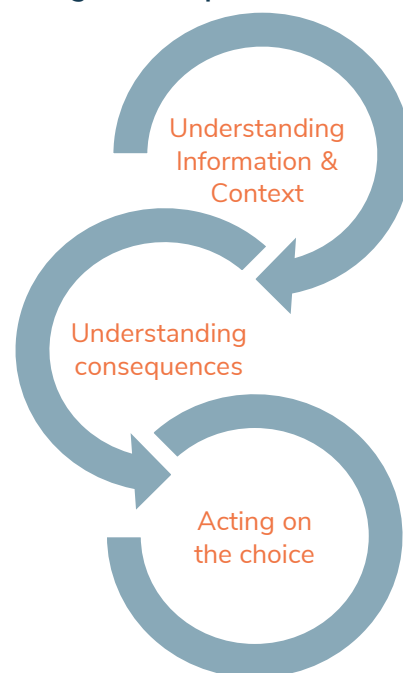
You want to buy a motorcycle but are not sure which model is best suited for you. You look up a few models, consult family and friends and have a chat with your mechanic on the models you are considering. Following more research and information regarding the choices available and inputs received from family, friends, and the mechanic, you decide to buy motorcycle B.

You want to purchase a TV but are not familiar with the kinds of TVs that are currently available in the market. A good friend of yours works in a TV store and understands your preferences well. On consulting him, he tells you about different options available – high definition, flat screen, etc. Knowing the options available based on your preferences, you choose TV model D of the four option your friend suggested.

to a particular decision. For example, consider the following situations:

The decisions to purchase Motorcycle B or TV D in the above examples are illustrations of how we all practice supported decision-making in everyday life, wherein even though you receive inputs from others in reaching your decision, the final decision nonetheless is yours and based on your will and preferences. In general, decision-making can be broken down into three steps (Figure 1).

Figure 1: Steps in Decision Making



STEP 1: Understanding Information & Context

Regardless of the decision being made is, it is helpful to have information and context about that decision. For example, while choosing clothes to wear, it is helpful to know what the weather is like and what the planned activities are for the day. The weather forecast helps you decide what might be the best suited choice of attire and the occasion provides the context for choosing them. The choice of attire may differ depending on the context, such as going to work versus going to a social gathering.

STEP 2: Understanding the Consequences

Once the information and context surrounding a decision are understood, there remain other decisions to make, such as choosing whether to wear the grey sweater or the yellow one. The choice of colour however is not the only consideration, there are also others linked to what the consequences may be. For instance, while both the grey and yellow sweaters are suitable, the yellow one has larger pockets. Choosing the yellow sweater would mean you can easily carry your wallet, keys and phone, while choosing the grey sweater would mean you have to carry a bag for your wallet, keys and phone.

STEP 3: Acting on the Choice

After considering the advantages and disadvantages of wearing the grey or yellow sweater, you decide to wear the grey sweater, because you feel safer carrying your belongings in a bag rather than in your pocket.

Complex Decisions

Decisions vary in their complexity and importance. Some decisions are very simple, such as choosing an outfit. Other decisions can be far more complex with more important consequences, such as choosing treatment for a medical condition. The level of assistance a person will require to make a decision will vary, depending on the person and the complexity of the decision being made. Complex decisions require more time or support to gather information, understand the consequences of making the decision and finding the correct assistance in making a choice. This is particularly true in the context of mental healthcare. Decision-making can also be a process since people may have

Sonu and Roop are both diagnosed with cancer. Sonu is a doctor, understands her condition and available treatment options. Roop is not a doctor and does not understand the diagnosis they have received. In deciding the course of treatment, Sonu is likely to consult her doctor and quickly arrive at a decision while Roop will need more time to learn about the condition and the treatment options available. Roop will also prefer to spend more time speaking with their doctor so that they can make an informed decision on which treatment option to pursue. At the end of the day, both Sonu and Roop have made autonomous, informed decisions, even though the decision-making process was more difficult and more time-consuming for Roop than it was for Sonu.

varying abilities to gather information, understand consequences, communicate, and act upon their decision. Consider the following example:

Sometimes, like Roop, we may all need more time and help to make an informed decision. Seeking support when needed helps us make better informed decisions. Regardless of the help that maybe needed in making the decision, the final choice is made by us as an autonomous, i.e., independent individual.

Decision-making processes may further be complicated and influenced often (if not always) by emotions, past experiences, and our hopes for the future. In most cases, decision-making cannot be considered a logical or rational exercise. In fact, **making irrational choices or bad decisions is simply a part of being human.**

SUMMARY

Some decisions are very simple, such as choosing clothes to wear. Other decisions can be far more complex with more important consequences, such as choosing treatment for a medical condition.

The level of help a person requires to make a decision varies, depending on the person and the complexity of the decision being made.

Feelings, experiences, and goals can also influence our decision-making.

What is Supported Decision-Making?

1. Supported Decision-Making

Everyday decision-making is the process of becoming informed, understanding consequences, and expressing one's preferences in executing a choice. Sometimes this process may include seeking support from others (as illustrated through previous examples). SDM is the same as regular decision-making, except that when someone needs help with decision-making, the forms of support or assistance required may be more specialised, e.g. use of legal tools, trusted support person or assistive aides to support

Pooja has schizophrenia. Having to make a decision by choosing between different outfits makes her anxious. When her mother asks her to pick an outfit for the day, Pooja feels nervous and anxious. To support Pooja in choosing her outfit for the day, her mother breaks down the process of choosing the outfit into smaller steps. She asks Pooja which colour she would like to wear. Based on Pooja's answer her mother lays out all the outfits in that colour. Pooja then chooses what she would like to wear for the day. By breaking down the decision-making process into smaller steps, Pooja's mother is helping Pooja make the decisions based on her own preferences.

PwPD in making and communicating their own decisions. The example below illustrates how SDM may look like for someone living with a psychosocial disability:

2. Best Interests

Rajul is a person with hearing impairment. They live with their aunt, who is also their guardian. Her guardian believes that it would be best for Rajul to stay at home instead of finding a job after completing their studies. Rajul however would like to work with children.

Substitute decision-making paradigms often work on the principle of "best interests", wherein the person making the decisions on behalf of the person with mental illness makes a decision based on what they think would be in that person's "best interests." Consider the following example:

Rajul has a severe mental health problem. Their guardian feels that that Rajul requires treatment or else their condition will worsen. Rajul doesn't wish to be admitted in a hospital and prefers to be treated at home around their loved ones. Under the substitute decision-making approach Rajul's guardian can decide to admit Rajul in a hospital for treatment (without Rajul's consent) since they feel it is in the best interests of Rajul to receive treatment in a hospital setting for a faster recovery.

Thus, making a decision on behalf of another person in their "best interests" might go against what the person actually wishes or desires. A "best interests" decision can conflict with the person's will and preferences and prevent them from exercising their right to make their own decisions.

3. Will and Preferences

People make a range of choices on an everyday basis: what to wear or eat, where to work, when and what kind of treatment to seek for an illness, etc. While making these choices, people, including PwPD make a choice or decision based on their preferences, such as what colour they like, what food they enjoy, what is meaningful work and what kind of treatment options they prefer. SDM means that any decision made by a PwPD must be according to their will and preferences. Will and preferences refers to a person's wishes, desires and choices which may be based on their personal beliefs, life history or what they find meaningful or valuable for themselves.

In the previous example under the supported decision-making approach, Rajul would decide whether or not they should be admitted in a hospital (Raju's will) and what kind of treatment they prefer (Rajul's preference). Rajul may need some help with this decision, for example, explaining the need for admission, the consequences of getting admitted and the alternatives to not being admitted in a hospital. After gathering the needed information, hearing the advice of their guardian and understanding the consequences of their decision, Rajul can decide if they would like to be admitted in a hospital or prefer an alternative form of treatment.

SUMMARY

It is the responsibility of service providers, family members, friends, colleagues, and service providers, to ensure that PwPD receive the support they need to make decisions, while ensuring their will and preferences are respected rather than make a decision on their behalf in their best interests.

PwPD as anyone else may require assistance in making their own decisions, big (e.g., when to seek treatment) and small (e.g., what to wear). The level of assistance or support required will vary depending on the person and the decision being made.

Will and preferences should always take priority over “best interests.”

4. Goals of Supported Decision Making

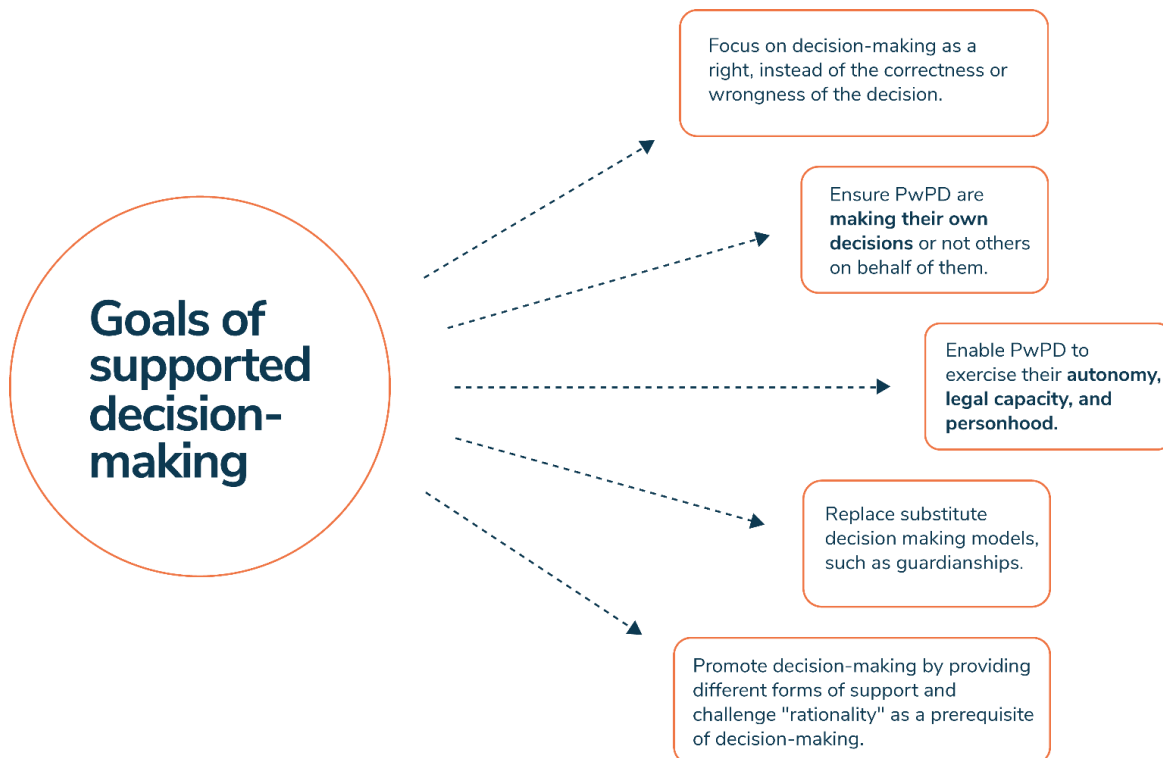


Figure 2: Goals of Supported Decision-Making

5. The Continuum of Decision Making

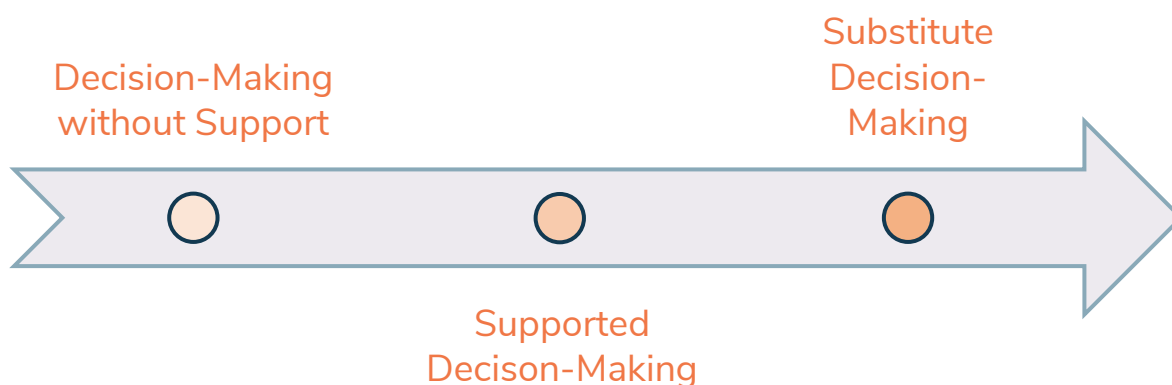


Figure 3: Continuum of Decision-Making

Supported decision-making lies on the continuum of types of decision-making. It is not the most independent form of decision-making, but it is least restrictive of personal autonomy and self-direction. It falls between decision-making without any help or support and substitute decision-making, whereby the person's capacity is taken away completely.

6. Supported Decision-Making under Mental Healthcare Act, 2017

Enacted in 2017, the Mental Healthcare Act ("MHCA") adopts a right-based approach, mandating supported decision-making in the context of mental healthcare, to regulate mental healthcare and treatment. While the MHCA does not define capacity, Section 4(1) of the act states that individuals (including PwPDs) shall be deemed to have capacity to make decisions regarding their mental healthcare and treatment, if such person has the ability to:

- **Understand** the information that is relevant to make a decision regarding treatment, admission, or personal assistance. (Such information should be provided to the person in simple language, sign language, visual aids, or any other means such that the person understands the information)
- **Appreciate** any reasonable and foreseeable consequence of a decision or lack of decision on one's treatment, admission, or personal assistance.
- **Communicate** the decision by means of (i) speech (ii) expression (iii) gesture or any other means.

Through various provisions the MHCA recognises that PwPD may exercise decisional capacity with or without support. The Act enables the right to supported decision-making through provisions for support measures such as Advance Directives and Nominated Representatives. These enable PwPD to exercise capacity and express their will and preferences regarding their mental healthcare and treatment.

Advance Directives (AD)

Under the provisions of the MHCA, every person (above 18 years of age), irrespective of whether they are a PwPD, has the right to make an advance directive for themselves. An advance directive is a declaration in writing on how a person wishes to be treated for a mental illness in a situation where they do not have capacity to make decisions regarding the same. In their advance directive, persons can specify the nature of treatment, care, and support that they want. Furthermore, they can specify treatment and care options that should not be considered, as well as how they wish to be treated (or not). Thus, advance directives ensure that mental healthcare and treatment for PwPD is provided in accordance with their will and preferences. In an advance directive, persons may appoint a nominated representative.

For an advance directive to be considered valid it must be registered with the relevant Mental Health Review Board (“MHRB”). Once an advance directive has been registered, mental health practitioners are obligated to provide treatment in accordance, provided that a copy of the advance directive has been given to them before beginning treatment. In case of there being multiple advance directives, only the latest one will be considered valid and representative of the person’s will and preferences. Advance directives are not applicable when a person regains capacity.

An advance directive can be reviewed or challenged by a mental health professional, care-giver or relative before a MHRB on grounds that (i) the advance directive was not made by the person out of their own free will (ii) there is a change in circumstances since the advance directive was written (iii) the person was insufficiently informed to make a decision (iv) the person lacked decisional capacity to take mental healthcare and treatment decisions while preparing the advance directive, or (v) the advance directive is contrary to the law or constitutional provisions. Advance directives can be altered, modified, or cancelled as per the MHRB’s findings based on the criteria mentioned above.

The format for drafting an Advance Directive is given below:

FORM FOR MAKING, AMENDING/ REVOKING AND CANCELLING ADVANCE DIRECTIVE

1. Name (Attach copy of photo identity document proof):
2. Age (Attach copy of age proof for being above 18 years of age):
3. Father's/ Mother's Name:
4. Address (Attach copy of proof):

(Note: Any valid identity proof like Birth Certificate, Driving License, Voter's Card, Passport, Aadhaar card, etc. shall be admissible as address proof and age proof.)

5. Contact number(s):
6. Registration no. of previous advance directive (to be filled in case of amendment/revocation/ cancellation of advance directive):
7. I wish to be cared for and treated as under (not to be filled in case of revocation/cancellation of advance directive):
8. I wish not to be cared for and treated as under (not to be filled in case of revocation/ cancellation of advance directive):
9. Any history of allergies, known side effects, or other medical problems:
10. I have appointed the following persons in order of precedence (Enclosed photo ID and age proof), who are above 18 years of age to act as my nominated representatives to make decisions about my mental illness treatment, when I am incapable to do so (not to be filled in case of revocation/cancellation of advance directive):

(a) Name: Age:

Father's/Mother's name:

Address:

Contact number(s):

Signature:

Date:

(b) Name:

Age:

Father's/Mother's name:

Address:

Contact number(s):

Signature:

Date:

(Any number of nominated representatives can be added)

11. Signature of applicant: Date:

12. Signature of witnesses:

13. Mr./ Ms. _____ has the mental capacity to make/ amend/ revoke/ cancel an advance directive at the time of signing this form and has signed it in our presence of his/ her own free will.

Witness 1: (Name)

(Signature)

Date:

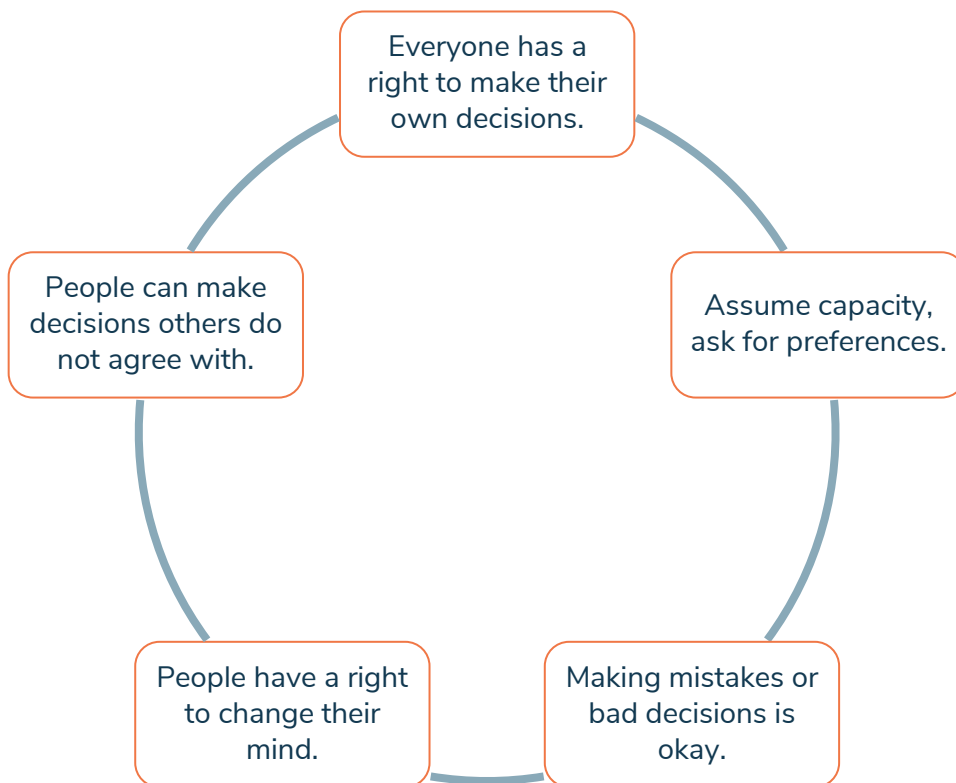
Nominated Representatives (NR)

PwPDs have the right to appoint any person of choice as their nominated representative. The nominated representative is duty-bound to provide support while the person undergoes mental healthcare and treatment. Under the provisions of the MHCA a person may appoint any number of Nominated Representatives as long as the persons being appointed as the nominated representative are adults, competent to discharge duties and give consent in writing.

A nominated representative is obligated under statutory functions to provide support to PwPD to make their own decisions, particularly with regard to providing support in making treatment decisions; applying for supported admissions & discharge; seeking information about the person's diagnosis and treatment; applying to the MHRB against rights violations, etc. However, if a PwPD is unable to make their own decisions even with support or are being treated through supported (involuntary) admissions, the nominated representatives may be required to make decisions on their behalf and must do so keeping in mind the person's life history, values, past preferences and cultural background.

Principles of Supported Decision Making

Many mental health professionals and service providers assume that a PwPD will not or cannot make decisions on their own. In some situations, service providers may reinforce this belief by only communicating with caregivers and unintentionally preventing PwPD from making decisions about their own care. In this section, we lay out 5 principles of SDM, which can help mental health professional and service providers incorporate more forms of SDM in their practice, such that they enable PwPD to exercise autonomy and develop



important decision-making skills, in the context of their mental healthcare.

Figure 4: The 5 Principles of Supported Decision-Making

Principle 1: Everyone has a right to make their own decisions, even if they need support.

The fundamental principle of SDM is that every person, including PwPD, have the right to make their own decisions. That is not to say that they may not need support in doing so, rather it implies that people have the right to be the final decision-maker in the making decisions that will impact them. Mental health professionals and service providers should continually encourage and support PwPD to make their own mental healthcare and treatment decisions.

Principle 2: Presume the person has capacity and ask for their preferences.

For each and every potential decision, service providers should assume that PwPD have capacity, i.e., that the PwPD will be able to understand information related to the decision, its potential consequences, and will be able to communicate their decision, even if it requires support with any or all of these steps. Capacity is decision-specific, and different levels of support may be needed depending on the kind of decision to be made. Service providers should ask PwPD for their preferences after explaining the different treatment options, risks and benefits associated with each option. For example, when a PwPD requires support in deciding what treatment to pursue for a mental illness, the service provider should ask for preferences, such as “Would you prefer to take Medicine A or B?” or “Would you prefer to take oral medication or try ECT?”

Principle 3: Making mistakes or bad decisions is alright and does not mean that the person lacks capacity to make decisions.

It is natural for any person to make mistakes or wrong decisions – this is a part of decision-making and the experience of being human. In fact, one of the ways we can improve our decision-making skills is to learn from our mistakes or bad decisions and use those experiences to inform our future decisions. While refraining people from making their own decisions can prevent them from making mistakes, it also deprives them of the opportunity to improve their decision-making skills. The possibility of making mistakes or bad decisions does not justify taking away a person’s right to make their own decisions.

In the context of mental healthcare, there is a possibility that a person's decision can have life-threatening consequences, and in such situations, service providers will need to thoroughly explain the potential dangers of making a particular decision. As long as the PwPD understands the information presented and the potential consequences of their decision, they are free to make a bad decision or even refuse treatment altogether. Most decisions, though, do not have catastrophic consequences. For example, the choice between two types of medication may not be life-threatening even if the PwPD refuses to take medication. It is important to remember that capacity is determined on a decision-by-decision basis and that making a bad decision or mistake in one context does not take away a person's capacity to make other decisions.

Principle 4: People have the right to change their mind.

Just as mistakes are common in decision-making, so is changing one's mind. People frequently decide on one course of action, but later choose another. Sometimes people try something and then decide they do not like the experience. Sometimes they think about their choices and on further reflection decide the initial choice was not the best option. We change our minds all the time in life, and service providers should be aware that PwPD may also change their minds on various decisions, including treatment decisions. Service providers should support a change in course just as they would support any other decision made by the PwPD, all the while explaining the risks and benefits involved and any potential consequences.

Principle 5: People can make decisions others do not agree with.

In life, we often make decisions that our families, friends, and even healthcare professionals do not agree with, presumably because we know ourselves and our situations best. It can be very difficult to have someone make a decision that is contrary to our personal opinion and preference. Such a situation, however, may get more complicated in circumstances where a PwPD is making a decision contrary to the opinion of their mental health professional or service provider.

During training, service providers are conditioned into believing that PwPDs will simply follow their recommendations and advice. However, it is important for service providers to remember that while a PwPD may not have the same level of expertise as them, they may want to exercise autonomy and have a greater say in their treatment and care decisions. Such instances must be viewed by service providers as a sign of the PwPD expressing interest in their own care and willingness to learn about the

options available to them. While sometimes the PwPD may eventually decide on a course that is not recommended, it is important that their decision be respected.

SUMMARY		
Everyone has the right to make their own decisions, even if they need support to do so or others do not agree with their choices.	For every decision, service providers should assume their PwPD has capacity and ask for his or her preferences on that particular issue.	Supported decision-making, like any decision-making, will lead to mistakes and bad decisions sometimes, but this is part of the human experience and can help develop better decision-making skills. Making bad or wrong decisions does not mean the person lacks decision-making abilities

Strategies for Mental Health Professionals & Service Providers for Supported Decision-Making

Since SDM is a fairly new approach, particularly in India, this guide provides some strategies to assist mental health professionals and service providers in making the transition from substitute decision-making to SDM. The following strategies can be used interchangeably, however, they are not meant to be a one-size-fits-all solution.

Strategy 1: Take the stance of an educator.

- One of the simplest ways a mental health professional or service provider can make the shift towards SDM is by viewing themselves as educators using their expertise to educate and inform PwPD, rather than act as decision-makers.

- In a helping stance, it is important to encourage independence, explain important information, and help the decision-maker act on their choice.
- To take a helping stance, first put yourself in the shoes of the PwPD. If you were in their situation, what is the kind of information would you have needed? Who would you have consulted? What forms of support would you require? After answering these questions, put yourself back in your shoes and help the person gather and understand the required information to make an informed choice.

Strategy 2: Make it simple.

- As illustrated earlier using the example of Pooja, sometimes an easy way to explain something is by breaking it into smaller, simpler steps. This may be used as a strategy for written documents and in-person assistance.
- The key is to break down complex information into smaller, less overwhelming units of information, and using those to convey the information needed to make a decision.

Strategy 3: Be creative.

- Sometimes, even after information has been broken down into smaller parts, it may be challenging to explain or convey it using conventional and traditional means of communication.
- In such situation, a little bit of creativity always comes in handy! For instance, you could use other tools such as drawing, to convey information pictorially or act out what you are trying to convey. In such situations it is suggested to find the most effective means of communication, when more conventional or traditional forms fail.

Strategy 4: Change the language.

- Often, professional and treatment related documents are written, and information is provided using language that is technical or inaccessible to a lay person. It is therefore recommended to re-write such documents in a simpler language or convey the information using more basic forms of communication.
- Sometimes the dialect of the language spoken by the service providers may not be understood by the PwPD, thus it is important to

make sure that information is presented in a language that is easily understood by the PwPD and their caregivers.

Strategy 5: Make time for explanation.

- When trying to understand something that is particularly difficult, it often takes time to not only listen to explanations, but also to process and absorb the information. To make the process of supported decision-making less frustrating for you and the PwPD, build time into your daily routines for explanation.
- For very busy mental health professionals and service providers, have your staff prepare brief documents about various conditions, medicines, treatment options, etc., which can be given to PwPDs and caregivers and once they have read the documents, have them review the information with a staff member.
- Remind other service providers and your staff that it may take longer for some PwPD to understand, process the information provided and arrive at a decision.

Strategy 6: Promote independence and responsibility.

- Sometimes when we assume a caregiving role, we begin to do things on behalf of the person we are providing care to, rather than encouraging them to take initiative and responsibility for themselves. That is not to say that those being cared for can do everything on their own, but there are certainly tasks and decisions that can be done and made independently, especially with encouragement and support from caregivers and service providers.
- A common concern among service providers is that if they let PwPD make autonomous decisions, they may make bad decisions, leading to the service provider being held accountable. However, it is important to remember that everyone, including PwPD, must take responsibility for their own decisions. A majority of decisions made do not lead to catastrophic consequences or outcomes; these include making choices regarding what to wear or eat and when to sleep, even if the choices made may not be the most appropriate.
- For more significant decisions, service providers can put safety nets in place, such as explaining to the person's caregiver how to properly administer a medication or giving the PwPD a phone number to call in case of questions. Other safety nets may include agreeing that the

PwPD will not be forced to take medication in general, but in exchange, the PwPD consents to take a calming medicine if they experience severe symptoms that they are unable to manage.

- Please note, any agreements of this nature should be in writing, understood by the PwPD and caregiver, and should only be used as a last resort.

Strategy 7: Be an advocate.

- Sometimes what we need more than a service provider is an advocate – someone who is willing to stand up for us to make sure we are exercising our rights and that our choices are respected. This is an extremely important role for mental health professionals and service providers since they also deal with family members, caregivers, other professionals, and society at large, who may not be familiar with SDM approaches.
- In some situations, it is up to the mental health professional or service provider to tell others that the PwPD has the right to make their choices independently and that it may take longer or require more effort to make decisions. Furthermore, service providers must explain and advocate for SDM and protect the rights of PwPD to make their own decisions.

SUMMARY

There are various strategies mental health professionals and service providers can use to ensure that PwPDs are making their own decisions, and that those decisions are supported and respected.

The seven strategies provided here are not an exhaustive list but can help mental health professionals and service providers make the transition from substitute decision-making to supported decision-making.

These seven strategies may be used in varying contexts or as a combination, such that they are personalised to cater to the needs of PwPD.

Supported Decision-Making in Practice

Healthcare and treatment-related decisions can feel like a complex area for applying supported decision-making approaches given India's cultural context and ground realities. Physicians and healthcare professionals are perceived as being in a position of power, as a result of which people often feel uncomfortable asking for more detailed explanations or choosing a treatment option different from the one recommended. Making treatment-related decisions can be more complicated compared to making other life decisions, since they often depend on a variety of factors, including but not limited to opinions of healthcare professionals, specialised and technical information, family medical history, personal health problems, etc.

However, like with any other decision, people make decisions based on their preferences even while choosing treatment options. For instance, a person may choose to take daily medication (orally) or choose to take a monthly injection. Furthermore, people may also have preferences for the kind of health care professionals and services they would like to access. This is equally true for PwPD and there are various supported decision-making tools that can help them make informed treatment decisions such as advance directives or assistance from a trusted support person.

Crisis Situations

In certain circumstances, particularly in crisis situations, it may be challenging to facilitate SDM especially when the person is at risk to themselves or others. However, there are always steps that can be taken to ensure that the person's rights are respected. When faced with a crisis, the first step for any intervention should always be to ask the person what can be done to help. Respect and acknowledgment of the person's emotions can go a long way in preventing further escalation. For example, using phrases such as:

- “Hello Reet, my name is Dr. Anshu. I am a psychiatrist here at the clinic. You seem very upset at the moment, is there anything I can do to help?”
- “Hello, my name is Soma. I'm a nurse here at the hospital. I've seen you here before, but you don't seem like yourself at the moment. Is there anything I can do to help?”

Some PwPD may want medication, but others may want to be in a quiet room (not seclusion) or to have a certain family member present. There may be others who just want someone who will listen to why they are feeling so upset. If the person does not respond, responds in a way that is not understandable, or rejects any form of help, give them some space and time till they are calmer or feeling better.

If the person seems agitated or is likely to become aggressive, direct other people away from the area. Every five minutes or so, check in with the person to see if they need anything, till the crisis has passed. Once the crisis is over, speak to the person about the crisis and try to understand if there are specific triggers or signs to tell when a crisis may arise. Work with the person to make a recovery plan or draft an advance directive which identifies the person's triggers and treatment preferences in the event of a crisis in the future. Make sure you inform them of their rights in such situations.

If the person is harming themselves or behaving in a manner that threatens their life or safety, or that of others, explain to them that as a healthcare professional and someone who cares, you cannot let them harm themselves or others. Explain that you would be obliged to intervene if the behaviour continues and describe what steps may be taken. For example:

- “You are hitting your head against a wall, and I am concerned you will hurt yourself. As a doctor/nurse, it is my job to help you. If you continue, I will be obliged to intervene. It will need me to physically move you away from the wall. If you become aggressive, my colleagues too would have to intervene, and we may have to forcefully administer medication. I do not wish to do so and request you to please sit down here. Do you understand what I am saying?”

Once the crisis has passed, speak to the person, and tell them of what steps you had to take and explain why. Then work with the individual to develop a recovery plan or draft an advance directive stating the person's preference for treatment to refer to in case of a crisis in the future.

Mental health professionals and service providers must comply with the provisions of the Mental Healthcare Act, 2017 while providing support or treatment to PwPD in crisis or emergency situations. They must ensure that any treatment or support provided does not violate any legal safeguards or the rights of PwPD.

Supported Decision-Making in the Context of Mental Healthcare

Situation 1: Mehul has just been diagnosed with schizophrenia. Given his other medical conditions, allergies, and family history, there are three potential courses of treatment: A, B, and C.

The examples below are presented to illustrate different practical approaches for mental health professionals and service providers to implement SDM in various real-life situations in the context of mental healthcare. These examples have been linked to the principles and strategies of SDM explained in the previous sections. For the purpose of these examples, we will refer to a fictitious person named Mehul who has a severe mental health problem. Though PwPD can often manage some of their more severe symptoms, for purposes of illustration, Mehul in some of the examples below is portrayed as experiencing severe symptoms and requiring a high level of support from his service providers.

What should you do?

- Using SDM, both the service provider and the caregivers will have to provide Mehul with the opportunity and encouragement to choose the potential course of treatment on his own (Principle 1).
- The service provider must remember that Mehul can choose another course of treatment, which the service provider does not agree with, or even refuse treatment (Principle 5).

Situation 2: Mehul arrives at a clinic, along with his primary caregiver. He is dishevelled, appears agitated, and is muttering under his breath. The caregiver tells the nurse at the reception that he needs medication

Service Provider DO'S

- ✓ **Explain** to Mehul what schizophrenia is and how it will impact his life. Also explain the three treatment options available, including the risks and benefits of each (Strategy 1).
- ✓ **Encourage** Mehul to be independent in choosing the course of treatment once he has gathered and understood all the information about each choice and the potential risks (Strategy 6).
- ✓ **Advocate** for Mehul, both in the home to ensure his decision is respected, as well as with any other individuals who may doubt his abilities because of his severe mental health problem (Strategy 7).

Service Provider DON'TS

- ✗ **Tell** Mehul which treatment to follow or explain only the options recommended by the service provider.
- ✗ **Persuade** Mehul to pursue a particular course of treatment, especially without explaining him all his options.
- ✗ **Provide** any treatment without Mehul's informed consent.

What should you do?

- Using SDM, Mehul's service providers should assume that Mehul has the capacity to make the decision about whether or not to receive medication. Furthermore, the service provider should ask him what his preference is, for instance an injection or oral medication, and which medication (Principle 2).

- The service providers should give Mehul the opportunity to make a potentially bad decision to refuse any medication – it's possible Mehul may become more agitated and possibly aggressive, but until his rights begin to infringe on the rights of others (i.e., he physically harms someone), his decisions must be respected (Principle 3).

Service Provider DO'S

- ✓ **Ask** Mehul how you can help him and offer to explain potential treatment options (Strategy 1).
- ✓ **Explain** the options and services available, such as counselling or medication (Strategy 5).
- ✓ **Encourage** Mehul to make his own decision regarding treatment, even if the caregiver offers consent (Strategy 6).

Service Provider DON'TS

- ✗ **Restrain** or seclude Mehul.
- ✗ **Give** Mehul any medication or treatment without his informed consent.
- ✗ **Allow** the caregiver to give consent on Mehul's behalf for any treatment.

Situation 3: Mehul arrives at the emergency room, and his caregiver tells the hospital staff that Mehul is having thoughts of self-harm, and the caregiver would like to admit him to the psychiatric ward.

What should you do?

- Using SDM, Mehul's service providers should assume that Mehul has the capacity to make treatment decisions and ask Mehul about his treatment preferences before asking the caregiver (Principle 2).
- Mehul's service providers should interview Mehul about his symptoms without the caregiver present if Mehul prefers to be interviewed alone, and even if the caregiver protests (Principle 5).

Service Provider DO'S

- ✓ **Have a conversation** with Mehul about any provisional diagnoses and explain his treatment options (Strategy 1).
- ✓ **Breakdown** the choice of potential treatment into simpler ones, such as where he prefers to be treated and who will be his mental health professional. (Strategy 2).
- ✓ **Encourage** Mehul to make his own decision about his treatment and to take responsibility for that decision (Strategy 6).

Service Provider DON'TS

- ✗ **Admit** Mehul to the psychiatric ward on the caregiver's word alone, without his consent.
- ✗ **Pressure** Mehul to pursue a particular course of treatment if he prefers a different option.
- ✗ **Use** covert medicine to treat Mehul if he refuses to take medication.

Situation 4: Mehul comes to the outpatient unit of psychiatry department for his therapy appointment, accompanied by his caregiver. In the past, Mehul has stated he does not mind if his caregiver is present during the therapy session. You notice that during the session the caregiver is speaking a lot about Mehul, while he is saying little.

What should you do?

- Using SDM, Mehul's service provider should ask Mehul if he prefers to have his caregiver be in the room during sessions or if he prefers to meet alone (Principles 1 & 2).
- Despite the fact that Mehul's caregiver likes the current arrangement, the service provider should support Mehul if he decides to change his mind and prefers to not have his caregiver present during the therapy session (Principle 4).

Service Provider DO'S

- ✓ **Have** a conversation with Mehul and inform him about the benefits and drawbacks of having therapy sessions with the caregiver present (Strategy 1).
- ✓ **Encourage** Mehul to be independent and make the decision he wants over what the caregiver wants (Strategy 6).
- ✓ **Support** Mehul's decision and advocate for it if the caregiver is upset (Strategy 7).

Service Provider DON'TS

- ✗ **Tell** Mehul that he should be happy with the current arrangement.
- ✗ **Permit** the caregiver to remain in the sessions if Mehul has changed his mind about the caregiver's presence.
- ✗ **Ask** the caregiver for their preference and act according to it.

Situation 5: Mehul would like to go watch a movie with his friends. The last time he was in a crowded place, he became very anxious and upset. His caregiver worries that if he goes for the movie, he may have a similar experience.

What should you do?

- Using SDM, Mehul's service provider and caregivers should understand that Mehul has the right to make the decision about whether or not to go watch a movie with his friends, even if accomplishing this decision requires some planning and support (Principle 1).
- Even though Mehul's service provider thinks it is a bad idea for Mehul to go to the movies with his friends, the provider should respect Mehul's decision and help him put an action plan in place in case he feels unwell (Principle 3).

Service Provider DO'S

- ✓ **Create** a safety plan with Mehul that lays out his preferences in the event he feels anxious, such as calling his service provider or having a friend helping him return home (Strategy 3).
- ✓ **Take time** to explain the concerns to Mehul and his caregiver, and make sure both understands the safety plan in case Mehul experiences difficulties (Strategy 5).
- ✓ **Encourage** Mehul to go to the movies with his friends and take ownership of his safety plan (Strategy 6).

Service Provider DON'TS

- ✗ **Tell** Mehul he cannot go to the movie.
- ✗ **Convince** Mehul's friends or Mehul's caregiver that he is too unwell to go out with his friends for a movie.
- ✗ **Tell** Mehul's caregiver to attend the movie with Mehul if he prefers to go only with his friends.

Situation 6: Mehul's advance directive states that he prefers to see his doctor before receiving any medication. He has also stated his preference for certain medication. While waiting at the hospital, Mehul gets agitated and the hospital staff tells the caregivers, who are Mehul's trusted support persons and are aware of his preferences, that they would like to get their consent to give Mehul calming medication.

What should you do?

- Using SDM, Mehul's service provider must remember that Mehul has the right to make decisions, even in crisis situations, though he may require more support to understand his options and act on a choice while in the situation (Principle 1).
- Mehul may make decisions or express preferences through his advance directive that his caregivers and service providers may not agree with; nevertheless, his will and preferences must be respected (Principle 5).

Service Provider DO'S

- ✓ **Ask** Mehul what things may help him calm down while waiting for his appointment, such as moving to a quieter room or listening to music (Strategy 3).
- ✓ **Insist** that Mehul be able to see his doctor prior to receiving any medication and advocate for his choice with other service providers (Strategy 6).
- ✓ **Explain** to other hospital staff that Mehul has an advance directive and make sure relevant staff have a copy (Strategy 5).

Service Provider DON'TS

- ✗ **Let** the caregiver make any treatment decisions on behalf of Mehul if he is able to express his preferences and/or has an advance directive.
- ✗ **Take** informed consent from the caregivers for any treatment unless Mehul has specified that this is ok in the event of a crisis.
- ✗ **Ignore** treatment preferences laid out in Mehul's advance directive or provide treatment without his informed consent.

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