

Manual on Supported Decision-making



– for Caregivers



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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 caregivers in incorporating supported decision-making strategies into their daily lives 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 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 supported decision-making in all areas of life for persons with disabilities, including health care and treatment-related decisions.

According to the Mental Healthcare Act, 2017, caregivers, 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 caregivers understand what SDM means 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 caregivers understand SDM and propose strategies they can use in their everyday live 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?

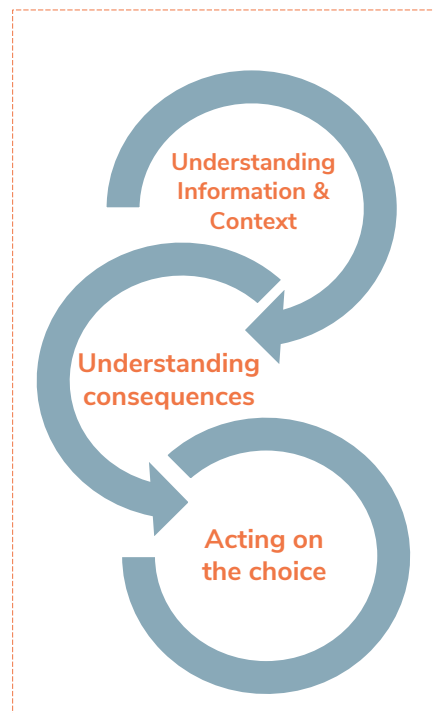
You want to buy a motorcycle but are not sure which model is best suited for you. You look up a few models, consult family and friends and have a chat with your mechanic on the models you are considering. Following more research and information regarding the choices available and inputs received from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

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 to a particular decision.

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

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-

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 may be 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.

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

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 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

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 may 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

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.

decision, Rajul can decide if they would like to be admitted in a hospital or prefer an alternative form of treatment.

4. Goals of Supported Decision Making

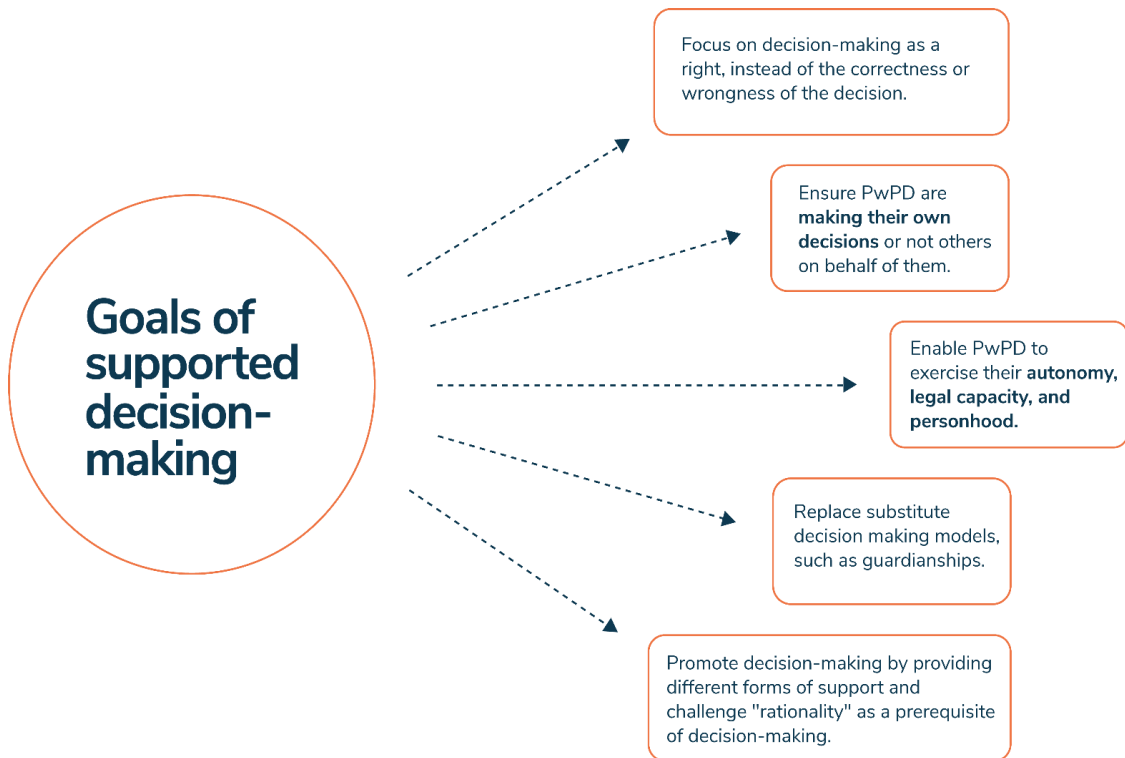


Figure 2: Goals of Supported Decision-Making

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.”

5. The 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

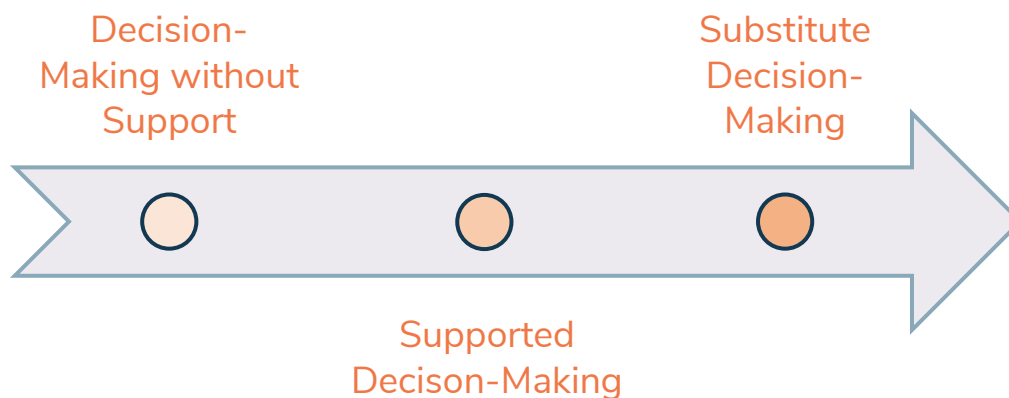


Figure 3: Continuum of Decision-Making

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 or not 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: _____

Witness 2: (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.

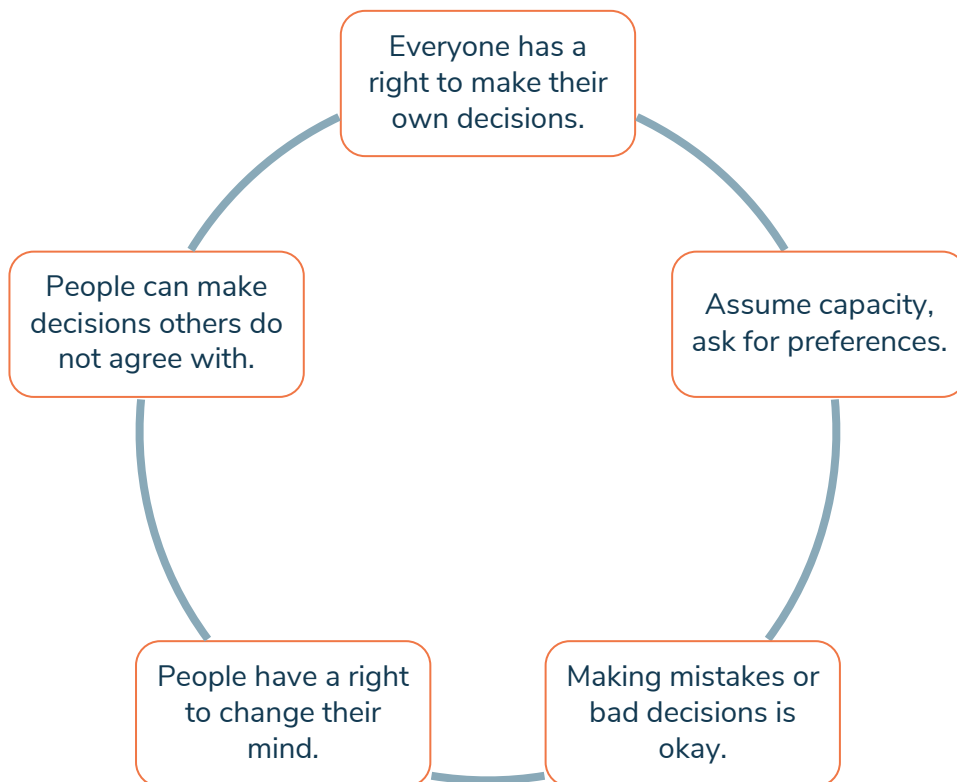


Figure 4: The 5 Principles of Supported Decision-Making

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 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

Supported Decision-Making Strategies for Caregivers

Since SDM is a fairly new approach, particularly in India, this guide provides some strategies to assist caregivers 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 a helping stance.

- One of the most basic ways a caregiver can make the shift toward supported decision-making is by changing their attitude and being encouraging instead of overprotective or more simply put, by taking a helping stance.
- Taking an educator stance involves encouraging independence, explaining important information and ultimately helping the person (making the decision) make their choice.
- To take an educator 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 or the language spoken by the service providers may not be understood by your family member or they may communicate using other means. In that case, ensure information is presented or translated in a language or form your family member can easily follow. In such scenarios, use your personal knowledge of how your family member prefers to communicate and help with translations.

Strategy 5: Make time for explanation.

- When trying to understand something that is particularly difficult, it often takes more 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 your family member, build time into your daily routines for explanation.
- When visiting others or professionals, remind them that it may take more time for your family member to understand something and ultimately make a choice.

Strategy 6: Promote independence and responsibility.

- Sometimes when we assume the 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 caregivers is that if they let PwPD make autonomous decisions, they may make bad decisions, and the caregiver would be held responsible. 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, caregivers can put safety nets in place, such as creating an action plan in the event of a crisis or having their

family member practice managing small amounts of money before progressing to larger sums.

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 caregivers since they also deal with service providers, other family members, other professionals, and society at large, who may not be familiar with SDM approaches.
- In some situations, it is up to the caregiver to tell others that their family member has the right to make their choices independently and that it may take longer or require more effort to make decisions. Furthermore, caregivers 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 Strategies in Practice

The examples below are intended to provide caregivers with potential ways to implement supported decision-making in various everyday situations. 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 living with a mild mental illness, typically doing well. He only requires moderate support from his caregivers. Every once a month or so, Mehul has an episode in which the severity of his symptoms is much higher than usual and includes hallucinations. On such occasions Mehul requires higher levels of support from both his caregivers and service providers.

Situation 1: Mehul likes to work on his computer until very late at night, but this worries his caregivers. They want Mehul to go to bed earlier so he can have a good night's rest. They tell Mehul he must go to bed by midnight every night.

What should you do?

- ✘ Using SDM, Mehul's caregivers should assume that Mehul has the capacity to make the decision of when to go to bed and ask him for his preferred time to sleep (Principle 2).
- ✘ The caregivers should also give Mehul the opportunity to make a potentially bad decision to stay up all night working on the computer – it's possible he may learn from the experience that staying awake all night affects his concentration and may even increase his symptoms, but regardless, the decision is his to make (Principle 3).

Caregiver DO'S

- ✓ **Have a conversation** about healthy sleep habits with Mehul (Strategy 1).
- ✓ Do **help Mehul understand** potential consequences of staying awake at night, including potential health impacts (Strategy 5).
- ✓ **Encourage** Mehul to make his own decision regarding when he sleeps (Strategy 6).

Caregiver DON'TS

- ✗ **Tell** Do not tell Mehul when he should go to sleep or impose a curfew.
- ✗ **Persuade** Mehul to change his sleep habits.
- ✗ **Give** Mehul medicines to make him fall asleep, especially without his knowledge.

Situation 2: Mehul has expressed to his caregivers that he wants to live with his friends rather than at home. While his caregivers are sad that Mehul does not want to live with them, they worry about what could happen if Mehul lived somewhere else. They would like to tell Mehul he cannot live with his friends.

What should you do?

- ✗ Using SDM, Mehul's caregivers should remember that Mehul has the right to make decisions affecting his life, including his living arrangements, even if he needs support in making the decision, such as finding a suitable flat and managing the rent (Principle 1).

- ✂ Mehul's caregivers must understand that Mehul can make decisions that they do not agree with, such as his choice of wanting to live with his friends or the location of the flat.

Caregiver **DO'S**

- ✓ **Have** a conversation with Mehul about ways to assist him in making the decision to move out and help him act on his choice (Strategy 1).
- ✓ **Explain** and break down the choice into simpler ones, such as where Mehul would like to live, what type of flat he would prefer, which friend(s) he would like to live with, how much he could pay in rent, etc. (Strategy 2).
- ✓ **Encourage** Mehul to make his own decision about living arrangements and to take responsibility for those decisions. Including upkeep of the flat and paying rent (Strategy 6).

Caregiver **DON'TS**

- ✗ **Tell** Mehul that he cannot live outside of the home.
- ✗ **Pressure** Mehul to live at home.
- ✗ **Assume** legal guardianship and prevent him from moving out of the house.

Situation 3: Mehul earns a modest salary working at a day care centre for persons with disabilities and generally relies on his caregivers for financial assistance, including for managing money. Whatever money Mehul earns, he hands it to his caregivers who then buy clothes, food, etc. on Mehul's behalf. Mehul had previously told his caregivers that he liked this arrangement, but recently has asked if he could manage some of his own money and finances.

What should you do?

- ✂ Using SDM, Mehul's caregivers should assume that Mehul will be able to make financial decisions and ask him which financial matters he would like to take more control of and what assistance he may need from his caregivers or others in doing so (Principles 1 & 2).
- ✂ Despite being happy with the current financial arrangement, Mehul's caregivers should encourage Mehul to change his mind about the current arrangement if he desires to do so (Principle 4).

Caregiver DO'S

- ✓ **Have a conversation** with Mehul about financial management, the various aspects involved, and how to best be of assistance (Strategy 1).
- ✓ **Practice** roleplays, such as paying for groceries or opening a bank account, to help Mehul understand financial management and learn other necessary skills (Strategy 3).
- ✓ **Simplify** the language of any relevant financial documents in a way that Mehul can understand (Strategy 4).

Caregiver DON'TS

- ✗ **Tell** Mehul that he should be happy with the current financial arrangement.
- ✗ **Assume** Mehul is incapable of handling financial matters or managing money.
- ✗ **Give up** on explaining various aspects of financial management, even if it takes time and creativity for Mehul to fully understand the information.

Situation 4: Mehul has told one of his caregivers that he would like to get a job in the community instead of working at the day care centre for persons with disabilities. Mehul knows his caregiver will not approve of him seeking alternate employment, because he thinks Mehul will make a bad choice of employers and make mistakes on the job.

What should you do?

- ✦ Using SDM, caregivers will need to give Mehul the opportunity and encouragement to make this decision, even if he ultimately chooses a job that causes him stress and he makes mistakes as an employee (Principle 3).

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.

- ✂ Caregivers must remember that Mehul can make decisions that they do not agree with, including the decision to seek employment in the community (Principle 5).

Caregiver DO'S

- ✓ **Breakdown the decision** to work into smaller parts such as where Mehul might like to work, what skills he has, what kinds of working environments he may enjoy, etc. (Strategy 2).
- ✓ **Encourage** Mehul to be independent, in finding his own transportation to and from work, choosing appropriate work clothes, and managing his salary (Strategy 6).
- ✓ **Advocate** for Mehul, at home to ensure his decision is respected, as well as with his potential employers who may doubt his abilities because of his disability (Strategy 7).

Caregiver DON'TS

- ✗ **Tell** Mehul he cannot work in the community.
- ✗ **Persuade** Mehul to work in places only the caregivers consider it "safe".
- ✗ **Discourage** Mehul from seeking other opportunities if he does not succeed in finding a job at first.

What should you do?

- ✂ Using SDM, Mehul's 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).

- ✂ Be understanding that if Mehul goes out with friends, he may later decide he would rather come back home before the movie is over (Principle 4).

Caregiver 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 make sure he 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).

Caregiver DON'TS

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

Situation 6: Mehul's caregivers would like for Mehul to get married.

What should you do?

- ✘ Using SDM, Mehul's caregivers should assume that Mehul has the capacity to decide whether or not he would like to get married and should ask him whom he would like to marry (Principle 2).
- ✘ Mehul has the right to choose his own partners, even if his caregivers disapprove of the partner, or even decide to not get married at all (Principle 5).

Caregiver DO'S

- ✓ **Ask** Mehul whether he would like to get married, explain both the positive and negative aspects of getting married (Strategy 1).
- ✓ **Encourage** Mehul to make his own decision, and if he decides to get married, encourage him to take appropriate spousal responsibilities (Strategy 7).
- ✓ **Help** Mehul find a suitable partner (Strategy 3).

Caregiver DON'TS

- ✘ **Tell** Mehul that he must get married.
- ✘ **Tell** Mehul whom to marry or what kind of partner to choose.
- ✘ **Get** Mehul married without considering his will and preferences or taking his consent.

Situation 7: Mehul is feeling unwell and tells his caregivers he would like to go to the hospital. Mehul has written an advance directive, expressing his treatment preferences in the event of not being able to make decisions for a particular period of time. In his

What should you do?

- ✂ Using SDM, Mehul's caregivers should assume that despite feeling unwell, Mehul has the capacity to decide whether he would like to be treated (Principle 2).
- ✂ Mehul's caregivers should respect his choice of seeking treatment at Hospital B, instead of Hospital A, even though his caregivers prefer Hospital A (Principle 5).

Caregiver DO'S

- ✓ **Ask** Mehul if he would like to go to Hospital A or Hospital B. If he is unable to express his preference, follow the advance directive (Strategy 1).
- ✓ **Encourage** Mehul to express his preferred choice of treatment and consider the treatment options he does not want (Strategies 3 & 4).
- ✓ **Help** Mehul create an advance directive in preparation for a crisis if he so desires and help him understand his options in case of a crisis (Strategy 5).

Caregiver DON'TS

- ✗ **Take Mehul** to Hospital A if he has expressed that he prefers Hospital B.
- ✗ **Leave** Mehul's advance directive at home – bring a copy to the hospital.
- ✗ **Assume** that Mehul will no longer be able to make decisions for the duration of the crisis – assume capacity on a decision-by-decision basis.

Situation 8: Mehul's advance directive states that he would prefer to see his doctor before receiving any medication, and in the event that his caregivers (who are his trusted support persons) think Mehul should receive medication, Mehul has listed his preferences for certain medications. Once at the hospital, Mehul becomes very agitated in the waiting room and the hospital staff tells the caregivers they would like to get their consent to give Mehul calming medication.

What should you do?

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

Caregiver DO'S

- ✓ **Ask** Mehul what things may help him calm down while waiting for his doctor, such as moving to a quiet room or listening to music (Strategy 3).
- ✓ **Insist** that Mehul be able to see his doctor prior to receiving any medication (Strategy 6).
- ✓ **Explain** to the hospital staff that Mehul has an advance directive and provide them with a copy (Strategy 5).

Caregiver DON'TS

- ✗ **Make** any treatment decisions for Mehul if he is able to express his preferences and/or has an advance directive.
- ✗ **Provide** informed consent on Mehul's behalf for any treatment unless he has specified that you may do so on his behalf in the event of a crisis.
- ✗ **Let** the service providers ignore treatment preferences laid out in Mehul's advance directive or provide treatment without his informed consent.

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