


# Shared Decision-Making in Mental Health and IDD



# Objectives for Today's Talk

- ❖ Understand the relationship between Shared Decision Making (SDM) and self-determinism
- ❖ Understand how consumers can apply principles of SDM to mental health decision-making
- ❖ Raise awareness about “voice” and “choice” in mental health





Range of Decision-making options based on individual's capacity

# Informed Consent in Mental Health

- Staff and family members can assist the consumer in collecting information, reviewing the information and problem solving.
- The fact that someone needs assistance to choose does not mean that they should not have a choice
- If it is clear someone does not understand and can not give informed consent on his/her own behalf, the surrogate (proxy, substitute) decisionmaker should base decisions on the known preferences, beliefs and values of the individual





## Helping people with decision making

- Supported decision-making means helping a person understand, make and communicate her own decisions.
- If someone makes her own decisions without support that is not supported decision-making
- If someone makes decisions for the person, that is not supported decision-making

## Supported Decision-making

# What is Shared Decision Making (SDM)?

- SDM is a major indicator of person-centered care. Health care practitioners and consumers can work together to make decisions about treatments, services and supports based on data to evaluate the relative risks and benefits of various approaches, expected outcomes of different courses of action (including taking no action) and they can balance this data with consumer preferences and values
- Providers and consumers agree on a plan
- The consumer has influence, input and control over his/her healthcare decisions



# Activities associated with SDM



- Learning about one's own health and understanding your health condition
- Recognizing that a decision needs to be made and becoming informed about the options
- Understanding the “pros” and “cons” of various options
- Using decision making tools to evaluate your options
- Preparing to talk to your health care provider
- Collaborating with one's health care team
- Adhering to decisions generated through shared decision making

# What are some decisions relevant to mental health?

- Do I **choose** to recognize that I have a mental health disorder?
- Do I **choose** to learn more about my disorder and best practice recommendations about treatment for my disorder?
- Do I **choose** to consult with others (which others?) about seeking treatment?
- Do I **choose** to seek the services of a psychiatrist or APN or consult with my primary?
- Do I **choose** to take the medications prescribed to me?
- Do I **choose** to attend a partial care program?
- Do I **choose** to pursue counseling or some psychosocial intervention?

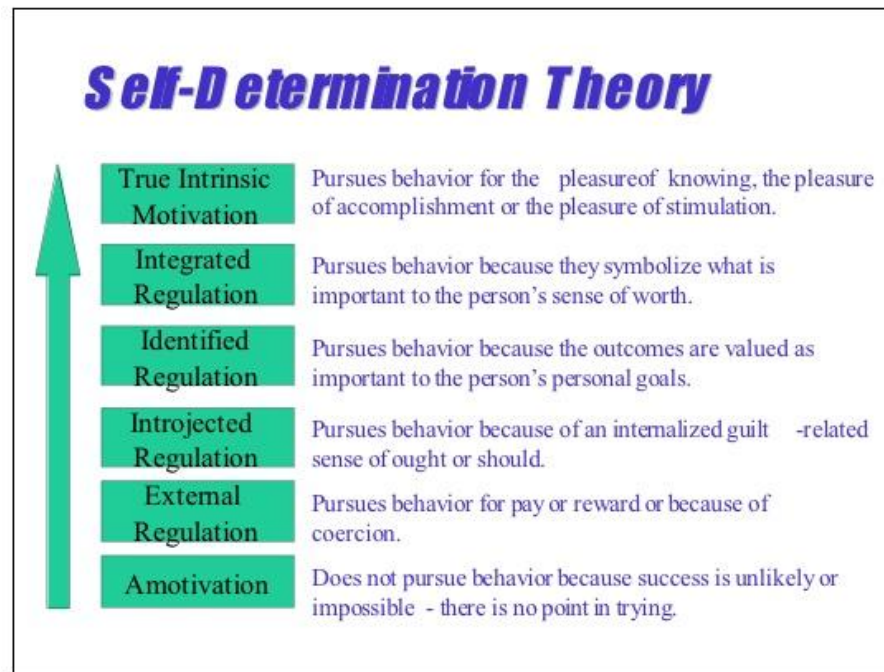


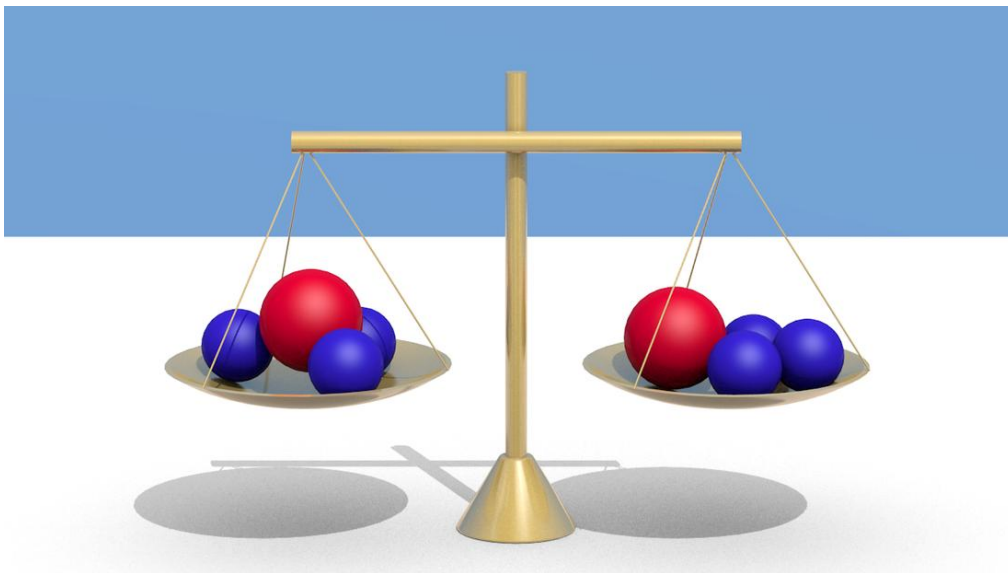
## What is the connection between decision-making and self-determination?

- To the extent that someone has input, influences and control his/her own decisions about mental health, that person is self-determining.



# How do we increase self-determination through decision-making?





## How to balance duty to care with support for choice, voice and self-determination

- We are trained to assist vulnerable individuals and act in ways that help keep them safe, but...
- Do the individuals we support have opportunities for choice, self-expression and self-determination?
- If someone is diagnosed with a mental illness or significant behavioral health challenge, does this preclude the individual's rights to live in accordance with his/her values and preferences?

# Person-centered versus Illness-centered care

- Driven by strengths and values rather than by diagnosis
- ✓ Holistic care
- ✓ Advances preferences and choices instead of needs and best interests
- ✓ Helps individuals reach their valued health outcomes
- ✓ Considers Quality of Life



# Misconceptions and Negative Stereotypes that impact upon our support of SDM

The doctor or mental health professional is the expert and knows better than the person with intellectual or developmental disability

Because the individual has a developmental disability, he/she is not cognitively capable of making decisions about his/her own mental health

Because the individual has a mental health diagnosis (including a history of hospitalization), he/she is incapable of making decisions about his/her life

Because the individual is dependent upon others for personal assistance, he/she is incapable of directing his/her own care

Because the person needs help in making decisions in one area, he/she cannot make his/her own decision in any area (globalization of incapacity)



## We all occasionally make poor choices...

- I am on an 1800 calorie diet to lose weight but I have ordered this for dessert last time I went out to dinner with my family
- I incurred many dirty looks and comments from my relatives who let me know in no uncertain terms (verbally and non-verbally) that they did not approve of my dessert selection
- Do I need someone to make my food choices for me or prevent me from eating out in restaurants? How can you engage me in a discussion about my choices without judging me or trying to control my choices? BTW, would you talk to my daughters and sons-in-law about this without getting my permission to do so?





We All Are Occasionally Unrealistic,  
confusing what we want with what  
we need or can obtain...

- I would like to live in a mansion in Monterey—however, I cannot afford to do so...
- Do I need a limited guardianship for residential decision-making if I insist that this is what I prefer as my residential arrangement?
- What are some of the ways in which you can speak with me or engage me in an exploration of my options and reach a realistic decision without foregoing control over my living situation?

## Why is shared decision making important?

- It is helpful when there is more than one reasonable option for care
- It is helpful when no one option has a clear advantage
- It is helpful when the possible benefits and harms of each option affect consumers differently
- To the extent that the consumer “owns” his/her own condition and is involved in managing it, that person is more likely to be adherent to treatment





STEP  
**1**

**S**eek your patient's participation.



STEP  
**2**

**H**elp your patient explore & compare treatment options.



STEP  
**3**

**A**ssess your patient's values and preferences.



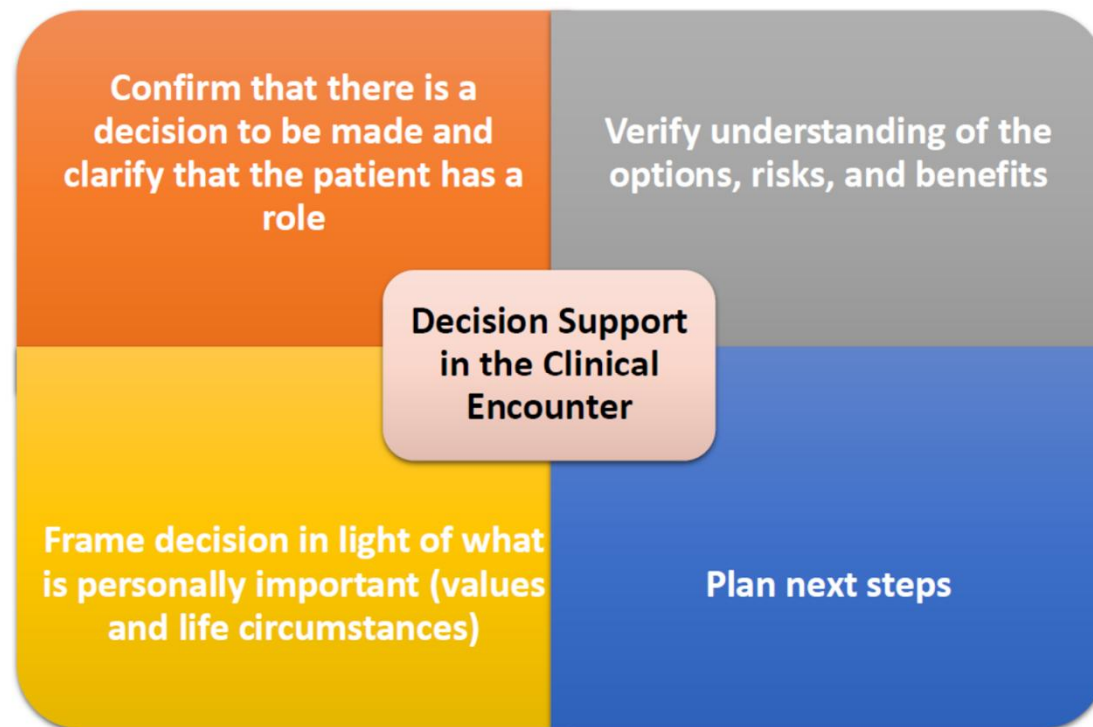
STEP  
**4**

**R**each a decision with your patient.



STEP  
**5**

**E**valuate your patient's decision.



<http://decisionaid.ohri.ca/decguide.html>

# Shared Decision Making

- Tools help with:
- Collaboratively setting goals for medical/mental health appointments
- Empowers a better conversation between health practitioner and consumer about care
- Provides opportunities, through reflective exercises, to raise awareness and build skills
- The consumer is more involved, more informed and health practitioners are more confident in their care provision

## SHARED DECISION MAKING TOOLS

Empowering Patients to Make Confident Decisions



**PATIENT/CAREGIVER + ADULT CHILD**

Collaboratively set goals for doctors appointment



**PATIENT/CAREGIVER**

Reflective exercises creates awareness and builds skills



**PHYSICIAN + PATIENT/CAREGIVER**

Patient/Caregiver is empowered to have a better conversation with doctor



**ADULT CHILD + PATIENT/CAREGIVER**

Adult child is more involved and informed while Patient/Caregiver has more confidence in their care decisions

# Choice presumes the ability to communicate



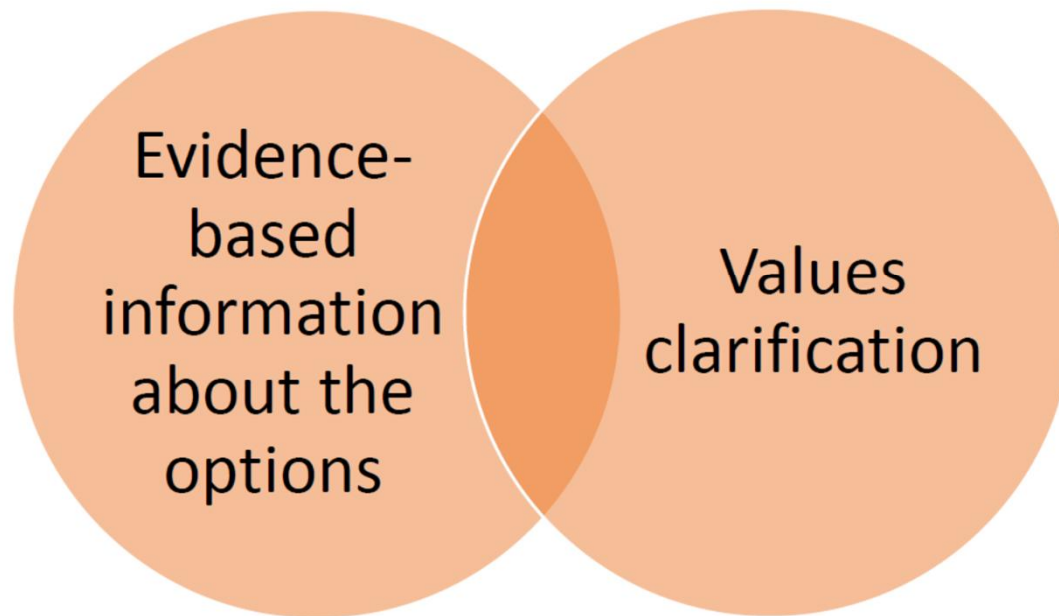
- Individuals with limited language skills need opportunities to express their wants, needs and preferences
- Picture Exchange Communication Systems (PECS)
- Communication Boards
- Pictorial Calendars
- Translators
- Voice and Choice



## Lifestyle options to consider including positive routine

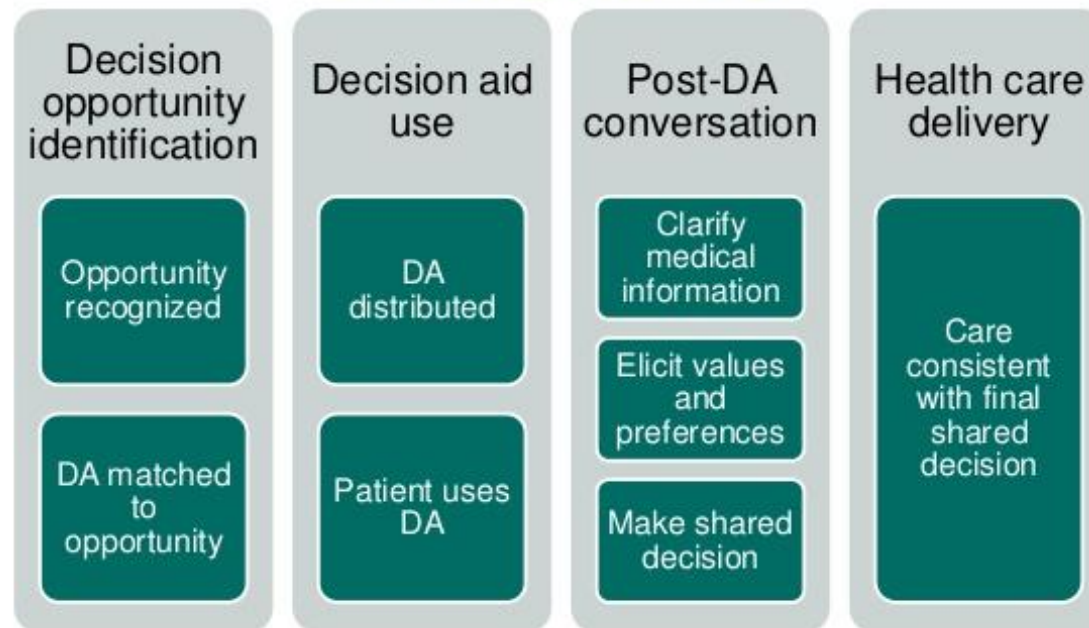
- Includes choice in activities
- Meaningful work and activity
- Balances necessary tasks with preferred activities
- Provides opportunities for social connection
- Provides opportunities for skills building
- Includes opportunities for exercise and movement
- Best practice mental health treatment usually involves medication management of symptoms and psychosocial intervention

## Decision Aids

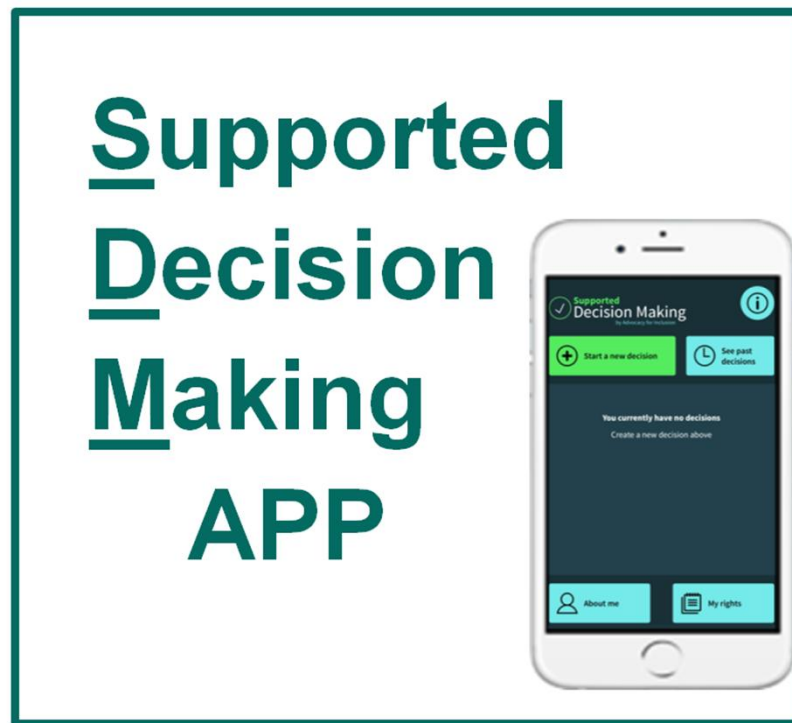


<http://decisionaid.ohri.ca/decguide.html>

## ***Key Steps of Shared Decision Making Based on Decision Aids***



# Supported decision-making





# Decision Aids

## Decision Aids

- **Designed to**

- Provide information on options
- Help people participate in decision making
- Help clarify and communicate personal values

- **NOT designed to**

- Advise people to choose one option over another
- Not meant to replace physician consultation

**PREPARE PATIENTS TO MAKE  
INFORMED, VALUES-BASED DECISIONS  
WITH THEIR PHYSICIANS**



## Cochrane Reviews of Decision Aids

Improve

- knowledge

Improve

- realistic expectations

Lower

- decisional conflict

Improve

- patient – practitioner communication

Source: Stacey D, et al. Cochrane Database of Systematic Reviews 2014, Issue 1 .

# A Conversation about Bipolar Disorder

- Your doctor has said you have Bipolar Disorder. Tell me how you understand this and what you know about this condition?
- What does it mean to you to have this condition?
- What do you think you need to manage your problem well?
- Who else is involved in helping you to make a decision?
- There may be other decisions you have to make because of your condition. If I understand something about your preferences, I will be better able to help you

## Additional ways to introduce the SDM Conversation

- *We have several ways of helping someone with a diagnosis of Major Depression. Let's work together so we can come up with the decision that's right for you.*
- People have different goals and concerns. As you think about your choices, what's important to you?
- *Do you want to think about the decision with anyone else? (family member, friend, clergyman, psychologist, another staff person...). Is there someone else who will be affected by your decision? Is there someone who might be able to help you sort things out?*

# Tips for Shared Decision Making

- Invite the consumer to participate in care planning
- Present available and realistic options
- Provide information regarding the benefits and risks of various options including choosing to do nothing
- Ask the consumer what she is concerned about and what is important to her
- If the consumer is having difficulty making a decision, let her know she has time to think things over, and that you are glad to answer any questions she may have. Find out what other information or support she may need in order to make a decision
- Lay out the next steps, check for understanding, and discuss any barriers to carrying out the decision



**Dartmouth Center for Shared  
Decision Making**

[http://med.dartmouth-hitchcock.org/csdm\\_toolkit.html](http://med.dartmouth-hitchcock.org/csdm_toolkit.html)

**Ottawa Hospital Research Institute**

<http://www.ohri.ca/home.asp>

**Mayo Clinic**

<http://www.mayoclinic.org>

Resources

# How can we promote SDM in mental health

- Increase opportunities for functional communication (voice)
- Increase opportunities for choice
- Widely disseminate information about mental health and relevant treatment
- Be available to answer questions, elicit conversation on informed consent and differentiate among supported, shared and substituted decision-making

