

# Practical tools to support decision making

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# Webinar Agenda

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- What does it mean to “support decision making”?
- Tool Box 1: My beliefs and values.
- Tool Box 2: An ethical framework to support person-centred decision making.
- Tool Box 3: Understanding how communication influences a person’s ability to make decisions.
- Tool Box 4: Tips and resources to support inclusive communication.
- Every day life.



# What does it mean to “support decision making”?



- Balancing independence versus inter-dependence
- Expanding civil rights – to make them effective – not limiting them.
- Providing supports that .... build capacity.
  - .... promote the centrality of will and preference.
  - .... assist a person to make choices and decisions.
  - .... enable people to understand and express.
- Providing supports that are person-centred, local and community based.

# What does it mean to 'support decision making'?

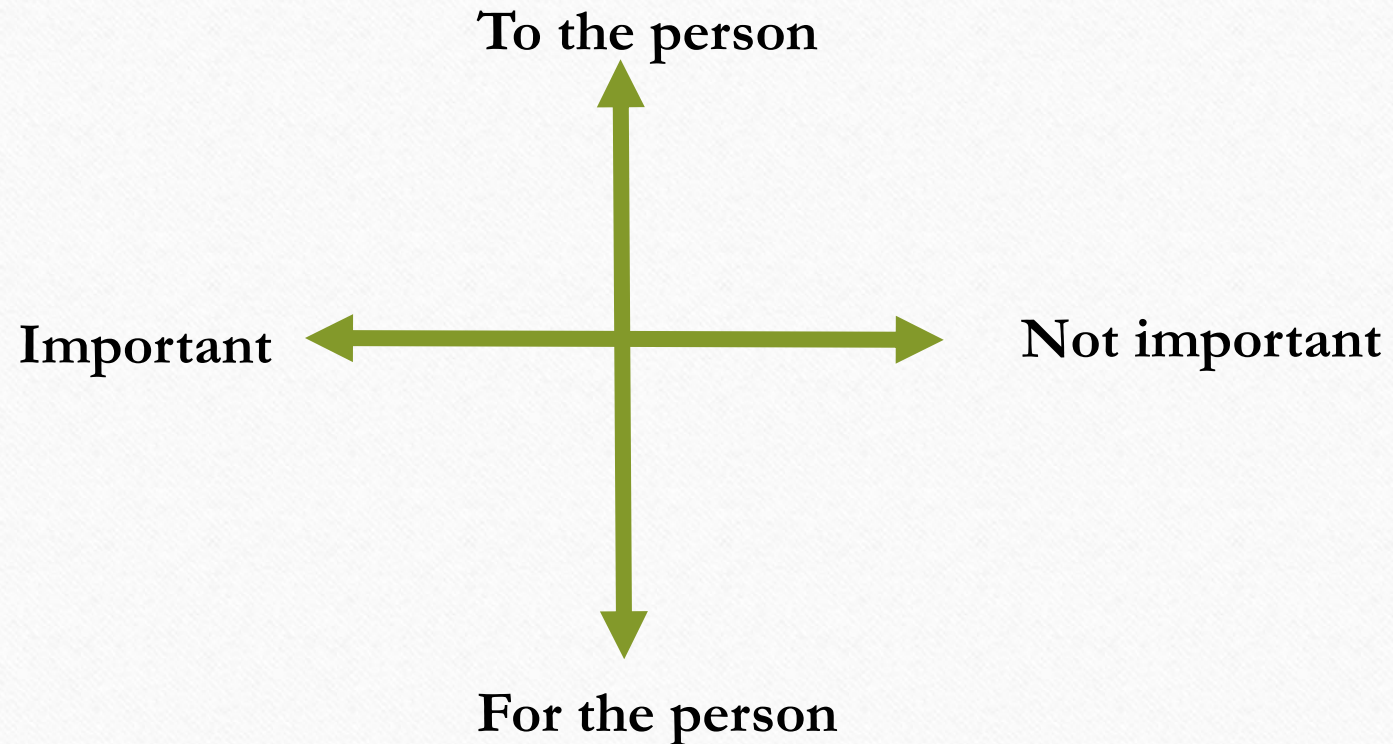
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# What does it mean to 'support decision making'?

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The value is to be found in supporting a person to make their own decision regardless of my perception of how complex or important the decision appears to be.

*Not for me to decide what decisions are important to a person.*

The basic premise should be the same – I work to support people to make their own decision whenever and however possible –ensuring people have the EXPERIENCE of making decisions, thereby developing their own confidence and competence to do so.

# What does it mean to “support decision making”?

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- Gerard Quinn (2013) reminds us that how we support people to be involved in and make their own decisions will evolve as our experience in doing this evolves.
- He also says that supports and tools we use to support decision making should look outwards i.e. beyond the person themselves ....
- And many of the tools I touch on today aim to do exactly that.



# TOOL BOX 1 – My beliefs and values

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- *My belief that the person has capacity* to make their own decisions unless/until the contrary is shown.
- *My ability to observe* the person's will and preference
- *My intention to really understand* the specific decision that is to be made and *to understand the implications* of the outcome of the decision.
- My understanding whether *this decision is important to the person or important for the person*



# TOOL BOX 1 – My beliefs and values

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- *My influence over the timeline* for making this decision – hugely variable and to *advocate* for more time if it's needed, wherever possible.
- *My co-ordination of who* is getting involved. And to be *assertive* in identifying that only those in the person's agreed circle of support should be getting involved.
- *My knowledge of people's right to receive information in a way they understand and my commitment to upholding that right*

# Theory versus practice

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# Self-reflection

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- During the pandemic, it could be said that some of these beliefs and values have sometimes been challenging to fully implement. Or situations have become even more complex.
- *Has it been challenging for YOU as a healthcare worker?*
- *Has it been challenging in YOUR SERVICE?*
- *Is there SPACE, for you or your service, to acknowledge these challenges?*
- *What tools do we need to do something about it?*

# TOOL BOX 2: An ethical framework to support person-centred decision making (SMH, 2020)

## A: The Decision

(reasonableness, openness, transparency)

1. What decision(s) need(s) to be made?
2. Why do we need to make this decision?
3. Who needs to be involved in making this decision?
4. What options are there (including not acting)?
5. Consider the risks and benefits of all options.

## B. Involvement of the Person in the Decision Making Process

(inclusiveness, person-centredness, consent)

1. Have you established the person's will and preference?
2. What steps will support the person to engage in the decision making process?
3. Has the person accessible information about the situation?
4. Nominate a support person for the service user.
5. Support person explains options and info. to the person.



# Ethical Framework, contd.

## C. Make a Decision

1. Does the proposed measure minimise harm?
2. Is the proposed measure proportionate (to the benefits of doing it and the risks of not doing it)?
3. Is it fair and reasonable? (Does it treat the person as equal to all others? Is it based on best evidence?)
4. Are we fulfilling our duty to provide care?
5. Is the decision making process open and transparent?
6. Have all key stakeholders been included?

## D. Make a Plan to Review/Revise the Decision (responsiveness, accountability)

1. Is the decision making responsive? (How will it be revisited as the situation changes? How will complaints/appeals be managed?)
2. What are the systems of accountability? (Who is responsible for the decision? Who has oversight?)
3. How has all of this recorded in the person's file? (rationale for decision and the process)

# Examples of ethical framework in practice

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- How to best support service users who have to self-isolate for reasons associated with COVID.
- How to manage requests for visits by SMH residents to family homes and visits to SMH house residences by family members.
- How to best support service users who have had limited or no access to traditional day services since the beginning of the year.
- How to balance the will and preference of one individual with the will and preferences of all those they live with.
- How to decide whether exceptions to restrictions needed to be explored and under what circumstances.



# Communication and person-centred decision making

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- A person's communication strengths and needs WILL influence their ability to contribute to decision-making processes.
- This is because communication difficulties can make it more difficult for people to understand, think and talk (or communicate about) about decisions.

## TOOL BOX 3:

# Understanding how communication influences a person's ability to make decisions

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- Auditory memory – retaining information provided verbally in the short term and longer term.
- Visual memory – retaining visually presented information.
- Symbolic understanding – person's ability to understand visual information : objects, colour photographs, black + white photos, line drawn symbols, printed words.
- Verbal (Language) comprehension – understanding the basic concepts of what is being considered; the load of information in each sentence used; the complex grammar structures (if..... because... probably... since... although); the choices being put before them.



## TOOL BOX 3:

# Understanding how communication influences a person's ability to make decisions

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- Expressive communication ability – having access to the right communication system – how does the person communicate expressively? Do they use verbal language or other means? If they do communicate verbally, do they have access to the right vocabulary to express their opinions around this topic, are they able to form sentences to discuss options and ask questions?
- Social/ Pragmatic skills – Have much experience does the person have in making decisions and in communicating their opinions? Are they comfortable expressing their thoughts in an assertive way? Have they got the opportunity to do so?

# Communication and person-centred decision making

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People with communication difficulties must be supported to:

- Make decisions,
- Demonstrate their strengths and abilities, and
- Express their wishes and preferences about different decision options.

An accurate understanding of a person's communication strengths and needs directly relates to our estimate of a person's ability (capacity) to make a decision in their lives.



# RCSLT (2018)

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- “Mental capacity assessors” who are not able to identify and support individual communication needs effectively may make inaccurate judgements about a person’s mental capacity
- People who are erroneously judged to lack capacity will be denied the opportunity to make autonomous decisions.
- People who are erroneously judged to have capacity may not fully understand the implications and consequences of the decisions they are asked to make.
- People’s health and quality of life may be affected negatively if they are not fully supported to participate in decisions about their care and treatment.

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# HOW?



# Inclusive Communication

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- **What is inclusive communication?**
- Inclusive communication is an approach to communication which enables as many people as possible to be included in that interaction.
- This approach:
- Recognises that all human beings use many ways of understanding and expressing themselves.
- Encourages, supports and enables people to use whatever ways of understanding and expressing themselves which they find easiest.

RCSLT 2018

# Inclusive Communication.





# TOOL BOX 4: Tips and Resources to facilitate inclusive communication

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- Person-centred decision making with people with complex communication needs will take time. What is within your control? Make the most of what time is available to you.

- Learn about the person's communication profile –

(A) What are their everyday receptive (i.e. comprehension) skills and what supports increase their understanding (e.g. objects, photographs, pictures, Lámh, sign language, written language)?

(B) Do they communicate verbally (single words, phrases, sentences) or non-verbally (vocalisations, body movements, body language, eye contact, gestures)?

(C) What is the person's preferred ways of communicating? Do they use alternative methods of communicating? (Lámh, visual supports, AAC devices)

**Really listen to what the person is communicating to you – regardless of how they are communicating that information.**

# TOOL BOX 4: Tips and Resources to facilitate inclusive communication

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- Ask the person themselves about their preferred methods of communicating.
- Talk to someone who knows the person well and ask them for information about the person's communication profile – family, friend, support staff.
- Read the person's **Communication Passport** or **Hospital Passport**(please!)
- Speak to a front line staff member or clinician from the person's service (Person-In-Charge, Key Worker, Speech and Language Therapist, Psychologist, Psychiatrist, Social Worker etc.) and ask them for support/ input.
- Referral to Speech and Language Therapy if required.
- All with consent!



## TOOL BOX 4: Tips and Resources to facilitate inclusive communication

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- Remember, we want supports to ‘look outwards’ – so not just about the person’s inherent skill set.

# TOOL BOX 4: Tips and Resources to facilitate inclusive communication

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- Communication Environment:





# TOOL BOX 4: Tips and Resources to facilitate inclusive communication

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## Be a Supportive Communication Partner

- Make it easier to pay attention

-Gain the person's attention, reduce distractions, reduce background noise

## Make listening easier (say less)

-Use simplified (reduced) language, chunk instructions and information.

## TOOL BOX 4: Tips and Resources to facilitate inclusive communication

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- Make it visual (Show me)
  - Use visual supports (pictures/photographs/objects).
- Make it multimodal (stress)
  - Use a total communication approach, by combining gestures, visuals, Lámh, body language, facial expressions.
- Give time (Go Slow)
  - Some people need 10+ seconds to process and respond to verbal information.



# Every day life examples: Communication Passport

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- Communication Passports describe how a person communicates and how others should communicate with them. They are practical and person centred documents. Information is clear and easy to understand and presented in an accessible way if meaningful to the person. They are helpful when new or temporary staff or volunteers meet the person, to get to know the person's communication better and how best to help them communicate.

# Communication Passport



My name is Christopher.  
I like you to call me Christy.  
This is my communication passport.  
Please read it.  
It will help you understand how I  
communicate and how you can  
communicate with me.



## How I make choices

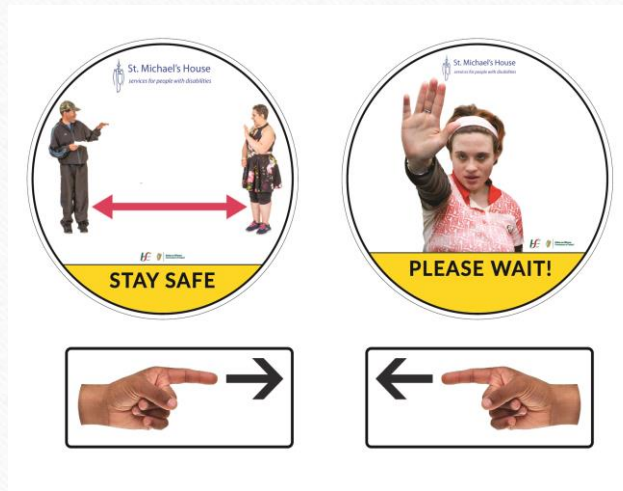


- I make my choices using words. I will tell you what I want.
- If you don't understand me, you can show me some objects or pictures and ask me to choose. I can point at what I want.
- It helps me when you offer me choices in the real life context (i.e. give me options about dinner when I'm in the kitchen)
- It is important to me to choose what I wear, what I eat, and what I am going to do in the evening.



# Every day life examples: Accessible Information

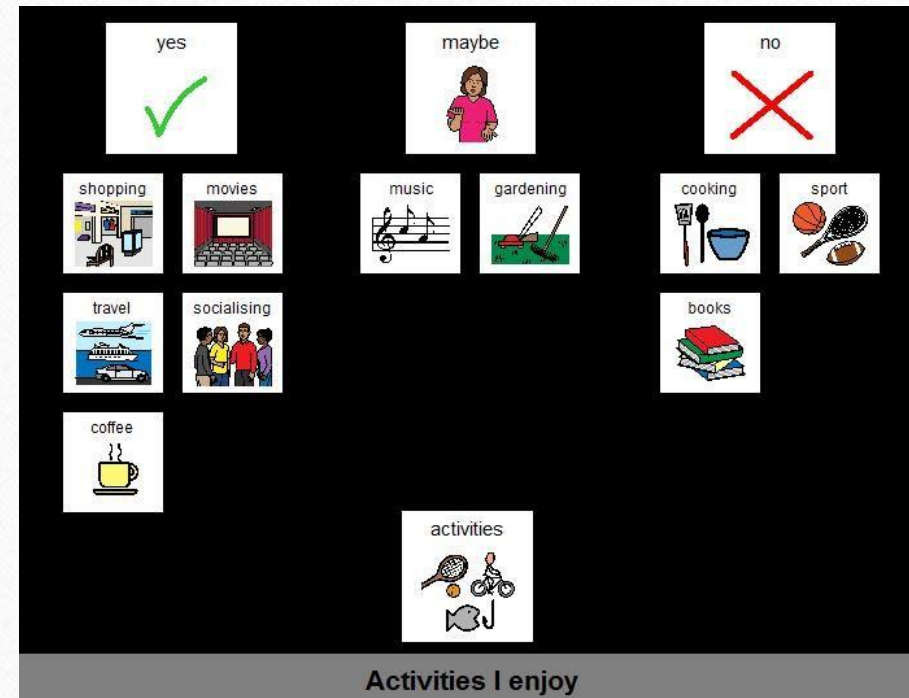
- Giving people meaningful information in a way they can understand.
- Accessible information can look very different for different people



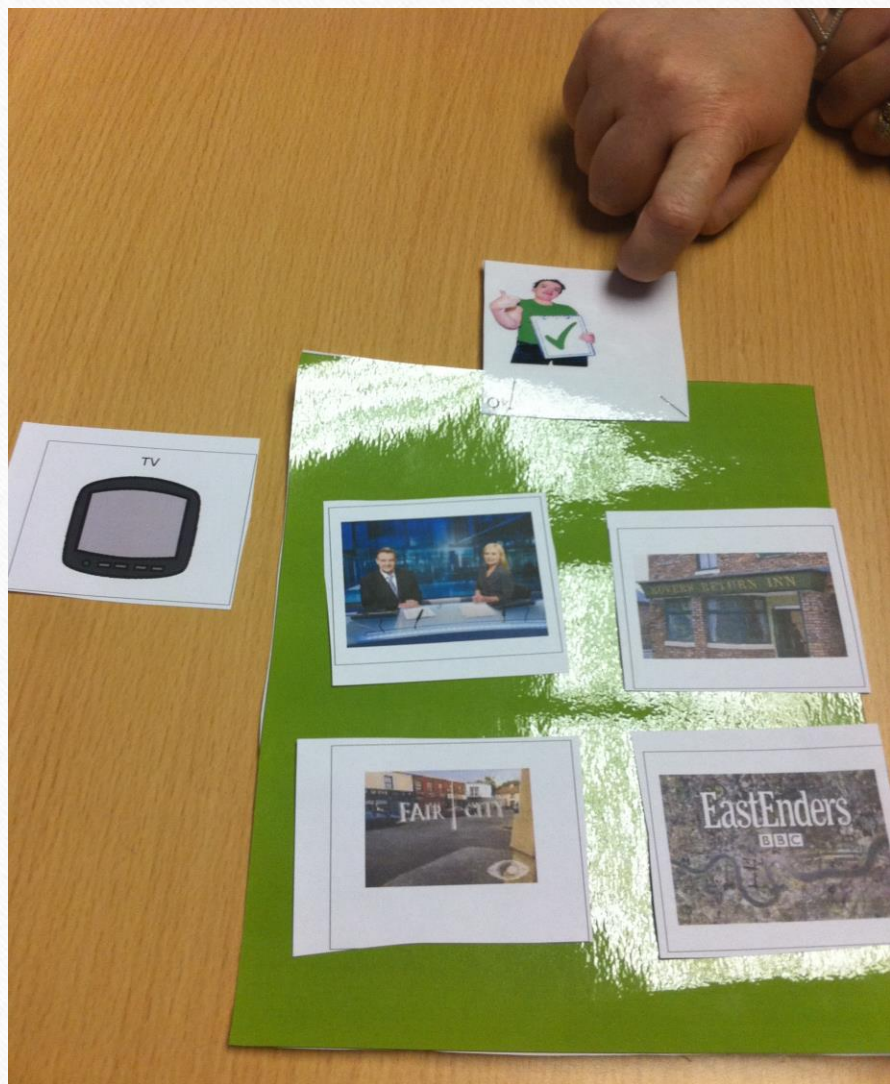
Going to the hospital with Coronavirus.	
	I am very sick. I have Coronavirus.
	I need to go to hospital.
	The nurses and doctors in hospital will take care of me.
	They will wear safe clothes. They will wear an apron and gloves.
	They will wear special goggles called goggles.

# Every day life examples: Talking Mats

We often use Talking Mats to find out what a person thinks about a topic. The aim is to facilitate a topic of discussion using pictures and a mat. Often, the person is shown a series of pictures about a topic and they use the mat to show what is important to them or not important to them, or what they like/don't like.













# Every day life examples – from Olwen O'Meara (SLT, St. Michael's House)

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- A service user with an intellectual disability who needed support around their decision to use a medical device.
- They were prescribed a medical device to be used every night following discharge from hospital. The person found it difficult to consistently use it, and a staff member found that there were no accessible health education materials available to explain the basis for the device to the individual.
- The staff member thought about the person's current communication profile. The staff member then created a document to support the person to understand why they needed to use the device, how to use it, and what the benefits were of using it. The service user was supported using these new materials to successfully use the device, as it was presented in language they understood, and with visuals.
- The original document was then brought to the SLT department, and adapted with the support of a consultation group of service users (some with experience of the device itself).
- The group created an easy read guide on how to use the medical device. It is held by the nursing department and can be individualised for anyone who needs to use it. It has been used in SMH and outside SMH to support individuals using this device.

# In conclusion

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I can support decision making by :

- ✓ Checking in on my beliefs and values.
- ✓ Applying an ethical framework.
- ✓ Understanding how communication influences a person's ability to make decisions.
- ✓ Using tips and resources that support inclusive communication.