

Supported Decision Making: What Does It Look Like?

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Exercise

- Think of a time when you had to make a major decision. How did you make that decision? Who was involved?
- Think of a time when you had to make a decision and you didn't feel you had enough knowledge or expertise to make it. What did you do?

Outline

- **Supported decision making**
 - Definition
 - Use
 - Values
- **Background**
- **International & provincial laws**
- **Cases**
- **Concerns**
- **Discussion**

What is Supported Decision Making?

- **An alternative to guardianship or substitute decision making that involves providing appropriate, tailored assistance to individuals when they need it with making decisions**
 - Support is provided by a support person, support network or an advocate
 - Governed by legislation in some jurisdictions

Supporting Decision Making

- **Support network**
 - Family, friends
 - Court-appointed or volunteer advocates
- **Relationship**
 - Identify values
 - Understand the individual
 - Good communication is essential

Roles – Support Person/Network

- **Explains issue(s) (if necessary)**
- **Explains options (if necessary)**
- **Ensures understanding**
- **Provides guidance through the decision process**
- **Interprets signs and preferences of the decision maker (if necessary)**
- **Reminds others of personhood and capacities of the decision maker**

Who Can Use Supported Decision Making?

- **Anyone whose capacity to make decisions is for some reason reduced or fluctuating**
 - Individuals with cognitive disabilities
 - Individuals with dementia and similar conditions
 - Individuals with psychiatric disabilities
 - Children
- **Formal requirements**
 - Individual is able to understand what supported decision making is and what it means for them (Yukon)
 - Individual is able to make a representation agreement (BC)

When Should Supported Decision Making Be Used?

- **Depends on context**
 - Some agreements specify contexts where support is needed
 - Should be responsive to actual needs for support
- **Proportionality**
 - "Responsive to impact on rights and interests"

Background]

“**MINDFUL** that persons with intellectual disabilities have often been excluded from decisions about their human rights, health and well-being, and that guardianship laws have historically been used to deny persons with intellectual disabilities their right to make decisions;...” (The Montreal Declaration on Intellectual Disabilities)

Natural Lack of Capacity

- **People with disabilities, especially cognitive and psychiatric disabilities, are presumed to lack capacity**
 - People with cognitive/intellectual disabilities are not given opportunities to develop skills necessary for autonomy
- **People with reduced or fluctuating capacity are often presumed to lack autonomy in all aspects of life**

Guardianship & Substitute Decision Making

- **In these cases, someone is appointed to make decisions for an individual**
- **Guardianship**
 - Decision maker appointed by court order
- **Substitute Decision Making**
 - Decision maker appointed by individual or by legislation

Disability Rights Movement

- **Emphasizes the fundamental equality of all people with disabilities**
- **Reacting to a history of segregation, social exclusion, warehousing, paternalism, and being denied the opportunity to make decisions for themselves**

From Paternalism to Autonomy

- **Social, legal, and medical shift from an acceptance of paternalism to an emphasis on individual autonomy as an important value**
- **No one is better situated to evaluate what is “best” for an individual than that individual herself/himself**
- **People with disabilities continued to experience increased paternalism and reduced respect for their autonomy**

Autonomy, Personhood, and Equality

- **Capacity for autonomy linked to status as a person (and therefore a right holder)**
- **Personhood as an essential aspect of equality**
- **Recognition of autonomy particularly important for equality for people with disabilities**
- **Presumption of capability (until incapacity is empirically demonstrated)**

Autonomy and Decision Making

- **Right to make decisions includes right to make “bad” decisions**
- **Tend to focus more on questions of capacity when the person is making a decision that the health care team doesn’t agree**
- **3 aspects of informed consent:**
 - Informed
 - Capacity
 - Freedom from coercion

Relational Autonomy

- **Recognizes impact of oppression on capacities for autonomy**
- **Understands autonomy as something developed through relationships and interactions with others**

Supporting Decision Making

- **Make information accessible**
 - Plain language translation
 - Explore alternate methods of communication
 - Ensure understanding
- **Build capacity**
 - Model process of working through decisions
 - Experience with decision making and consequences of decisions
- **Ensure freedom from coercion**
 - Multiple conversations
 - Multiple supporters
 - Independent advocates and monitors
 - Formal processes – e.g., appeals

The “Dignity of Risk”

Places “greater value on respecting the individual’s right to decide – even when a person’s choices may seem foolish to others – than on protecting the “best interests” of the individual” (Hommel 230).

Values and Supported Decision Making

- Respect for persons
- Respect for personal autonomy
- Equality
- Inclusion
- Avoiding harm

Legislation

- **International Law**
 - PAHO/WHO *Montreal Declaration* (2004)
 - UN *Convention on the Rights of Persons with Disabilities* (2006)
- **Canadian Context**
 - Manitoba: *Vulnerable Persons Living with a Mental Disability Act*
 - British Columbia: *Representation Agreement Act*
 - Yukon: *Adult Protection and Decision-Making Act*

Substitute Decision Making

- **Last resort and a temporary measure on the supported decision making model**
- **Based on (in ranked order)**
 - Wishes
 - Values
 - Best interests

Cases

- **Case #1: Coffee and Donuts for Breakfast**
 - How would this case be different if supported decision making techniques were used?
 - Why might it be beneficial to use supported decision-making in this case?
- **Case #2: Selling the Farmhouse**
 - How would this case proceed differently if supported decision making was used?
 - Why might it be beneficial to use supported decision-making in this case?

Concerns with Supported Decision Making

- Potential for abuse
- Resources
- Commitment for members of support network
- Appropriateness of supporters
- Avoiding unintentional paternalism
- Avoiding unintentional neglect
- Resolving conflicts
- Assessment of suitability for supported decision making
- Others?

Resources

- See handout

Questions and Discussion
