

# Consent, Capacity and Developmental Delays

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## Consent and Ethics...

- Ethically based informed consent goes far beyond "agreeing to" or the "granting of" permission.
- It is rather the respectful process of providing information, answering questions and aligning the proposed intervention with the values and wishes of the client.

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## Benefits of assessing consent and respecting consent ....

- Not only does respecting a person's capacity have legal and ethical importance it can result in increased respect and improved quality of life.
- It is important to be certain that 'client centered care' is actually working for client self determination. It is easy to go wrong in this area.

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## Ethics, autonomy advocacy

- Generally our first duty is to autonomous choice before health care perceptions of best interests.
- Well established in law.
- Advocacy is first directed to capable patient choice.

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## Risk aversion in the helping professions..

- Risk aversion tends to be high for many staff and families working with people with developmental delays.
- Risk avoidance tends to be linked to professional responsibility and perceptions of competence.
- Perceptions of risk has deep social and cultural roots with people with developmental delays.
- May blunt our duties toward advocacy and personal choice.

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## Diagnosis by observation..

- To infer a person's internal subjective experience when the person is unable to describe it directly.
- Much of the commonly used psychiatric classification system, *DSM-IV-TR*, relies on the patient's **description** of how he or she **feels**.
- The care giver attempts to deduce the person's mental or emotional state from his/her behaviour.

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## Are we asking the right questions?

- Can She manage independently?
- Is she capable of making this decision?
- Can he manage this program?
- What does he want to do?
- Is he safe?
- Can we make the environment safer?
- What does the family want us to do?
- How can we maximize safety and functioning and well being?

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## Consent and Capacity

Treating and understanding individuals with developmental delays research suggests....

- The amount of time given by health care workers for individuals with developmental delays for processing information was often inadequate.
- In some residential community settings, there was little in the way of exercising choice regarding a broad range of activities including where to live, leisure activities and even what to eat.
- Further studies using picture communication symbols with intellectual delays showed many clients had the ability to express dislikes and likes on topics including leisure, people, transportation and daily activity.
- Allowing individuals with intellectual delays to have choice greatly promotes self-esteem and independence.

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## Consent is a human right ....

- We tend to teach and discuss consent without focusing on the purpose of consent laws.
- It is important to remember what has happened in the past to fully understand why we do this.

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### Why is consent such a problem?

- Research shows that a significant number of people in health care and the helping professions do not fully understand the legal and ethical foundations of consent.
- A great deal of confusion exists related to "best interests".
- What training modeling are new staff receiving?

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### Consequences of respecting consent

- There will be some clients living with higher risks.
- Clients who may well respond to treatment may not receive it.
- May be difficult for families.

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### Attitudes toward people with intellectual disabilities just barely emerging from paternalism

- Moral obligation to 'protect the vulnerable'
- Slowly moving from 'protecting the vulnerable' to 'assisting the vulnerable'
- Our perceptions of best interest can be a great challenge in respecting independence and choice

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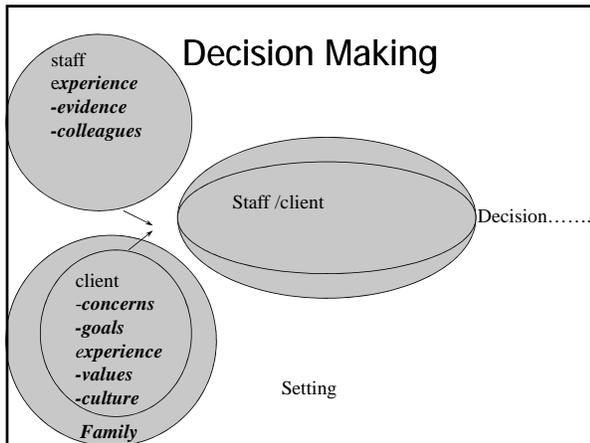
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- ### The anatomy of consent
- Must be voluntary
  - Must be capable
  - Must be informed

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- ### Voluntary
- Protection from contrary family opinions
  - Protection from contrary helping profession opinions
  - Must not be obtained with any sense of obligation or indebtedness to care givers.

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### Capable....

- Not a matter of *our* interpretation of best interests
- Does the client *understand* what is being proposed
- Does the client *appreciate* what is being proposed.

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### Remember ....

- *Clients can* disagree with staff and still be capable....

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### What is capacity?

*A person is considered to have capacity with respect to making a treatment decision if he/she:*

- A) has the ability to *understand* the information that is relevant to the treatment decision
- B) is able to *appreciate* the foreseeable consequences of consenting or refusing to consent to treatment
- C) is able to reach a decision

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Criterion 1:  
***Understand***

- As a construct, to 'understand' refers to a person's cognitive abilities to factually grasp and retain information.
- To the extent that a person must demonstrate understanding through communication, the ability to express oneself (verbally or through symbols or gestures) is also implied.

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Criterion 2:  
***Appreciate***

- Can the client evaluate his/her decision?
- The 'appreciate' standard attempts to capture the evaluative nature of capable decision making, and reflects the attachment of personal meaning to the facts of a given situation.
- Explores ***both*** patient's reasoning process and personal meaning given to various outcomes

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Presumption of Capacity

- It is important to explore the legal tenet of 'presumption of capacity' further. The Capacity Assessment Office of the Ontario Ministry of the Attorney General states that there should be ***reasonable grounds*** to prompt an evaluation of capacity.
- "Routine screening of whole classes of individuals cannot and should not be endorsed, as this prejudices an individual's capacity based on class membership. For example, it is incorrect to assume that all intellectually disabled persons must be incapable by virtue of their disability."

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## Understanding "ability...."

- "... The *Health Care Consent Act* requires a person to have the **ability** to appreciate the consequences of a decision.
- It does not require actual appreciation of those consequences. The distinction is subtle but important. . .
- A lack of appreciation may reflect the attending staff member's failure to adequately inform the patient of the decision's consequences.

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## Understanding risk...

- The Ministry of the Attorney General (2005) states:
- "not whether the person's actions or choices appear reasonable or will put them at increased risk, but whether the individual is able to **understand** critical information and **appreciate** the reasonably foreseeable consequences of his or her decisions or lack of them.
- Unless there is clear and compelling evidence of impaired "ability to understand and appreciate", the assessor can not use a finding of incapacity as a means to manage risk."

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## A client's capacity is not based on language/communication skills ..

- Remember, for those with aphasia or perhaps autism, their capacity may be masked by an inability to communicate, and therefore are at risk of being judged incapable to make a decision.....

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## Global Incapacity has no legal bearing.....

- Many people in the helping professions continue to believe in the concept of global incapacity, that is, a client either has or does not have capacity to make decisions.
- This thinking is apparent when there has been a finding of "incapacity" documented in the clients file.

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## Cognitive Testing...

- Health care professionals who are not familiar with the legal requirements of capacity evaluation frequently resort to formal tests that measure cognition and memory.
- Their logic may be understandable in that the tests reveal the patient's cognitive abilities, which are tied to executive functioning and activities of daily living.
- Yet, assessments of memory or cognition *are not* assessments of decisional capacity.
- These tools test the wrong elements and are not acceptable to make a determination of capacity.

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## The Nature of Capacity

- **Capacity can be:**
  - 1) A matter of degree
  - 2) Can be highly variable

***Remember capacity is always decision-specific***

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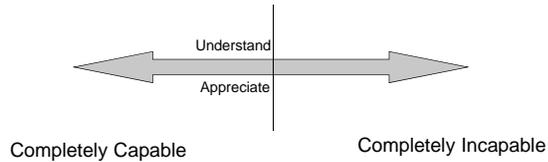
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## Capacity: A Matter of Degree

- Capacity exists along a continuum



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## Share Your Capacity Assessment

- Rely on team members as much as possible for support and clarity
- This will strengthen your position and avoid the pitfalls of personal bias

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## Declaring a person incapable cannot be used as a clinical management strategy...

- *It is not appropriate to invoke this legislation to control patients where there is no evidence to that they are not behaving voluntarily*

### **Potential behaviours...**

- eccentricity
- spend lavishly
- adopt a risky lifestyle
- failure to thrive

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*Responses to questions.....*

- Make sure it isn't a problem of not understanding the *question*, or not being able to understand the question (the focus is on decision-making ability).
- Try re-wording the question to allow for an appropriate response.

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*Problem Solving*

- Try to think of ways to educate and inform the client.
- Be creative, use tools to help. Capacity exists if a person can make decisions even with assistance.
- (e.g., memory aid, written instructions)

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*Communicating.....*

- Try to help the client to tell you if they understand
- Look for alternate, non-verbal ways that will allow them to show they comprehend the information

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*Clarity.....*

- If need be, present information in a simpler form
- There is evidence that breaking information down helps people understand it better
- In those with limited verbal skills, visual aids can improve understanding

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