

# The International Journal for Direct Support Professionals

## Considering Consent and Capacity

By: Andria Bianchi

It is typically the case that people have the right to consent (or refuse) to proposed care or treatment recommendations if they are capable. However, some clients with whom we work, namely those with intellectual and developmental disability (IDD) may be considered “incapable” of making their own care-related decisions. But what does it mean for a person to be (in)capable? In order for a client to be recognized as capable, do they need to be able to communicate in a particular way? Does having a cognitive impairment make a person incapable of consenting to their own care decisions? If a person is “incapable,” then should and/or how much should their preferences and desires matter?

In order to introduce the concepts of consent and capacity, as well as to explore the above-mentioned questions, I’m going to refer to [Ontario’s Health Care Consent Act](#) (HCCA) as a starting point. My reason for referencing Ontario is because it is the jurisdiction wherein I practice as a bioethicist. (Based on my understanding, similar definitions of capacity do exist elsewhere, though you’ll want to confirm by referencing relevant legislation.) However, learning about criteria for ‘capacity’ is just one part of what it means to be a direct support professional who works with persons with IDD and wants to practice in an ethically defensible manner. Expanding beyond capacity and thinking about how we should manage circumstances and support decision-making for those who are ‘incapable’ is a complex and essential topic to consider, irrespective of the location in which we work.

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### What does capacity require? What does it mean for my client to be “capable”?

Under Ontario’s HCCA, a person can consent to a proposed treatment recommendation if they are capable. The term “treatment” is defined quite broadly in that it refers to “anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment, plan of treatment or community treatment plan”.

There are two parts to capacity. According to the HCCA, someone is capable to make their own decision(s) if they can:

- 1) Understand the proposed treatment recommendation
- 2) Appreciate possible consequences of the proposed treatment/non-treatment

Capacity is always presumed. Consequently, care providers are responsible for presuming capacity for every client, irrespective of their initial presentation or IDD.

Furthermore, it is important to note that “capacity” is: (1) decision-specific, (2) treatment-specific, and (3) time-specific. This means that a client may be capable of making a care-related decision at one time, and incapable of making other decisions at other times. It is seldom the case that a person is “globally” or entirely incapable of consenting to any and all treatment-related decisions.

### **How do I determine capacity based on the above criteria? In practice, what does it mean for a person to “understand” and “appreciate”?**

There are different ways to assess for capacity.

In order to determine if a person understands the proposed recommendation, consider the question: Can the client explain the proposed treatment to you in their own way (e.g., “You’re asking me to decide if I want to do/take/receive X”)? Ultimately, can they demonstrate that they know what the decision is about?

In order to determine if a person appreciates the possible consequences of the decision/non-decision, consider: Does the client know that all potential benefits and risks are relevant to and would be experienced by *them* (as opposed to someone else)? Are they asking questions about how they/their life may be influenced by the decision (e.g., “When should I take this medication?” “Will I feel pain?” “How long will the injection take?” Etc.)?

When working with clients with IDD, it may be the case that different methods of communication are used when demonstrating understanding and appreciation. For instance, a client may not demonstrate their understanding through typical vocalization. It may be the case that the client with whom you are working primarily communicates using gestures, pictures, or with the support of technology.

Communication differences are not in and of themselves relevant to capacity. In fact, the onus is on the care provider/treatment-proposing clinician to communicate in a manner and take into consideration client’s communication differences and needs when determining capacity. For instance, if a client primarily communicates using technology, or in a language other than the providers’, then providers are expected to ensure the technology is available and interpretation support is provided. Clients can – and should – be empowered to communicate in a way that allows them to demonstrate capacity. The onus is on us to help empower them.

### **Who determines if a patient is capable/incapable?**

The person proposing the care/treatment recommendation (i.e., the person most familiar with the recommendation, potential benefits, risks, relevant consequences) is responsible for determining capacity. However, many others may play a supportive role in assessing capacity, perhaps especially those in direct support professional roles.

For instance, suppose a client with whom you work has an appointment with a psychiatrist. Upon learning about the client’s anxiety, the psychiatrist recommends that the client take a medication. If the psychiatrist does not know the client/have a good baseline from which they can make an assessment about the client’s capacity to consent and/or, if they are unaware of how to most effectively communicate with the client, then they may ask others for support. Ultimately, although the psychiatrist (i.e., the treatment-proposing clinician) is responsible for verifying the client’s capacity (or lack thereof), they can ask others for support with interpreting

how the client's cognitive and/or communication challenges may/may not be influencing decisional capacity. Direct support professionals are often in an ideal position to comment on these elements which may assist with capacity determinations.

### **My client makes “risky” decisions. Does this mean they are incapable?**

A risky decision does not necessarily mean that a person is incapable. Capable individuals have the right to make “risky” decisions; this is sometimes referred to as the “right to risk.”

Additionally, it may be worth highlighting that a “risky” decision from one perspective may not be “risky” from other standpoints. Based on various factors, it is possible that our clients may define, think about, value, and/or tolerate risk differently than ourselves.

If, based on our individual and professional perspectives, a client is making a “risky” decision, then we'll want to ensure that they are capable of making this decision, especially if the likelihood of them experiencing harm is quite high. In other words, if there is a high chance that the client may be at significant risk of harm, then the threshold for capacity should be quite high. In these cases, taking sufficient time to ask the client to demonstrate their understanding, as well as consequences associated with their decision is appropriate.

To assist with circumstances involving capable, albeit risky, decision-making, we may want to engage with clients in a shared process of risk mitigation. For instance, if a client does not want to eat/get dressed/take their PRN, and if they are presumably capable of making this decision, perhaps we can work with them to reduce the most significant potential risks. For instance, if a client does not want to take their PRN, are they willing to explore and engage in other strategies that may provide some similar benefit? If they do not want to eat, are they willing to consume a recommended nutritional supplement (e.g., Ensure)? Ultimately, if a capable person makes a less-than-ideal and potentially risky decision, can we work with them to reduce the most significant and most likely risks?

### **My client is definitely incapable of making a decision(s). What should I do?**

Deeming a client ‘incapable’ for any decision is extremely significant. One reason that it's significant is because of the importance of respecting autonomy. Autonomy is one of the most frequently cited bioethics principles; respecting a person's autonomous decisions is often seen as an important part of providing ethical care (particularly in societies that value individualism and independence). When a person is incapable of consenting to care decisions related to themselves, then their autonomous preferences may not be realized or respected.

Given the importance of autonomy and individual decision-making, it is worth asking whether we can help to optimize a client's capacity in advance of them being labelled ‘incapable.’ For instance, we may want to ask questions included in the below (non-exhaustive) list for non-emergency decisions:

- Does a client's cognition, lucidity, and corresponding capacity differ depending on the time of day? For instance, are they typically more coherent and better able to demonstrate capacity in the afternoon vs. the early morning? If yes, then we should assess for decisional capacity when they are most likely to be capable.
- Is a health condition influencing their capacity (e.g., Do they have an untreated infection causing delirium)? If yes, treat the underlying cause in an effort to optimize capacity moving forward.
- Is the client fatigued? If yes, try to re-engage in a decision-making conversation/seek consent when the patient is most awake/likely to be capable.
- Are we presenting information in an accessible manner based on the client's needs? If the client may benefit from having information communicated in pictures, in writing, in a particular language, etc., then the onus is on us to ensure accessibility.

- Is the client empowered to communicate with us in a manner that is most effective for them? For instance, if a client prefers to communicate using a supportive technology, then is this technology available for them to use during our conversation?

If we've tried to optimize the client's capacity and they are, indeed, incapable, then the client's substitute decision-maker(s) would be responsible for consenting to the treatment proposal. However, it is still important to offer opportunities for meaningful inclusion and participation. An "incapable preference" is still a preference, and, as such, ought to be known and taken into due consideration by the authorized decision-maker(s). Learning about and trying to honour one's incapable preference(s) (even if only to a partial extent) can help to honour a person's autonomy, demonstrate trustworthiness, and practice equity in allowing a person in a position of vulnerability (by virtue of being deemed incapable) to have their voice heard.

### **What is supported decision-making and how might it help?**

It may be the case that some clients with IDD have fluctuating capacity or some degree of impaired capacity for many care-related decisions. In these circumstances, a model of supported decision-making may be helpful to consider. Supported decision-making is not a legally recognized concept in Ontario, but the general idea may be helpful when thinking about how we can (and should) optimize capacity and involve clients in decision-making conversations.

Supported decision-making is a model in which a person with impaired capacity receives some decision-making support from a trusted person(s); the trusted person's role is not to make the decision, but rather to enhance the client's self-determination. For instance, a support person may attend appointments, take notes, help interpret information, discuss options with the client, etc. However, the client would make the final decision.

Supported decision-making has been recognized as a 'middle ground option' for people whose capacity may fluctuate and/or who may benefit from some support through their decision-making process.

### **Case Example**

Adi is 25 years old with moderate developmental disability. Adi understands some English, though the language that he grew up hearing is Tamal. Adi has an older brother with whom he has a positive and trusting relationship; his brother was his primary caregiver for years.

Recently, Adi moved into a group home, and each year the group home strongly recommends that residents receive their flu shot. In order to make the flu shot accessible, clinicians from the community offer it in the home. Anyone who consents to the flu shot can receive it.

Adi was considered incapable of consenting to personal care decisions in the past, including medication recommendations and dental surgery. However, Adi's care team, including his direct support professionals, believe he may be able to understand and appreciate information about the flu shot (e.g., risks, benefits) if the information is presented in a manner that works for Adi.

In an effort to optimize Adi's capacity (and since an immediate decision was not required), the direct support professionals, in collaboration with other team members, develop a social story to explain the process of receiving a flu shot. At first, Adi winces on the page which shows a flu shot being administered. He shakes his head when asked, "Will you take the flu shot?"

Adi's brother visits the home, where he speaks about the flu shot and goes through the social story in Tamal. Adi expresses fear that the flu shot will hurt him. Adi's brother provides an honest answer (it might hurt a little bit and then go away), and also says he can hold Adi's hand if Adi decides to get the flu shot.

A few days later, Adi communicates that he will get the flu shot. The clinician uses accessible language and pictures to ask Adi about the shot. Adi answers by pointing to pictures and making hand gestures and noises. Adi's direct support professionals and his brother help with interpretation. Given that the likelihood of and type of risks associated with the flu shot are relatively low (from the clinician's perspective), she determines that Adi's responses meet the threshold of capacity, and Adi's consent is documented.

In short, although Adi may be incapable of meeting the threshold of capacity for more complex and/or risky decisions, his capacity was optimized, and he was capable of making a personal decision in this case. Adi's direct support professionals and brother were essential in optimizing his capacity.

### **Conclusion**

On first glance, determining a person's capacity to consent to care recommendations may seem rather straightforward. Can the person understand the information? Can they appreciate the potential consequences? If the answer is "yes" to each of those questions, then they are capable.

Upon further reflection, however, many shades of grey become apparent, particularly when working with people with IDD. Although capacity is meant to be presumed for all, it may be the case that some persons with IDD are incorrectly and unjustly presumed incapable, perhaps particularly amongst those well-intentioned clinicians working outside of the developmental sector.

Direct support professionals have an opportunity to play an essential role in contributing to more thorough and developmental-specific discussions and assessments related to capacity.

Assessing capacity (when appropriate) is apt, though direct support professionals may also assist with optimizing capacity, empowering effective communication, and promoting inclusion. These elements are important to ethical care provision, and each of us may have a role to play.

### **About the author**

Andria Bianchi, PhD, is a Bioethicist at the University Health Network and Surrey Place in Toronto, Ontario. In her role, Andria supports staff, clinicians, clients, and families when they encounter complex ethical dilemmas. Much of Andria's work involves consulting on questions related to consent and capacity for persons with intellectual & developmental disability, as well as cognitive impairments.

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