

# The International Journal for Direct Support Professionals

## “But they’re incapable...”: Considering the Ethical Significance of Assent and Dissent

By Andria Bianchi

As a direct support professional (DSP) who works with people with an intellectual or developmental disability (IDD), it may be the case that you accompany the people you support to various activities and places, including clinical appointments. You may also be responsible for care provision and offering supportive interventions aimed to benefit their health, well-being, and/or quality of life. In some of the clinical appointments that the people you support attend, the primary clinician(s) may need consent for what they are recommending. Similarly, the interventions you offer may require consent.

### Consent and Capacity: A Refresher

As mentioned in a previous article, when a proposed treatment (e.g., a preventative, diagnostic, therapeutic intervention) is recommended to a person with IDD, it is typically the case that consent is required. Consent may also be needed when it comes to interventions related to hygiene, nutrition, ambulation, dressing, and other activities of daily living (ADLs).

Depending on the jurisdiction within which you work, different criteria may exist in terms of the types of interventions and treatments that require consent, as well as what consent ought to entail. There may also be different conceptions of what it means for a person to be capable of consenting or refusing to consent to a proposed intervention. Under Ontario’s Health Care Consent Act, capacity involves a person being able to: (1) understand the information relevant to making a decision, and (2) appreciate the reasonably foreseeable consequences of consenting or refusing to consent to a care proposal. In accordance with this Act, the person recommending the proposed intervention is the one responsible for obtaining consent and gauging potential incapacity.

### The person I support is not capable of consenting. What happens now?

When a person is incapable of consenting to a proposed intervention, the precise next step may differ depending on where you live/work, as well as the particular features of the circumstance (e.g., an emergency vs. non-emergency situation). In many contexts, the next step will involve turning to a specific substitute or surrogate decision-maker (SDM), i.e., someone who is legally authorized to make decisions on behalf of a person who is incapable of consenting.

Editors: Angie Nethercott, M.A., RP  
Chanelle Salonia, Ph.D., BCBA



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## **The person I support is incapable of consenting to a proposed intervention that requires consent. Does this mean that their preferences do not matter?**

In order to answer this question, let's consider the following case example:

*Jamie is 37 years old with diagnoses of mild intellectual disability, autism spectrum disorder, and generalized anxiety disorder. Jamie lives in a group home where you work as a DSP. Jamie's mother lives in a town close to the group home and seldom visits. Jamie and his mom have a tense relationship. Jamie has no other family or friends.*

*Recently, you accompanied Jamie to his psychiatrist appointment. After communicating with Jamie about how he is doing in relation to his anxiety, the psychiatrist seeks your perspective, acknowledging that you are with him more than anyone else. You highlight the ways in which Jamie is thriving, though you also note that he has been very anxious lately, perhaps because there has been a lot of staff turnover and some new residents in the home. Jamie expresses his anxiety through immense restlessness and difficulty concentrating on tasks, even those that are familiar and typically enjoyable for him.*

*In response to your report, and based on his observations and communication with Jamie, the psychiatrist suggests trying a new medication for Jamie's anxiety. Although Jamie has been on a similar medication for years, the psychiatrist is of the opinion that it is not working as effectively as possible.*

*Jamie is incapable of consenting to many personal care decisions, including this medication proposal. As such, the psychiatrist calls Jamie's mother as his surrogate decision-maker, and she consents to the new medication. While listening to the psychiatrist's discussion with his mom, Jamie shakes his head and starts to grunt. Back at the group home, Jamie closes his mouth when you try to give him the medication.*

In this circumstance, Jamie is incapable of consenting to the proposed treatment recommendation in accordance with legislative requirements, which is why the psychiatrist turned to his mother. However, the DSP knows that Jamie's head shaking, grunting, and unwillingness to take his medication is indicative of his refusal ... but it's not a capable refusal. So, what is it? And does it matter?

### **Assent and Dissent**

When a person provides an uninformed or incapable refusal that is expressed through verbal or non-verbal indicators (e.g., saying "no," resistance, reluctance, turning away, shaking head) then this is referred to as *dissent*. Dissent is an incapable refusal – an unwillingness to proceed with whatever is being proposed and/or occurring.

Conversely, assent describes a person's incapable or uninformed agreement or willingness to pursue a particular act. Similar to expressions of dissent, assent may be expressed through different verbal or non-verbal indicators (e.g., saying "yes," nodding, attempting to do something).

The concepts of assent and dissent are frequently used in paediatric contexts and/or in research environments when participants are incapable of consenting. To offer a simple example of assent: Suppose a five-year-old child is required to get a vaccination. The child is unable to understand and appreciate the potential consequences of receiving vs. not receiving the vaccination, thereby making them incapable of consenting. If the child puts their arm out to receive the vaccination when asked to do so, then the act of putting their arm out would be indicative of assent. Although they are incapable of consenting, the child expresses a

*willingness* to participate. Conversely, if the child covers their arm, says “no,” and tries to run out of the room, then these acts would indicate dissent. Although they are incapable of refusing to consent, the child expresses an *unwillingness* to receive the vaccine.

## Responding to Assent and Dissent

It is sometimes the case that a person’s assent and dissent are simply ignored. The rationale *not* to acknowledge, consider, and/or honour one’s assent or dissent may be something like: “The SDM consented. Therefore, we can proceed with [an action] regardless of the individual’s incapable preference.” It’s true that insofar as consent has been obtained appropriately, then care providers *can* proceed accordingly. However, ethics is about what we *should* do, taking all things into consideration. Should we consider the incapable preference of the person supported by care providers? Should we give any weight to their assent or dissent? If so, to what extent? When? If not, why not?

From an ethics perspective, an expression of assent or dissent by the person supported by DSPs (and others) often deserves some exploration as a part of what it means to provide person-centered care. Trying to understand their willingness or, more frequently, unwillingness to act in accordance with their SDM’s consent can sometimes allow us to gain fruitful information and alleviate concerns (if they are dissenting). Once concerns are alleviated, then perhaps they may assent, thereby allowing us to provide care that reflects their preferences and values *and* accords with the SDM’s consent. For instance, if we learn that Jamie’s dissent is motivated by the size of the new medication tablet, then we’ll be able to find out if the tablet can be crushed. Once the tablet is crushed, then perhaps Jamie may assent to taking it.

In order to determine how much we should consider and weigh a person’s assent and dissent, it is sometimes helpful to ask: What possible consequences may arise if we respect their incapable preference? Are the possible consequences likely to occur? Are they significant? Are they reversible? In the case of Jamie – if the new medication is *not* administered, and if the consequences of failing to do so are significant and likely, then it may be ethically indefensible to honour Jamie’s dissent. If this is the case, then we may decide to administer the medication and try to seek Jamie’s assent in the future. If, however, the consequences are relatively low (all things considered), then respecting Jamie’s incapable expressed preference and/or exploring alternative options may be ethically defensible. In short, incapable preferences matter. However, the extent to which they ought to guide our actions will differ depending on the circumstance.

To offer a different kind of example that may be experienced by DSPs, consider the following:

*Sam is 22 years old with diagnoses of moderate developmental disability and Prader-Willi syndrome. Sam was recently offered a space in the group home you support after living with his mother and younger sister for the course of his life thus far. Sam’s mom wanted to keep Sam in their family home, but after he caused significant property destruction which inadvertently harmed his sister, she agreed to the group home placement.*

*As a consequence of his Prader-Willi syndrome, Sam desires food on a consistent basis and is incredibly impulsive. When denied food (particularly when it is out in the open), Sam becomes angry, aggressive, and will often engage in property destruction. As a part of his support plan for the group home, an interdisciplinary team recommends locking the kitchen cabinets, establishing set schedules for meals, and having supervision during mealtimes. The team also recommends having a PRN medication available (i.e., an “as-needed” medication) in case Sam’s cravings for food influence his behaviours to escalate to a point where he may cause harm to self or others. The PRN medication would serve as a pharmacological intervention that would force Sam to calm down.*

*Sam is incapable of consenting to the proposed plan of care. Consequently, the team turns to his mother as SDM. Sam's mother consents to the team's proposal. In a spirit of transparency, the clinical team informs Sam that if he: (a) wants food, (b) starts to behave in a way that is difficult to manage and may cause harm to self or others, and (c) does not calm down after using non-pharmacological behaviour interventions, then the team may administer a medication to make him calm down and feel better. In response, Sam says "No medicine", shakes his head, starts to become angry, and begins to pace.*

In this circumstance, an intrusive measure is being recommended as a part of a plan of care. This plan requires consent. Through his actions, it is evident that Sam is unwilling to agree to or participate in the proposed plan. Though incapable of consenting in a manner that meets legislative requirements, Sam's response indicates his dissent.

As noted above, there may be some circumstances where a person's assent or dissent deserves significant weight. In order to determine whether and, if so, the extent to which Sam's dissent ought to be respected, it may be worth considering: What would happen if Sam's dissenting perspective regarding the use of pharmacological interventions is respected to the fullest extent possible? Respecting Sam's dissent would presumably mean that no pharmacological interventions would be used *even if* he is engaging in otherwise unmanageable and significant property destruction, harm to self, and/or harm to others. If this is a reasonable assumption about what may occur, then respecting Sam's dissenting view may cause a disproportionate amount of harm in comparison to the harm experienced by administering an undesired PRN, which would be difficult to defend.

In response to this circumstance wherein a person with IDD's dissent is not respected, DSPs are in a perfect position to offer an important person-centred response by comforting Sam, seeing if he may be open to assenting in the future, and/or to helping Sam navigate the proposal to which he dissents. Perhaps a DSP can validate Sam's feelings, help him remember that he does not want to destroy property or hurt people (thereby helping him recognize a possible justification for the PRN), etc. DSPs are often regarded as trustworthy providers to whom the people they support can turn. As such, DSPs are uniquely and perfectly positioned to offer a valuable response in circumstances where a decision is made without the consent or assent of the person they support. Additionally, though the work that they do, DSPs can help others remember that the person they support is someone who has preferences, values, wishes, and desires, even if they are considered "incapable" at times.

## **Conclusion**

It is typically the case that people have the right to consent (or refuse to consent) to proposed care or treatment recommendations if they are capable. However, some of the people with whom we work, namely those with IDD, may be considered "incapable" of making their own care-related decisions.

If someone is incapable of consenting to a treatment recommendation or plan of care, then their SDM is typically responsible for consenting on their behalf. However, this does not necessarily mean that the individual's incapable expressed preference(s) ought to be ignored. Depending on the circumstance, an expression of assent or dissent may, at times, deserve significant weight as a part of what it means to provide person-centred care. DSPs have an important role to play in interpreting assent and dissent, determining to what extent one's assent or dissent ought to be respected, and offering valuable person-centred care irrespective of whether a person is "incapable."

## About the author

Andria Bianchi, PhD, is a Clinical Ethicist at Unity Health Toronto. As part of her role, Andria provides ethics support to Surrey Place, where she consults with staff, clinicians, clients, and families who encounter complex ethical dilemmas in the developmental sector.

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