

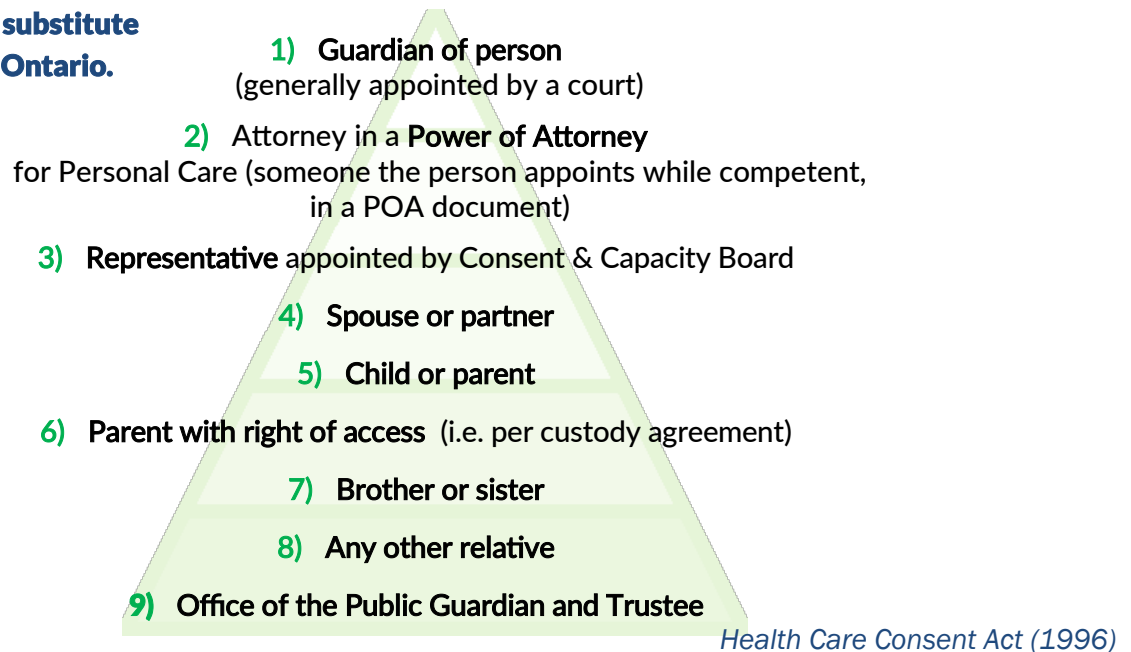
Health Care Decision Making

The ability to make decisions for ourselves is a human right. This is part of the ethical principal known as autonomy. When it comes to making a health care decision, our current laws state that people can make their own decisions—unless there are grounds to think a person does not have the mental ability to do so. This can happen if a person is temporarily incapacitated (e.g. in a coma), and decisions need to be made, or if someone has a more chronic disability that affects decision making.

For people with intellectual and developmental disabilities (IDD), there may be times when health care decisions can be made by the person. Other times, even if information is explained clearly or repeated, the decision may be too complex given the person’s abilities, and someone else is needed to make the decision.

This follows the current laws in Ontario which are based around a concept known as **substitute decision making**. This means that people are deemed to be either **capable** of making their own health care decision, or **incapable** of making their own health care decision. When a person is found to be incapable, a **substitute decision maker** (SDM) makes the decision. As a direct support professional (DSP), you cannot be a SDM for the person you support. In fact, the laws in Ontario are very specific on who can be a SDM. In order, they are:

The “Hierarchy” of substitute decision making in Ontario.



So, even if a person does not have any family members involved, there is always a SDM that can be appointed. As a DSP, you can be very helpful by ensuring that you assist the person you support to have up-to-date contact information for their SDM—in case this is needed, and that this is shared with the health care provider. You can also discuss with the person you support the benefit of keeping their SDM informed of any health care appointments, in the event there is a decision the health care provider will call upon them to make.

What does capacity mean?

Legal capacity means having the ability to **understand the information** that is being presented (for example, knowing the risks and benefits of the decision), and to **appreciate how it relates to you** (for example, being able to explain what happens if you agree to treatment, but also understand the consequences if you refuse treatment).

If a person understands and appreciates the information, they have the right to say no, or to make a bad or foolish decision. In fact, people do this all the time!

What health care decisions are included?

In Ontario, the law specifies that health care decisions include “**medical treatment**”. This is anything done for a “*therapeutic, preventive, palliative, diagnostic, cosmetic or health related purpose and includes a course of treatment*”. Examples could include things like having a pap test, starting new medications, having a biopsy, going for surgery, or getting physiotherapy. It also includes decisions about going into a long-term care home and personal support services. It does not include asking questions about your health history.

Who determines if a person is capable to make the health care decision?

The person proposing the treatment (the doctor, therapist, etc.) is the one to determine a person’s capacity to decide whether or not they wish to proceed. Usually, capacity is presumed – meaning, it is only questioned if the health care provider feels there are significant grounds to think a person can’t make the decision. Having an intellectual or developmental disability (IDD) may be a situation where the health care provider takes some extra time to explain and assess the person’s decision making abilities. Capacity needs to be assessed for each decision. This means that people may be able to make some decisions, but not other decisions AND that people may be able to make a decision at one point in time, but not at another time.

What is your role, as a direct support professional?

As a DSP, your role could include things like:

- Role modelling and encouraging effective communication and accommodations, so that the individual can be provided the best opportunity to participate in the decision making process. If there are any specialist reports (e.g. psychology or speech and language pathology) that provide strategies for how best to communicate with the person, encourage that these be shared and reviewed by the health care provider.
- Ensuring that the person you support has familiar, positive faces around who can be trusted allies and support them through any big decisions. Knowing who might be a person’s SDM, in case they are needed for decision making.
- Bringing the SDM’s contact information to the appointment, especially if their information has changed.
- Contacting the SDM in advance of the appointment, so they are aware that they may be contacted, if the doctor feels it is necessary (i.e. if the doctor feels the person is not capable to make a health care decision).

Once a decision has been made by the SDM, you have an important role in helping the individual to understand the decision, and to follow through or participate in the treatment that was agreed to by the SDM. Getting this agreement is called **assent**.



Let's review!

What are things you, as a DSP, can do?

Check the ones you think are correct. The answers are below.

- 1. Make a decision for a person (act as their SDM).
- 2. Have up-to-date information for the SDM, and share this with the health care provider.
- 3. Sway or influence a person's decision.
- 4. Convince a person to make a decision that they do not understand.
- 5. Help contact the SDM, so they can speak with the health care provider.
- 6. Encourage a person to participate in a treatment for which there hasn't been any consent.
- 7. Encourage the person you support to be included in the decision making process.
- 8. Once a decision has been made, support the person to understand and follow through.
- 9. Remind a health professional that you are not the SDM—but you can provide up-to-date contact information.
- 10. Assess if a person has capacity for medical treatment.
- 11. Role model effective communication to the health care provider.
- 12. Suggest accommodations that might enhance the abilities of the person you support.



Answer key:

2, 5, 7, 8, 9, 11, 12 Yes, you can do these things.
Keep up the great work!

#1, 3, 4, 6, 10: No, you cannot do these things. Please review this section again or speak with your manager.