



PRACTICE ADVICE

SUBSTITUTE DECISION MAKERS' RIGHTS

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WORKING EFFECTIVELY WITH SUBSTITUTE DECISION MAKERS: CONSENT AND THE LAW

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Every SLP and audiologist wants to develop a productive working relationship with Substitute Decision Makers (SDM); these include the partners, parents, family members and significant others in the patient/client's life. However, frequently we interact with these individuals at a vulnerable time. Parents are worried that their child's speech, language and hearing skills are not developing as they should, and whether this signifies a greater problem. Partners are dealing with the shock of their loved one having a stroke or traumatic brain injury and the resulting loss of communication. People are coming to terms with a medical diagnosis with significant implications to their loved one's quality of life.

Families are trying to make the best decisions for their child or adult family member, but they can also come to us with other issues and stresses in their personal lives, which can cause pitfalls as we negotiate what is best for the child or adult we serve. Parents or adult family members do not always agree with each other or with our recommendations. However, Ontario has two different pieces of legislation governing consent to treat, and consent to collect, use and disclose personal health information, and it has institutions which can help us to overcome more extreme situations and guide us in our dealings with SDMs.

CONSENT TO TREATMENT

The legislation governing consent to treatment is the [Health Care Consent Act](#) (1996). The Act obliges us to obtain informed consent. It requires the health professional to give the individual reasonable information regarding treatment, including the risks and benefits, and an opportunity to ask questions and have them answered to the individual's satisfaction. The Health Care Consent Act refers to 'treatment', but allows for service providers to apply the legal tenets to screening and assessment. CASLPO, in 2007, determined that members must obtain informed consent for all screening and assessment as well as treatment services.

CHILDREN

Parents are the joint and equally ranking SDMs for a child, and they both have to give consent to treatment on behalf of their child. However, if only one parent attends an initial screening or assessment you can accept one parent consenting for both, if you think the

consent is being given in good faith. In other words, when you ask if the absent parent is in agreement with your course of action, and there is nothing leading you to believe that this is not the case, you can proceed and document that consent was obtained.

FREQUENTLY ASKED QUESTIONS

Q: What do I do when the separated parents of a child I am treating are in conflict and it seems that they do not agree with each other on principle? They take turns in bringing the child to therapy and now one of them is saying that they cannot bring him. I am really worried that the child, who has significant needs, will suffer.

If you are working with parents who are divorced or separated and only one parent has custody, then that custodial parent is the SDM, and will provide consent for you to screen, assess and treat the child. In this situation, the 'access parent' does not have the right to consent, or otherwise, to his or her child's therapy, even if he or she stipulates that he or she does not agree with the assessment or intervention plan.

If the parents are separated or are divorced and have joint custody, then both parents must give consent to screen, assess and treat. What should members do if both parents do not agree with and consent to an intervention plan? Unless you receive consent from both custodial parents you cannot proceed with your intervention. If you feel that the communication well-being of the child is at risk, and parental agreement seems remote, then you should consider contacting the [Office of the Public Guardian and Trustee](#) (OPGT). The OPGT has a Treatment Decision Unit, staffed by consultants who consider themselves to be 'decision makers of last resort'. On contacting them, you will be assigned a consultant according to your geographic area who will discuss all of the options with you first, before making a decision on behalf of the child.

OPGT contact information: Tel: (416) 327 -6683, Toll Free: 1-800-366-0335

Website: [Office of the Public Guardian and Trustee](#)

Q: I am currently seeing a teenager who wants to end therapy. His parents do not agree with his decision. He would benefit from further intervention (he is very dysfluent), but I can see that he really wants to stop.

The Health Care Consent Act does not specify an age at which an individual is able to consent, or withdraw consent, to treatment. Whether a child can in fact withdraw consent depends on whether he or she understands the relevant information and appreciates the reasonably foreseeable consequences of his or her decision. When providing service to an older child who does not want to pursue therapy, against parental wishes, try to negotiate a solution. Potential solutions might include a break in therapy and re-evaluation at a later date, or agreed upon time-specified blocks of therapy. If the parents persist, and the teenager is capable of making a decision to withdraw consent to treatment (he or she has the ability to understand relevant information and appreciate the reasonable foreseeable consequences of a decision or lack of decision), then you should seek advice from your manager, an ethicist or your employer's lawyer.

ADULTS

Q: An elderly patient who is in our Complex Continuing Care unit has been designated *Nil Per Os* (NPO) because of severe swallowing difficulties. This was agreed to by one of her adult children. The other adult children disagree with the decision and they are threatening legal action.

Adult patients or clients have the right to give or withhold consent to treatment. The adult maintains this right even if there is a Power of Attorney for Personal Care (POA) or a SDM identified on the medical record, and even if another health care professional has found the adult lacking in capacity for a previous decision. The Health Care Consent Act directs health professionals to presume that the individual has the capacity to give consent. If, however, you suspect that the individual does not have the capacity to provide informed consent, then you must evaluate his or her capacity. Capacity is defined in the Health Care Consent Act as the ability to understand relevant information and the ability to appreciate the reasonably foreseeable consequences of the decision or lack of decision.

Should the adult require a SDM to consent to treatment, because of a lack of capacity, then the highest ranking individual on the list provided by the Ministry of the Attorney General is selected. The list is as follows:

- 1) a court appointed guardian;
- 2) the person named in the Power of Attorney for Personal Care;
- 3) a representative appointed by the Consent and Capacity Board;
- 4) the spouse or partner;
- 5) the adult child or parent;
- 6) brother or sister;
- 7) any other relative by blood, marriage or adoption; or
- 8) the Office of the Public Guardian and Trustee.

If two equally ranking people (two or more adult children) fail to agree, and consent to treatment is not obtained, and the health care team have failed in their efforts to resolve the situation, you can contact the Treatment Decision Unit of the OPGT. As with the previous scenario, you will be assigned a consultant according to your geographic area and all options will be discussed before they make a decision on behalf of the adult.

SHARING PERSONAL HEALTH INFORMATION

The [Personal Health Information Protection Act \(PHIPA\)](#) (2004) governs the collection, use and disclosure of personal health information. PHIPA outlines the parameters regarding the individual's right to consent, to withhold or withdraw consent to said collection, use and disclosure of information.

YOUNG CHILDREN (0-12 YEARS)

Q: I am an audiologist practicing in a private clinic. Recently, a father came to the clinic

asking for information about his young child's hearing assessment. This father is separated from the mother who has full custody of the child. Am I allowed to give him the information?

When working with young children, the parents are joint Substitute Decision Makers (SDM) and are both entitled to the health information you generate in the form of reports, treatment goals, recommendations, etc. This right to information does NOT change, even if the parents are separated or divorced, and one of them does not have custody. In the course of your practice, you can be presented with a variety of legal parenting scenarios: joint custody, sole custody and access, and court-determined parallel parenting plans. With all of these situations both parents are allowed access to health information regarding their child and can request to see their child's record. According to the IPC's Order P-1246 (1996), the [Children's Law Reform Act](#) (1990) and the [Divorce Act](#) (1985) affords an 'access parent' the right to "be given information as to the health, education and welfare of the child". This would include information from audiology and speech language pathology screens, assessments and intervention. However, if there is a court order prohibiting a parent from receiving information, then that order must be followed. You should request to see the court order to determine precisely what information can and cannot be shared, and then document the details in the child's record.

TEENAGERS (13-18)

Q: I am a SLP providing outpatient voice therapy to a client who is 14 years old. This client has shared personal information with me (nothing to do with abuse) and has asked me not to tell his mother. What should I do if the mother asks?

PHIPA provides some flexibility regarding the interpretation of matters relating to this age group. It acknowledges that there are circumstances where individuals have the right to withhold consent to share their personal health information with their parents. For example, a fourteen-year old girl seeking information regarding safe sex might not want this to be shared with her parents. If teenager shares personal information with you in a therapy session, and the parent later questions you about it, you will have to use your professional judgement regarding the disclosure of such information. If you have any doubts, contact the Information and Privacy Commissioner for advice.

IPC contact Information: Telephone: (416) 326 3333, Toll free 1(800) 387 0073

Website: www.ipc.on.ca

ADULTS

Q: I work in a hospital and have been referred a patient for a swallowing assessment. When I went to read the patient's chart it had "Lock Box" written on the front. What does this mean?

Adults have the right to give, withhold or withdraw consent to collect, use and disclose personal health information. The adult maintains the right to decide even if there is a Power

of Attorney for Personal Care (POA) or a SDM identified in the medical record. If an adult decides that his or her information cannot be shared, the term 'lock box' is frequently used, in other words, the information is 'locked'. This may mean, for example, that the patient is willing to give and allow you to use information but not share that information with others, including members of the healthcare team; or, all/some family members are excluded from accessing the information. It is essential that you know exactly what information can and cannot be used and disclosed. Further information on the Lock Box can be found on the [IPC Fact sheet](#)

The right to decide on how personal information is collected, used or disclosed is lost if that adult is found lacking in capacity. We recommend that SLPs and Audiologists take the time and use resources to ensure that patients/clients understand the consent process and have an opportunity to communicate their wishes with regard to the degree to which their personal health information can be collected, used and disclosed. If an adult does not have the capacity to decide, the SDM makes the decision on the adult's behalf.

Q: In previous articles in CASLPO Today you have referred to the Office of the Information and Privacy Commissioner of Ontario. What is this office?

The Information and Privacy Commissioner of Ontario (IPC) is an officer of the Legislative Assembly of Ontario that acts independently of government to uphold and promote open government and the protection of personal privacy in Ontario. The IPC has responsibility for three Acts: [Personal Health Information Protection Act \(PHIPA\)](#), the Freedom of Information and Protection of Privacy Act (FIPPA) and the Municipal Freedom of Information and Protection of Privacy Act (MFIPPA).

The IPC's mandate is to:

- independently review the decisions and practices of government organizations concerning access and privacy;
- independently review the decisions and practices of health information custodians in regard to personal health information;
- conduct research on access and privacy issues;
- provide comment and advice on proposed government legislation and programs;
- review the personal health information policies and practices of certain entities under PHIPA; and
- help educate the public about Ontario's access, privacy and personal health information laws and related issues.

SUMMARY

As healthcare professionals we want the best for the patients or clients we serve and fostering good relationships with SDMs is frequently part of that service. If you have a good understanding of the legislation governing the two types of consent, and know where to go to seek advice, patient autonomy can be preserved and the best interests of your patients/clients can be maintained. If you have any further questions regarding this area of

practice, please contact CASLPO.

BIBLIOGRAPHY

- Health Care Consent Act (1996)
- Personal Health Information Protection Act (2004)
- Information and Privacy Commissioner of Ontario
- Office of the Public Guardian and Trustee
- The Consent and Capacity Board