

BACKGROUND

The Role of Family Caregivers in Treating Severe Mental Illness

Introduction

This backgrounder was produced by the Family Alliance on Severe Mental Illnesses (FASMI). Its purpose is to explain why family caregivers must be given essential information concerning relatives with severe mental illness. The backgrounder was prepared by Dr. Richard O'Reilly and Dr. John Gray. The former is a consultant psychiatrist and professor emeritus at Western University. The latter is a psychologist with 30 years of experience in the Canadian mental health system and is author of *Canadian Mental Health Law and Policy*.

What is a Psychotic Illness?

A psychosis, such as schizophrenia, is a severe mental illness in which the person loses contact with external reality. Psychotic illnesses are characterized by delusions and hallucinations. A delusion is a fixed, false belief that is not shared by the person's peer group. Hallucinations are the experience of perceptions, usually voices or visions, without a stimulus.

Other common symptoms of psychotic illnesses are thought disorder, anosognosia, and impaired motivation.

Thought disorder is a disruption of thought processes and is sometimes referred to as "formal thought disorder." Thought disorder may be so severe that a person's speech becomes unintelligible.

Anosognosia is a common symptom of psychotic illnesses and of neurological diseases such as after some types of strokes. A person suffering from anosognosia is unable to recognize they have a disability. Anosognosia is sometimes referred to as lack of insight but, importantly, it is caused by biological brain dysfunction and not by psychological mechanisms.

Lack of motivation or amotivation is associated with disrupted functioning of the frontal brain lobes. This causes the person to become increasingly apathetic and unable to reach out for assistance or plan for their future.

Approximately 3-4% of Canadians suffer from a psychotic illness during their lives.

Current Dysfunction in the Mental Healthcare System

Anyone who follows the media or walks through the centre of any Canadian city knows that our mental health system is failing to protect many of our most vulnerable citizens. The failure to provide treatment to people with severe mental illness is not due to a lack of funds but rather to a lack of commitment to provide treatment to our most ill citizens. Despite multiple infusions of money to mental health services in recent years, we have witnessed a deterioration in the care of people suffering from severe psychosis. This is because increases in funding have been directed to programs for people who have less severe psychological problems.

People who suffer from psychotic illnesses require specific services such as a hospital bed when they are acutely ill; assertive treatment teams to ensure they don't dropout of follow-up support programs; and appropriately staffed, long-term residential group homes, where they can live safely.

Without these services people with the psychotic illnesses often drop out of treatment and end up living on the streets. In fact, people who suffer from a psychotic illness already make up more than 20% of the homeless population. The experience of clinicians demonstrates that people with severe psychosis can only be successfully housed when they have received appropriate treatment for their illness

How did we get here?

Our current problems are rooted in the failed implementation of the policy of deinstitutionalization that took place from the 1950s on. Before the availability of antipsychotic medication, many people who developed a psychotic illness spent most of or their entire lives in hospital due to uncontrolled psychotic symptoms. The introduction of effective antipsychotic medication in the 1950s and 1960s allowed doctors to discharge hundreds of thousands of patients from large psychiatric hospitals. When treated with antipsychotic medication and discharged these patients still required intensive follow-up support and care in the community. Governments promised to use the savings from the closure of the large psychiatric hospitals to fund these essential community services. However, most savings were diverted to programs serving people with less severe problems because they were better able to lobby for their own needs.

Some writers refer to deinstitutionalization as an historic event, but Canada continues to reduce the number of psychiatric beds in our hospitals. In Canada psychiatric beds per capita have been reduced by more than 90% since the start of deinstitutionalization.

The Essential Role Families Play

Because of the limited availability of suitable community-based services, families have been forced to take on a greater role in providing care for their ill relatives. More than half of people who suffer from schizophrenia live with their family. In addition to providing shelter for their ill relatives, families look after other essential needs such as housing, nutrition, clothing, financial support, and transportation. Due to the inadequacy of community services, many family caregivers are also forced to act as de facto case managers – taking their ill relatives to clinical appointments, encouraging them to take essential medication, checking for the emergence of side-effects and monitoring for the return of psychotic symptoms

The Lack of Support for Family Caregivers

Common sense suggests that society would support families who provide this type of intensive care. Unfortunately, the reverse is true. Families report that they receive little support, and they specifically complain that mental health services fail to provide essential information needed to carry out the arduous task of caring for someone with a psychotic illness.

An individual who has anosognosia cannot recognize that they are ill and need treatment. As a result, a responsible and informed person must closely monitor the ill individual's treatment and response to that treatment. If the ill individual is a patient on an assertive treatment team, a clinician undertakes this role. However, as noted above, we do not have enough specialized services for individuals with severe mental illness, such as assertive community treatment teams. Consequently, it is family caregivers who must monitor treatment adherence and watch for early signs of relapse for most individuals who suffer from anosognosia. To provide effective monitoring and support those family caregivers must have information about their ill relative's symptoms, medication regimen, what to do in an emergency, etc. It is unacceptable that this critical information is withheld by hospitals and individual clinicians because of "privacy concerns."

The Failure to Share Necessary Information with Families

We support keeping an individual's personal health information private. However, this right to privacy is not absolute. All Canadian provinces and territories have legislation that identifies specific situations in which hospitals and individual clinicians must gather or disclose healthcare information even if they do not have a patient's consent to do so. We have listed the relevant legal provisions for each Canadian province and territory in the appendix to this document. Tragically, these legal requirements are often ignored. From the perspective of family caregivers, the three most important scenarios are:

1. The failure of clinicians to contact family members to obtain collateral

information.

2. The failure of clinicians to provide information to families in situations where that failure increases the risk of harm to the ill individual or to others.

3. The failure to recognize when an individual lacks the legal capacity to decide on the sharing or withholding of their health information.

Collecting Information without the Person's Consent

All Canadian jurisdictions have legislation that permits the collection of personal health information from third parties without the consent of the patient. The caveat is that the information is necessary to provide appropriate healthcare, and it is either not available from the patient in a timely fashion or is unlikely to be reliable when obtained directly from the patient. Despite the existence of this legislation, clinicians repeatedly fail to contact family caregivers to obtain collateral information in situations where the information is essential, such as following a suicide attempt or when the patient is delusional.

Release of Information without the Person's Consent

Although the media focuses on rare acts of violence against strangers, it is family caregivers who are most likely to be killed or seriously injured by a mentally ill relative. Yet clinicians often neglect to tell family caregivers that they are a focus of their ill relative's paranoid delusions.

The Capacity to Decide on Releasing or Withholding Information

All Canadian citizens have the right to make their own decisions about finances and healthcare, unless they lack the legal capacity to make these decisions. Lack of capacity is often caused by severe cognitive deficits, such as intellectual disability or dementia. Lack of capacity can also be caused by severe mental illness. For example, a person suffering from mania may believe they have invented a way to turn salt water into gold and, as a result, decide to cash in their RRSPs and buy a yacht. When a person lacks capacity for a specific type of decision that decision is taken by a substitute decision-maker as designated by the jurisdiction's law. The substitute decision-maker is usually a family member, but in some provinces, it is the public guardian.

Similar to treatment and financial decisions, many patients with intellectual disability, dementia and psychosis lack the capacity to decide if aspects of their health care information should be shared with others. Under provincial and territorial legislation, if someone is incapable of deciding whether their healthcare information needs to be shared this decision should be made by the appropriate substitute decision-maker. However, clinicians almost never use this component of the law, even when a patient is clearly

incapable of appreciating the need to disclose aspects of their healthcare information to their family caregivers. This causes major disruption and suffering for the patient, their family and society in general.

Why do Clinicians not Share Information with Families?

Aspects of privacy legislation in a few Canadian jurisdictions are barriers to the appropriate sharing of information with families, and these provisions should be amended. However, most jurisdictions have legislation that supports the appropriate sharing of information, and the primary problem is that hospitals and clinicians fail to follow the requirements of the legislation. So why do hospitals and clinicians not provide critical information to family caregivers and exclude them in treatment planning in general? In a review of studies that examined this question, researchers reported that the main reasons appear to be clinicians' ignorance of key aspects of privacy legislation, a management and professional culture that is unsupportive of family involvement, and a lack of training on how to work with patients in a family context (1).

How Can the Problem be Resolved?

Provisions in legislation that are a barrier to the appropriate sharing of information should be amended. Further, governments must, as a priority, ensure that clinicians are aware of the privacy legislation in their jurisdiction. To achieve these objectives government will need to partner with professional regulatory colleges and professional training schools in a concerted effort to ensure that clinicians understand and appropriately implement legislation on healthcare information. We hope that education will redress most of the current difficulties. However, we suspect that some form of ongoing monitoring of compliance with legislation will be required. This, presumably, will fall to regulatory colleges. FASMI is committed to seeing this change in the system and is willing to work with governments, regulatory colleges and professional training schools to develop appropriate materials.

(1) Eassom, E., Giacco, D., Dirik, A., & Priebe, S. (2014). Implementing family involvement in the treatment of patients with psychosis: A systematic review of facilitating and hindering factors. *BMJ Open*, 4, e006108.)

APPENDIX

In this appendix, we have extracted clauses from legislation governing the sharing of healthcare information in Canadian provinces and territories. This has been organized under four headings:

1. The collection of information without consent.
2. Disclosure of information without consent.
3. Capacity to release or withhold information.
4. Maintaining the source of information confidential.

Under each heading we start in British Columbia and move eastwards through the provinces, concluding with the territories.

This appendix is intended to aid the referencing and comparison of legislation. While we have made our best efforts to identify the relevant statutes and clauses, some provisions may have been overlooked, or we may have misunderstood which laws apply in specific contexts. Anyone using this appendix should consult the full legislation in the jurisdiction in which they work, and review any applicable guidelines issued by governments, health authorities or professional colleges. If necessary, seek advice from qualified legal counsel.

If you notice omissions or errors in our interpretation, we would appreciate hearing from you. Please send an email to fasmiadvocates@gmail.com with the subject line: “Information Sharing Legislation.”

COLLECTION OF INFORMATION WITHOUT CONSENT

BRITISH COLUMBIA

Freedom of Information and Protection of Privacy Act

27(1) A public body must collect personal information directly from the individual the information is about unless

(a.1) the collection of the information is necessary for the medical treatment of an individual and it is not possible

(i) to collect the information directly from that individual

Personal Information Protection Act

12(1) An organization may collect personal information about an individual without consent or from a source other than the individual, if

(a) the collection is clearly in the interests of the individual and consent cannot be obtained in a timely way,

(b) the collection is necessary for the medical treatment of the individual and the individual is unable to give consent,

Note: Our understanding is that the clinicians working in public institutions are required to use the Freedom of Information and Protection of Privacy Act, whereas those working in private settings are required to use the Personal Information Protection Act.

ALBERTA

Health Information Act

22(2) A custodian may collect individually identifying health information from a person other than the individual who is the subject of the information in the following circumstances:

(c) where the custodian believes, on reasonable grounds, that collection from the individual who is the subject of the information would prejudice

(i) the interests of the individual,

(ii) the purposes of collection, or

(iii) the safety of any other individual,

or would result in the collection of inaccurate information;

(d) where collection from the individual who is the subject of the information is not reasonably practicable;

SASKATCHEWAN

Health Information Protection Act.

25(1) Subject to subsection (2), a trustee shall collect personal health information directly from the subject individual, except where:

(b) the individual is unable to provide the information;

(c) the trustee believes, on reasonable grounds, that collection directly from the subject individual would prejudice the mental or physical health or the safety of the subject individual or another individual;

MANITOBA

Personal Health Information Act

14(1) Whenever possible, a trustee shall collect personal health information directly from the individual the information is about.

(2) Subsection (1) does not apply if

(b) collection of the information directly from the individual could reasonably be expected to endanger the health or safety of the individual or another person;

(c) collection of the information is in the interest of the individual and time or circumstances do not permit collection directly from the individual;

(d) collection of the information directly from the individual could reasonably be expected to result in inaccurate information being collected;

ONTARIO

Personal Health Information Protection Act

36(1) A health information custodian may collect personal health information about an individual indirectly if,

(b) the information to be collected is reasonably necessary for providing health care or assisting in providing health care to the individual and it is not reasonably possible to collect, directly from the individual,

(i) personal health information that can reasonably be relied on as accurate and complete, or

(ii) personal health information in a timely manner;

QUEBEC

Act respecting Access to documents held by public bodies and the Protection of personal information

64 No person may, on behalf of a public body, collect personal information if it is not necessary for the exercise of the rights and powers of the body or the implementation of a program under its management.

A public body may, however, collect personal information if it is necessary for the exercise of the rights and powers or for the implementation of a program of a public body with which it cooperates to provide services or to pursue a common mission.

Act respecting health and social services information

13 The collection of information by a body is limited to that which is necessary for the body to fulfil its mission or purpose, exercise its functions or carry on its activities, or implement a program under its management.

Note: We are unclear how these statutes operate in practice and do not know if they govern healthcare providers who are working in clinical practice. We discussed this with psychiatrists practicing in Quebec who told us that when they assess patients who are potentially suicidal some psychiatrists will contact family, or other people, to obtain collateral information when that is felt to be necessary. In these situations, the psychiatrists rely on authority of Section.74 of the *Act Respecting Health and Social Services Information* (see below in the section on Disclosure of Information without Consent). We caution that this is an interpretation of the legislation and encourage readers to seek expert advice about the relevance of this interpretation to specific clinical situations.

NEW BRUNSWICK.

Personal Health Information Privacy and Access Act

27(2) ... a custodian may collect personal health information relating to an individual without that individual's consent if the individual is incapable of providing consent and

(a) consent can not be obtained because

(i) there is no substitute decision-maker who can provide consent in a timely manner, or

(ii) the individual has been admitted to a psychiatric facility as an involuntary patient under the *Mental Health Act*, or

(b) the collection is necessary for the provision of health care to the individual.

28 A custodian shall collect personal health information directly from the individual to whom the information relates except if

(b) collection of the information directly from the individual could reasonably be expected to endanger the health or safety of the individual or another person,

(c) collection of the information is in the interest of the individual and time or circumstances do not permit collection directly from the individual,

(d) collection of the information directly from the individual could reasonably be expected to result in the collection of inaccurate information,

PRINCE EDWARD ISLAND

Health Information Act

18 A custodian shall collect personal health information directly from the individual to whom it relates except where

(b) collection of the personal health information directly from the individual could reasonably be expected to endanger the health or safety of the individual or another person;

(c) collection of the personal health information is in the interest of the individual and time or circumstances do not permit collection directly from the individual;

(d) collection of the personal health information directly from the individual could reasonably be expected to result in the collection of inaccurate information;

NOVA SCOTIA

Personal Health Information Act

31(c) the information to be collected is reasonably necessary for providing health care or assisting in providing health care to the individual and it is not reasonably possible to collect, directly from the individual,

- (i) personal health information that can reasonably be relied on as accurate, or
- (ii) personal health information in a timely manner;

NEWFOUNDLAND AND LABRADOR

Personal Health Information Act

31 A custodian may collect personal health information from a source other than the individual who is the subject of the information where

(b) the information is reasonably necessary for providing health care to the individual and it is not reasonably possible to collect it directly from the individual

- (i) personal health information that can reasonably be relied on as accurate, or
- (ii) personal health information in a timely manner;

YUKON

Health Information Privacy and Management Act

54 A custodian may collect an individual's personal health information from a person other than the individual only if

(b) where the custodian collects the personal health information for the purpose of providing health care to the individual, the personal health information is reasonably necessary for that purpose and the custodian reasonably believes that collection directly from the individual

(i) would prejudice the purposes of collection,

(ii) would delay the collection in circumstances where delay would negatively affect the custodian's ability to provide necessary health care to the individual on a timely basis,

(iii) could result in the collection of information that is not accurate, or

(iv) is not reasonably practicable in the circumstances; or

NORTHWEST TERRITORIES

Health Information Act

30 A health information custodian may collect from other personal health information about an individual from a source other than the individual, if

(c) it is not reasonably practical to collect the information from the individual;

(d) the custodian has reasonable grounds to believe that collection from the individual

(i) would prejudice

(A) the health or safety of the individual or another individual, or

(B) the purposes of the collection, or

(ii) is likely to result in inaccurate information;

NUNAVUT

Access to Information and Protection of Privacy Act

41(1) A public body must, where reasonably possible, collect personal information directly from the individual the information relates to unless

(2) A public body that collects personal information directly from the individual the information is about shall inform the individual of

Exception

(3) Subsections (1) and (2) do not apply if, in the opinion of the head of the public body concerned, compliance with them might result in the collection of inaccurate information or defeat the purpose or prejudice the use for which the information is collected.

DISCLOSURE OF INFORMATION WITHOUT CONSENT

BRITISH COLUMBIA

Freedom of Information and Protection of Privacy Act

25(1) Whether or not a request for access is made, the head of a public body must, without delay, disclose to the public, to an affected group of people or to an applicant, information

(a) about a risk of significant harm to the environment or to the health or safety of the public or a group of people, or

(b) the disclosure of which is, for any other reason, clearly in the public interest.

33(3) A public body may disclose personal information in any of the following circumstances:

(a) if

(i) the head of the public body determines that compelling circumstances that affect anyone's health or safety exist, and

(ii) notice of disclosure is mailed to the last known address of the individual the information is about, unless the head of the public body considers that the notice could harm anyone's health or safety;

ALBERTA

Health Information Act

35(1) A custodian may disclose individually identifying diagnostic, treatment and care information without the consent of the individual who is the subject of the information

(b) to a person who is responsible for providing continuing treatment and care to the individual,

(c) to family members of the individual or to another person with whom the individual is believed to have a close personal relationship, if the information is given in general terms and concerns the presence, location, condition, diagnosis, progress and prognosis of the individual on the day on which the information is disclosed and the disclosure is not contrary to the express request of the individual,

SASKATCHEWAN

The Health Information Protection Act

27(2)(a) A subject individual is deemed to consent to the disclosure of personal health information:

(a) for the purpose for which the information was collected by the trustee or for a purpose that is consistent with that purpose;

(b) for the purpose of arranging, assessing the need for, providing, continuing, or supporting the provision of, a service requested or required by the subject individual; or

(c) to the subject individual's next of kin or someone with whom the subject individual has a close personal relationship if:

(i) the disclosure relates to health services currently being provided to the subject individual; and

(ii) the subject individual has not expressed a contrary intention to a disclosure of that type.

(4) A trustee may disclose personal health information in the custody or control of the trustee without the consent of the subject individual in the following cases:

(a) where the trustee believes, on reasonable grounds, that the disclosure will avoid or minimize a danger to the health or safety of any person;

MANITOBA

Personal Health Information Act

22(2) A trustee may disclose personal health information without the consent of the individual the information is about if the disclosure is

(b) to any person, if the trustee reasonably believes that the disclosure is necessary to prevent or lessen

(i) a risk of serious harm to the health or the safety of the individual the information is about or another individual, or to public health or public safety

(ii) a risk of serious harm to the health or safety of the individual the information is about or another individual, or to public health or public safety;

ONTARIO

Personal Health Information Protection Act

40 (1) A health information custodian may disclose personal health information about an individual if the custodian believes on reasonable grounds that the disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm to a person or group of persons.

QUEBEC

Act Respecting Health and Social Services Information

74 A body may communicate information it holds in order to protect a person or an identifiable group of persons where there is reasonable cause to believe that a serious risk of death or of serious bodily injury, related in particular to a disappearance or to an act of violence, including a suicide attempt, threatens the person or group and where the nature of the threat generates a sense of urgency.

In such a case, the information may be communicated to the person or persons exposed to that risk, to their representative or to any person who can come to their aid. Only the information necessary for the objectives pursued by the communication may be communicated to them.

No judicial proceedings may be brought against a body for communicating information in good faith under this section. The same applies to any person who, on behalf of the body, participates in good faith in such a communication, even indirectly.

For the purposes of the first paragraph, “serious bodily injury” means any physical or psychological injury that is significantly detrimental to the physical integrity or the health or well-being of a person or an identifiable group of persons.

NEW BRUNSWICK

Personal Health Information Privacy and Access Act

39(1) A custodian may disclose personal health information without the consent of the individual to whom the information relates if the custodian reasonably believes that disclosure is required

(a) to prevent or reduce a risk of serious harm to the mental or physical health or safety of the individual to whom the information relates or another individual, or

(b) to prevent or reduce a risk of significant harm to the health or safety of the public or a group of people, the disclosure of which is clearly in the public interest.

PRINCE EDWARD ISLAND

Health Information Act

24(1) A custodian may disclose personal health information without the consent of the individual to whom it relates if the custodian reasonably believes that disclosure is required

(a) to prevent or reduce a risk of serious harm to the health or safety of the individual to whom it relates or another individual, or

(b) to prevent or reduce a risk of significant harm to the health or safety of the public or a group of people.

NOVA SCOTIA

Personal Health Information Act

38(1) (d) to any person if the custodian believes, on reasonable grounds, that the disclosure will avert or minimize an imminent and significant danger to the health or safety of any person or class of persons;

NEWFOUNDLAND AND LABRADOR

Personal Health Information Act

40 (1) A custodian may disclose personal health information without the consent of the individual who is the subject of the information where the custodian reasonably believes that disclosure is required

(a) to prevent or reduce a risk of serious harm to the mental or physical health or safety of the individual the information is about or another individual; or

(b) for public health or public safety.

YUKON

Health Information Privacy and Management Act

58 A custodian may disclose an individual's personal health information without the individual's consent

(h) ...if the custodian reasonably believes that the disclosure will prevent or reduce a risk of serious harm to the health or safety of any other individual, or will enable the assessment of whether such a risk exists;

NORTHWEST TERRITORIES

Health Information Act

58 (1) A health information custodian may disclose personal health information about an individual if the custodian has reasonable grounds to believe that the disclosure is required to prevent or reduce

(a) an imminent threat to the health or safety of the individual or another individual;

(b) a risk of serious harm to the health or safety of the individual or another individual; or

(c) an imminent or serious threat to public safety.

NUNAVUT

Access to Information and Protection of Privacy Act

48 A public body may disclose personal information

(q) when necessary to protect the mental or physical health or safety of any individual;

(s) for any purpose when, in the opinion of the head,

(i) the public interest in disclosure clearly outweighs any invasion of privacy that could result from the disclosure, or

(ii) disclosure would clearly benefit the individual to whom the information relates;

CAPACITY TO RELEASE OR WITHHOLD INFORMATION

BRITISH COLUMBIA

Freedom of Information and Protection of Privacy Act

33(1) A public body may disclose personal information in its custody or under its control only as permitted by subsections (2) to (9) or by section 33.3.

(2)(d) for the purpose for which the information was obtained or compiled, or for a use consistent with that purpose within the meaning of section 34 [*definition of consistent purpose*];

34 For the purposes of section 32 (a) or 33 (2) (d) or (w), a use of personal information is consistent with the purpose for which the information was obtained or compiled if the use

(a) has a reasonable and direct connection to that purpose, and

(b) is necessary for performing the statutory duties of, or for operating a program or activity of, the public body that uses or discloses the information.

Note: There is no reference to capacity to disclose or withhold personal health information in the Freedom of Information and Protection of Privacy Act. Our understanding is that these provisions allow a public body to release information over objection if that information is essential for the person's healthcare.

Personal Information Protection Act

15(1) An organization may use personal information about an individual without the consent of the individual, if

(a) the use is clearly in the interests of the individual and consent cannot be obtained in a timely way,

(b) the use is necessary for the medical treatment of the individual and the individual does not have the legal capacity to give consent,

ALBERTA

Health Information Act

35(1) A custodian may disclose individually identifying diagnostic, treatment and care information without the consent of the individual who is the subject of the information

(n) if that individual lacks the mental capacity to provide a consent and, in the opinion of the custodian, disclosure is in the best interests of the individual,

SASKATCHEWAN

Health Information Protection Act

56 Any right or power conferred on an individual by this Act may be exercised:

(b) where a personal guardian has been appointed for the individual, by the guardian if the exercise of the right or power relates to the powers and duties of the guardian;

(e) where the individual does not have the capacity to give consent:

(ii) by a person who, pursuant to *The Health Care Directives and Substitute Health Care Decision Makers Act, 2015*, is entitled to make a healthcare decision, as defined in that Act, on behalf of the individual;

MANITOBA

Personal Health Information Act.

60(1) The rights of an individual under this Act may be exercised

(c) by a committee appointed for the individual under *The Mental Health Act* if the committee has the power to make health care decisions on the individual's behalf;

(d) by a substitute decision maker for personal care appointed for the individual under *The Adults Living with an Intellectual Disability Act* if the exercise of the right relates to the powers and duties of the substitute decision maker;

(e) if the individual is a minor who does not have the capacity to make health care decisions, by one of the following persons:

(i) the minor's parent or guardian,

(ii) an alternate decision maker for the minor if the exercise of the right or power relates to the alternate decision maker's decision-making responsibility; or

Note: We could only find the above provisions relevant to capacity to consent to the release or withholding of information for people who are under the Mental Health Act, minors found above and people with intellectual disability.

ONTARIO

Personal Health Information Protection Act

Capacity to consent

21(1) An individual is capable of consenting to the collection, use or disclosure of personal health information if the individual is able,

(a) to understand the information that is relevant to deciding whether to consent to the collection, use or disclosure, as the case may be; and

(b) to appreciate the reasonably foreseeable consequences of giving, not giving, withholding or withdrawing the consent.

(2) An individual may be capable of consenting to the collection, use or disclosure of some parts of personal health information, but incapable of consenting with respect to other parts.

QUEBEC

Act respecting the sharing of certain health information

47 If the person to whom the health information relates is under the age of 14 or is incapable, refusal is expressed by the holder of parental authority or the tutor or mandatary of the person.

Act respecting health and social services information

26 The tutor or mandatary of an incapable person of full age has the right to be informed of the existence of and to have access to any information concerning that person that is held by a body. The tutor or mandatary also has the right to request the rectification of the information if it is inaccurate, incomplete or equivocal or if it was collected or is kept in contravention of the law.

NEW BRUNSWICK

Personal Health Information Privacy and Access Act

23(1) An individual is capable of consenting to the collection, use or disclosure of personal health information if the individual is able

(a) to understand the information that is relevant to deciding whether to consent to the collection, use or disclosure, as the case may be, and

(b) to appreciate the reasonably foreseeable consequences of giving, not giving, withholding or withdrawing the consent.

23(2) An individual may be capable of consenting to the collection, use or disclosure of personal health information at one time, but incapable of consenting at another time.

23(3) An individual is presumed to be capable of consenting to the collection, use or disclosure of personal health information.

23(4) A custodian may rely on the presumption under subsection (3), unless the custodian has reasonable grounds to believe that the individual is incapable of consenting to the collection, use or disclosure of personal health information.

PRINCE EDWARD ISLAND

Health Information Act

13(1) If this Act or any other enactment requires the consent of an individual to the collection, use or disclosure of personal health information by a custodian, the consent

(a) shall be a consent of the individual, if the individual is capable of granting consent, or the consent of a substitute decision-maker;

14(1) An individual is capable of consenting to the collection, use or disclosure of the individual's personal health information if the individual is able

(a) to understand the information that is relevant to deciding whether to consent to the collection, use or disclosure, as the case may be; and

(b) to appreciate the reasonably foreseeable consequences of giving, not giving, withholding or withdrawing the consent.

NOVA SCOTIA

Personal Health Information Act

3 (b) “capacity” means the ability to understand information that is relevant to the making of a decision related to the collection, use or disclosure of personal health information and the ability to appreciate the reasonably foreseeable consequences of a decision or lack of a decision;

19 (1) An individual may have the capacity at a particular time to consent to the collection, use or disclosure of some parts of personal health information but be incapable of consenting at another time.

(2) An individual may have the capacity to consent to the collection, use or disclosure of some parts of personal health information but be incapable of consenting with respect to other parts.

20 Where an individual is deemed to have the capacity to consent to the collection, use and disclosure of personal health information, this capacity to consent includes disclosure to a parent, guardian or substitute decision-maker where applicable.

NEWFOUNDLAND AND LABRADOR

Personal Health Information Act

7 A right or power of an individual under this Act or the regulations may be exercised

(b) where the individual lacks the competency to exercise the right or power or is unable to communicate, and where the collection, use or disclosure of his or her personal health information is necessary for or ancillary to a "health care decision", as defined in the *Advance Health Care Directives Act*, by a substitute decision maker appointed by the individual in accordance with that Act or, where a substitute decision maker has not been appointed, a substitute decision maker determined in accordance with section 10 of that Act;

(c) by a court appointed guardian of a mentally disabled person, where the exercise of the right or power relates to the powers and duties of the guardian;

(d) by the parent or guardian of a minor where, in the opinion of the custodian, the minor does not understand the nature of the right or power and the consequences of exercising the right or power;

(g) where an individual has been certified as an involuntary patient under the *Mental Health Care and Treatment Act*, by a representative as defined in that Act, except as otherwise provided in this Act.

YUKON

Health Information Privacy and Management Act

45(1) An individual is capable of consenting to the collection, use or disclosure of personal health information if the individual is able

(a) to understand the information that is relevant to deciding whether to consent to the collection, use or disclosure, as the case may be; and

(b) to appreciate the reasonably foreseeable consequences of giving, refusing, withholding or withdrawing the consent.

(2) An individual may have the capacity at one time to consent to the collection, use or disclosure of their personal health information but be incapable of consenting at another time.

(3) An individual may have the capacity to consent to the collection, use or disclosure of some portions of their personal health information but be incapable of consenting with respect to other portions of it.

NORTHWEST TERRITORIES

Health Information Act

Note: We could not find any reference to capacity in this act.

NUNAVUT

Access to Information and Protection of Privacy Act

Note: We could not find any reference to capacity in this act.

MAINTAINING THE SOURCE OF INFORMATION CONFIDENTIAL

BRITISH COLUMBIA

Freedom of Information and Protection of Privacy Act

22(1)The head of a public body must refuse to disclose personal information to an applicant if the disclosure would be an unreasonable invasion of a third party's personal privacy.

(2) In determining under subsection (1) or (3) whether a disclosure of personal information constitutes an unreasonable invasion of a third party's personal privacy, the head of a public body must consider all the relevant circumstances, including whether

(f) the personal information has been supplied in confidence,

ALBERTA

Health Information Act

11(1) A custodian may refuse to disclose health information to an applicant

(b) if the disclosure could reasonably lead to the identification of a person who provided health information to the custodian explicitly or implicitly in confidence and in circumstances in which it was appropriate that the name of the person who provided the information be kept confidential,

SASKATCHEWAN

Health Information Protection Act

38(1) Subject to subsection (2), a trustee may refuse to grant an applicant access to his or her personal health information if:

(a) in the opinion of the trustee, knowledge of the information could reasonably be expected to endanger the mental or physical health or the safety of the applicant or another person;

(c) disclosure of the information could reasonably be expected to identify a third party, other than another trustee, who supplied the information in confidence under circumstances in which confidentiality was reasonably expected;

MANITOBA

Personal Health Information Act

11(1) A trustee is not required to permit an individual to examine or copy his or her personal health information under this Part if

(c) disclosure of the information could reasonably be expected to identify a third party, other than another trustee, who supplied the information in confidence under circumstances in which confidentiality was reasonably expected;

ONTARIO

Personal Health Information Protection Act

52(1) Subject to this Part, an individual has a right of access to a record of personal health information about the individual that is in the custody or under the control of a health information custodian unless,

(e) granting the access could reasonably be expected to,

(i) result in a risk of serious harm to the treatment or recovery of the individual or a risk of serious bodily harm to the individual or another person,

(ii) lead to the identification of a person who was required by law to provide information in the record to the custodian, or

(iii) lead to the identification of a person who provided information in the record to the custodian explicitly or implicitly in confidence if the custodian considers it appropriate in the circumstances that the identity of the person be kept confidential; or

QUEBEC

Note: we are unsure how the province of Quebec manages this issue.

NEW BRUNSWICK

Personal Health Information Privacy and Access Act

14(1) A custodian is not required to permit an individual to examine or copy his or her personal health information under this Part

(c) if disclosure of the information could reasonably be expected to identify a third party, other than another custodian, who supplied the information in confidence under circumstances in which confidentiality was reasonably expected,

PRINCE EDWARD ISLAND

Health Information Act

10(1) A custodian may refuse to permit an individual to examine or copy his or her personal health information under this Part

(a) if knowledge of the personal health information could reasonably be expected to endanger the health or safety of the individual or another person;

(c) if disclosure of the personal health information could reasonably be expected to identify a third party, other than another custodian, who supplied the personal health information in confidence under circumstances in which confidentiality was reasonably expected;

NOVA SCOTIA

Personal Health Information Act

72 (1) Notwithstanding Section 71, a custodian may refuse to grant access to an individual's personal health information about that individual if it is reasonable to believe that

(h) granting the access could reasonably be expected to lead to the identification of a person who provided information in the record to the custodian in circumstances in which confidentiality was reasonably expected; or

NEWFOUNDLAND AND LABRADOR

Personal Health Information Act

58(2) A custodian may refuse to permit an individual to examine or receive a copy of a record of his or her personal health information where

(d) granting access could reasonably be expected to

(i) result in a risk of serious harm to the mental or physical health or safety of the individual who is the subject of the information or another individual,

(ii) lead to the identification of a person who was required by law to provide information in the record to the custodian, or

(iii) lead to the identification of a person who provided information in the record to the custodian in confidence under circumstances in which confidentiality was reasonably expected.

YUKON

Health Information Privacy and Management Act

27(1) Subject to subsection (3), a custodian must refuse to grant an individual access to any of the individual's personal health information in the custodian's custody or control that

(a) the custodian has reasonable grounds to believe would, if disclosed,

(i) cause serious harm to the health or the safety of any individual, or

(ii) identify a third party who supplied the personal health information in confidence under circumstances in which confidentiality was reasonably expected;

NORTHWEST TERRITORIES

Health Information Act

114 A health information custodian may refuse to disclose information to an applicant if the disclosure could reasonably be expected to lead to the identification of a person who provided personal health information to a custodian in confidence, whether explicitly or implicitly, and under circumstances in respect of which it is appropriate that the name of the person be kept confidential.

NUNAVUT

Access to Information and Protection of Privacy Act

21 (1) The head of a public body may refuse to disclose to an applicant information, including personal information about the applicant, where the disclosure could reasonably be expected to endanger the mental or physical health or safety of an individual other than the applicant.

(2) The head of a public body may refuse to disclose to an applicant personal information about the applicant if, in the opinion of a medical or other expert, the disclosure could reasonably be expected to result in immediate and grave danger to the applicant's mental or physical health or safety.

22 (c) has been provided to the public body, explicitly or implicitly, in confidence.

23 (3) In determining whether a disclosure of personal information constitutes an unreasonable invasion of a third party's personal privacy, the head of a public body must consider all the relevant circumstances, including whether

(f) the personal information has been supplied in confidence;

(g) the personal information is likely to be inaccurate or unreliable;

