

OFFICE OF WOMEN'S HEALTH  
RESEARCH CHAIR IN MENTAL HEALTH

# PRIVACY TOOLKIT

## PROTECTING PRIVACY RIGHTS OF YOUNG ADULTS WITH DEVELOPMENTAL DISABILITIES

A RESOURCE FOR **FAMILY CAREGIVERS**

VERSION 1, 2018



This project has been funded by the Office of the Privacy Commissioner of Canada (OPC); the views expressed herein are those of the author(s) and do not necessarily reflect those of the OPC.

# A PRIVACY TOOLKIT

This is a guide for FAMILY CAREGIVERS to help their young adults with developmental disabilities to protect the privacy of their personal information.

According to Canada's Personal Information Protection and Electronic Documents Act, Ontario's Personal Health Information Protection Act, and the Municipal Freedom of Information and Protection of Privacy Act, everyone has the right to the privacy of their personal information.

While prepared with care to ensure accuracy and completeness, this guide has no legal status.

For the official text of information privacy law, consult the Office of Privacy Commissioner website at [www.priv.gc.ca](http://www.priv.gc.ca) or call the office of the Privacy commissioner of Canada at 1-800-282-1376

## FOR MORE INFORMATION

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For more information on OPC contact:

Office of the Privacy Commissioner of Canada

Telephone: 1-800-282-1376

Website: [www.priv.gc.ca](http://www.priv.gc.ca)

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# DISCLAIMER

This toolkit was developed as a public resource for service providers who support young adults with developmental disabilities:

1. Within the public and private sector
2. In their decision-making, advocacy, education
3. To help them protect their rights to information privacy

This toolkit and the whole series of toolkits produced by the YADD Privacy Project, are based on several sources of information:

1. Comprehensive review of the literature
2. Policy reports
3. Relevant legislative Acts
4. Input from the YADD Privacy Project Advisory Committee, including young adults with developmental disabilities.

This toolkit is designed to support young adults with developmental disabilities and their families in protecting their rights for the privacy of their personal information, either in context of commercial activities or health and social related services within health care, private or community- based agencies.

The resource materials provided in this privacy toolkit are for general information purposes only.

This toolkit reflects interpretations and practices regarded as valid when it was published based on available information at that time.

This toolkit is not intended, and should not be construed, as legal or professional advice or opinion.

Service providers concerned about the applicability of privacy legislation to their activities are advised to seek legal or professional advice based on their particular circumstances.

Similarly, this toolkit should not be relied upon as a substitute for relevant legislation: PIPEDA, and/or the relevant provincial and municipal legislation that may apply. In the context of this toolkit, this means the Freedom of Information and Protection of Privacy Act (FIPPA) or Health Information Protection Act (PHIPA) or Municipal Freedom of Information and Protection Privacy Act (MFIPPA).

This toolkit considers federal legislation pertaining to all provinces and territories in Canada. However, due to the location of this research project, this toolkit specifically references Ontario legislation. In specific cases PHIPA may apply instead of PIPEDA, when referencing health information custodians, and municipal legislation that applies across Ontario.

To consider the relevant legislation in other provinces, please see the OPC website, "Overview of privacy legislation in Canada: under the sub-heading "Provincial privacy laws" where these are laid out. Available at: [https://www.priv.gc.ca/en/privacy-topics/privacy-laws-in-canada/02\\_05\\_d\\_15](https://www.priv.gc.ca/en/privacy-topics/privacy-laws-in-canada/02_05_d_15)

Provisions of each legislation have been simplified for the purpose of identifying issues for consideration when supporting young adults with developmental disabilities and their families. In addition, the Office of the Privacy Commissioner has an important role to play in providing guidance on how the Personal Health Information Protection Act, 2004 is being applied and interpreted.

You should monitor the Commission's website at <http://www.priv.gc.ca>

# FOUR FORMS OF PROTECTION

**MFIPPA:** Municipal Freedom of Information and Protection of Privacy Act

**FIPPA:** Freedom of Information and Protection of Privacy Act

**PHIPA:** Personal Health Information Protection Act

**PIPEDA:** Personal Information Protection and Electronic Documents Act

They all state that:

Personal information cannot be collected, used or shared without permission. Further, even if your young adult is required to provide personal information to get a service, they can still control how it is used, who it is shared with, and how long it is kept on file.



## MFIPPA

- Every individual has a basic right of access to personal information
- This act provides the right of access to information under the control of institutions
- Applies to individuals defined as health information custodians
- Exemptions include: 1) Relations with governments, 2) Third party information, Personal information, 3) Discretionary exemptions at the discretion of the decision maker (i.e. City Clerk)

## FIPPA

- Provincial legislation providing right to access to information under the control of institutions and protecting privacy of individuals regarding their personal information
- Similar to MFIPPA, provides right of access to information under control of institutions (applies to province)
- Applies to provincially mandated and controlled entities including hospitals, institutions, law enforcement and universities
- Exemptions include: 1) Third party information, 2) Discretionary exemptions



## PHIPA

- Every individual within the province of Ontario has a basic right of access to personal information
- Sets out rules, right of access to personal health information, providing right to request correction or amendment of personal health information
- Health sector privacy law that applies to collection, use, disclosure of personal information by, or to a health information custodian
- Exemptions include: 1) Limited protection if not health information, 2) Personal health information is not specifically under the control of health information custodian



## PIPEDA

- Every Canadian citizen has a right of access to personal information; applies within provinces without substantially similar legislation
- Sets out rules to govern collection, use and disclosure of personal information
- Every organization that organizes, collects, uses or discloses personal information in the course of commercial activities or about an employee of the organization collecting personal information that has to do with a federal project undertaking or business
- Exemptions include: 1) Personal information collection for personal or domestic purposes alone, 2) Personal information that is used for journalistic, artistic or literary purposes.

# STEPS TO PRIVACY

These simple steps can help you to clarify rules for collection, use, sharing, and safekeeping of information specifically for your young adult with developmental disabilities

## SUPPORTING YOUR YOUNG ADULT INVOLVES:

SUPPORTING YOUR YOUNG ADULT

1.

### **SUPPORT DECISION- MAKING**

Help your young adult to make decisions as to whether or not their personal information should be shared. See page 4.

2.

### **SET LIMITS, AND CONSENT**

Help your young adult to gain as much control and independence as possible with giving permissions and setting limits on what personal information will be collected, stored and shared. See page 5.

3.

### **ACCESS, SECURITY AND REPORTING**

Help support your young adult by encouraging them to check on their personal information and make complaints if the accuracy and completeness of their records is a problem. See page 6.

THE DECISION-MAKING TOOL ON THE FOLLOWING PAGES  
WILL GUIDE YOU THROUGH THE 3 STEPS OUTLINED ABOVE.

# Personal Information Cannot Be Collected, Used, or Shared With Others Without Consent From Your Young Adult

1

## SUPPORT DECISION MAKING

Remember if your young adult can make all the decisions he/she is best to obtain their personal information:

- Do they understand the general idea of what information is being asked for and why their answering indicates it? (yes)
- Do they understand what will happen if they do not provide answers? (yes)
- Do they have the ability to express their preferences or share or not to share their personal information?

Yes

No

**Support goals:**  
Your young adult can self-identify and give informed decisions. Informal support must be available to ensure parts of the decisional process.

**Considerable supports:**  
• Technical support  
• Adult supervision and  
• Regulation of interactions  
• Alternative formats for understanding and communicating

Ask questions! Help your young adult to make questions as available as possible or provide as best as possible:

- Why does this information need to be collected?
- What is the purpose of collecting, using and sharing the information?
- What part of the information request does not need to be collected for this purpose or at this level?
- Why collect the information?
- How will the information be used?
- What are the consequences if someone in particular is refused the collection, use or sharing of the personal information?
- Does the consent be collected?

2

## SET LIMITS AND CONSENT

Remember if you are involved in the collecting, use and sharing of your young adult's personal information:

- You can state why the collection that is requested for the purpose of gathering needed your young adult support?
- Are you sharing only with those people who should and understand what the information is for the support?
- Are you clear how long you are using adults personal information and how long it will be?
- Are you clear who can and not consent if you have those questions or when to ask when you feel it is best or complete?

Yes

No

1. Do you consent?
2. Are you clear the information privacy policy for the organization?
3. What rights will the service providers be given about the data information?

Share the your young adult's personal information is being used to use and share for making:

- How will the personal information be shared by someone?
- What procedures are in place to keep personal information consistent, this can use or make decision consent?
- How will the personal information be used?
- What procedures are in place to collect under the organization for using technology and digital support?

### GIVE CONSENT

Remember to make sure your young adult is or before you consent:

Your young adult can withdraw consent at anytime

3

## ACCESS, SECURITY AND REPORTING

Remember how you will give your young adult the control their personal information:

- Where is the personal information is stored?
- How can you tell your young adult when changes to your personal information in case it is not accurate or complete?
- Are there ways of the organization plan for sharing and storing personal information.  
(Other sites will be on their website are posted on their office)

Are you have a commitment about how your young adult's personal information is collected, used, or shared?

Yes

No

Continually keep in contact with the organization that has your personal information for any future questions or into time

Contact the organization or the Office of the Privacy Commissioner:

- The organization's website will have a page on who to contact with a privacy complaint.
- Contact [www.priv.gc.ca](http://www.priv.gc.ca) or the e-consentment: [http://www.priv.gc.ca/consentment/consentment\\_e.html](http://www.priv.gc.ca/consentment/consentment_e.html) or call toll free 1-800-926-1176

# STEPS TO PRIVACY

These simple steps can help you to clarify rules for collection, use, sharing, and safekeeping of information specifically for your young adult with developmental disabilities

## Personal Information Cannot Be Collected, Used, or Shared With Others Without Consent From Your Young Adult

1

### SUPPORT DECISION MAKING

**Determine if your young adult can make all of the decision to share or not to share their personal information.**

- Do they understand the general idea of what information is being asked for and why they are being asked for it? *AND*
- Do they understand what will happen if they do not provide consent? *AND*
- Do they have the ability to express their preference to share or not to share their personal information?

NO

YES

#### Support parts:

Your young adult can still make some part of the decision. ALWAYS support them to decide on as many parts of the decision as possible.

#### Accommodate, provide:

- Technology aids
- Extra explanation, time
- Repetition of instructions
- Alternative formats for understanding and communicating

**Ask questions! Help your young adult to ask as many questions as possible or you do so on their behalf:**

- Why does this information need to be collected?
- What is the purpose of collecting, using and sharing this information?
- What part of the information request does not need to be collected for this purpose or at this time?
- Who will see the information?
- Who will it be shared with?
- What are the consequences if consent or permission is refused for the collection, use or sharing of the personal information?
- How can consent be withdrawn?



These simple steps can help you to clarify rules for collection, use, sharing, and safekeeping of information specifically for your young adult with developmental disabilities

2

## SET LIMITS AND CONSENT

Determine if you can set limits on the collection, use, and sharing of your young adult's personal information?

- Can you share only the information that is required for the purpose of getting the service your young adult requires?
- Can you share only with those people who you and your young adult believe need the information for the service?
- Can you limit how long your young adult's consent/permission is valid (usually 1 year)?
- Can you find out who you can both contact if you have more questions or want to look into your file, or have a complaint?

NO

YES

1. Do Not Consent.
2. Ask to see the information privacy policy for the organization.
3. Meet again with the service provider to review based on new information.

Check that your young adult's personal information is being kept accurate and secure by asking:

- How is the personal information file checked for accuracy?
- What procedures are in place to keep electronic information, computers, files and use of mobile devices secure?
- How is the personal information stored?
- What procedures are in place within the organization to ensure security of technology and physical space?

## GIVE CONSENT

(Agree to share with your young adult or on behalf of your young adult)

Your young adult can withdraw consent at anytime.



# STEPS TO PRIVACY

These simple steps can help you to clarify rules for collection, use, sharing, and safekeeping of information specifically for your

3

## ACCESS, SECURITY AND REPORTING

Determine how you and your young adult can access their personal information.

- Where is the personal information is stored?
- How can you and your young adult make changes to your personal information in case it is not accurate or complete?
- Ask for a copy of the organization policies for sharing and storing personal information. (Often this will be on their website and posted at their office)

Do you have a complaint about how your young adult's personal information is collected, used, or shared?

NO

YES

Continue to keep in contact with the organization that has your personal information for any future questions you may have.

Contact the organization or the Office of the Privacy Commissioner:

- The organization's website will have a page on who to contact with a privacy complaint
- Contact [www.priv.gc.ca](http://www.priv.gc.ca) or file a complaint: <https://www.priv.gc.ca/en/report-a-concern/file-a-formal-privacy-complaint/> (Tel: Toll-free: 1-800-282-1376)

# PRIVACY TOOL

## SUMMARY

Here is a form that you and your young adult can use to collect the information from your service provider, and keep for your records.

**WHO IS COLLECTING MY INFORMATION?**

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**WHAT IS THE REASON FOR COLLECTING THIS INFORMATION?**

1. 

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2. 

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3. 

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**WHERE IS IT BEING HELD AND HOW WILL IT BE KEPT SECURE?**

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**WHO WILL IT BE SHARED WITH?**

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**WHAT TYPE OF INFORMATION IS BEING COLLECTED?**

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**WHO WILL HAVE ACCESS TO MY INFORMATION?**

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**WHO CAN I CONTACT WITH A QUESTION OR COMPLAINT?**

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**HOW LONG WILL IT BE KEPT?**

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# KEY TERMS



## GLOSSARY OF PRIVACY TERMS

### **Canadian Charter of Rights**

A treaty that consolidates human rights within Canada. The treaty states that everyone has a right to protect their personal data, that data must be processed for legitimate and specified purposes and that compliance is subject to control by an authority.

### **Choice**

An individual's ability to determine whether or how their personal information may be used or disclosed by the entity that collected the information. Also, the ability of an individual to limit certain uses of their personal information. For example, an individual may have choice about whether to permit a company to contact them or share their data with third parties. Choice can be express or implied.

### **Commercial Activity**

Under PIPEDA, "commercial activity" means any particular transaction, act or conduct, or any regular course of conduct, that is of a commercial character, including the selling, bartering or leasing of donor, membership or other fundraising lists. Non-profit associations, unions and private schools are likely to be found to exist outside of this definition.

### **Confidentiality**

The obligation of an individual, organization or business to protect personal information and not misuse or wrongfully disclose that information.

### **Consent**

This privacy requirement is one of the fair information practices. Individuals must be able to prevent the collection of their personal data, unless the disclosure is required by law. If an individual has choice (see Choice) about the use or disclosure of his or her information, consent is the individuals' way of giving permission for the use or disclosure. Consent may be affirmative; i.e., opt-in; or implied; i.e., the individual didn't opt out. (1) Explicit Consent: A requirement that an individual "signifies" their agreement with a data controller by some active communication between the parties. (2) Implicit Consent: Implied consent arises where consent may reasonably be inferred from the action or inaction of the individual.

### **Customer Access**

A customer's ability to access the personal information collected on them as well as review, correct or delete any incorrect information.

### **Data Breach**

The unauthorized acquisition of computerized data that compromises the security, confidentiality, or integrity of personal information maintained by a data collector. Breaches do not include good faith acquisitions of personal information by an employee or agent of the data collector for a legitimate purpose of the data collector—provided the personal information is not used for a purpose unrelated to the data collector's business or subject to further unauthorized disclosure.

### **Freely-Given Consent**

Consent that is given when the data subject has a genuine choice and there is no risk of coercion, deception, or intimidation if the data subject does not consent.

### **Information Privacy**

One of the four classes of privacy, along with territorial privacy, bodily privacy, and communications privacy. The claim of individuals, groups or institutions to determine for themselves when, how and to what extent information about them is communicated to others.

### **Information Security**

The protection of information for the purposes of preventing loss, unauthorized access and/or misuse.

**IAPP Privacy Glossary. Retrieved from:**

**[https://iapp.org/media/pdf/resource\\_center/IAPP\\_Privacy\\_Certification\\_Glossary\\_v2.0.0.2.pdf](https://iapp.org/media/pdf/resource_center/IAPP_Privacy_Certification_Glossary_v2.0.0.2.pdf)**

# THE PRIVACY PROJECT TEAM



## WOMEN'S HEALTH RESEARCH CHAIR IN MENTAL HEALTH

The Office of Women's Health Research Chair in Mental health is part of the Faculty of Health, at York University. We are interested in studying social factors that affect the mental health and wellbeing of women, youth, and children. To learn more about other projects conducted at this office, please visit: <http://nkhanlou.info.yourku.ca>

## ABOUT THE RESEARCHERS

Dr. Nazilla Khanlou is Associate Professor in the School of Nursing at York University; she is the Principal Investigator of this study and Chair of the Women's Health Research Office in Mental Health. Dr. Anne Mantini, is the Co-Investigator and a Research Associate in this office. Dr. Luz Maria Vazquez is the Research Coordinator, Dr. Attia Khan, Research Assistant, and Katie Degendorge is a lawyer on our team. Also on our team are the following community and research partners: Ron LaRoche, Director of Communications, Marketing and Fund Development for Community Living Ontario and Daniel Share-Storm, Marketing and Communications Coordinator for Community Living Ontario, also a well-known autism self-advocate and keynote speaker.

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## THE PRIVACY PROJECT IS ENRICHED BY THE MEMBERS OF THE PRIVACY PROJECT ADVISORY COMMITTEE, ROUNDTABLE DISCUSSION GROUP AND PRIVACY PROJECT WORKSHOP GROUP.

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