Durham Community Legal Clinic
& Access to Justice Hub

Submissions to Information Management Strategy and Policy Branch, Ministry of Health

Proposal Number:20-HLTC040, Amendment of Regulation O. Reg. 329/04 (General) under the Personal Health Information Protection Act, 2004 (PHIPA)

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Durham Community Legal Clinic

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About

The **Durham Community Legal Clinic** (DCLC) is a community legal clinic, primarily funded by Legal Aid Ontario (LAO). It was founded in 1985, and provides legal services, information, education, and representation for historically marginalized and low-income residents of Durham Region. DCLC also engages in advocacy and law reform activities, in particular to ensure that our laws properly consider the perspectives of historically marginalized and low-income Ontarians. The main legal areas of service DCLC provides includes housing law, social benefits, employment, human rights, and workplace safety.

In early 2019, DCLC established the **Durham Access to Justice Hub®** (the "Hub) with the assistance of LAO. This inter-agency and inter-disciplinary initiative intended to provide legal services beyond the income thresholds and subject matter of LAO, and other social, financial, and psychological services. These cooperative relationships seek to foster better client-centered services, reduce administrative barriers and silos, and improve efficiency of services that are funded or subsidized by taxpayer dollars. Some techniques used to achieve these goals include recruitment of volunteers to contribute towards improving access to justice, and by embedding students into workflows and innovative projects through experiential education.

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Overview

1. DCLC has reviewed proposed amendments to the *Personal Health Information Protection Act, 2004* (PHIPA)[1] regulations, which would name the Ministry of Children, Community and Social Services (MCCSS) as a prescribed ministry for purposes of section 46 of PHIPA.[2] We offer caution in these submissions specifically in relation to the impact these changes may have on the Ontario Disability Support Program (ODSP), specifically in the manner in which this proposed amendment would directly contradict the intent and purposes of PHIPA.
2. The Dec. 4, 2019 Auditor General's Annual Report noted that the average number of ODSP recipients increased in the past decade by 50 percent, from 247,500 in 2008/2009, to 370,700 in 2018/2019.[3] The cost of this program has increased by 75%, from $3.1 billion in 2008/2009, to $5.4 billion in 2018/2019.[4] This was the first time the Auditor General had audited MCCSS in the past decade.
3. Some of the reasons for this increased cost included an increase of ODSP applicants confirmed to be disabled after only a cursory review, a 56% increase.[5] The audit specifically mentioned that it was unclear as to how the rationale for meeting the definition of disability under the *Ontario Disability Support Program*

[1] SO 2004, c 3, Sch A.
[2] O. Reg. 329/04 (General).
[3] Auditor General of Ontario, "Ministry of Children, Community, and Social Services: Ontario Disability Support Program," *2019 Annual Report*, vol 1, ch 3, s 3.09, at 571, available at: <https://www.auditor.on.ca/en/content/annualreports/arreports/en19/v1_309en19.pdf>.
[4] *Ibid* at 512.
[5] *Ibid* at 529.

Act[6] was made in almost 20% of the approved applications.[7] The number of approved disability applications approved for life also increased 51%, with the lack of medical reviews confirming eligibility specifically flagged in this increase.[8]

4. Recommendation 6 in this report specifically called for recording the names and addresses of health-care professionals who complete disability applications, to identify professionals who complete a high volume of applications, or are responsible for a disproportionately high number of disability applications. The response by MCCSS is that they have worked with the Ministry of Health and Long-Term Care to obtain data to analyze these trends.[9]
5. The proposed changes to PHIPA may in fact assist in some of these issues, but require a broader context of changes introduced by MCCSS since the Auditor General's report. In implementing any changes to ODSP, MCCSS should still ensure that the client is in control of their medical information, and that any changes to their support do not occur without an opportunity to provide information that may not be available despite these changes to PHIPA.
6. Including MCCSS as a "prescribe ministry" under the regulations allows the Ministry to request personal health information from a health information custodian, such as a doctor or treating health care professional. The purpose for this

[6] 1997, SO 1997, c 25, Sch B.
[7] *Supra* note 3 at 514.
[8] *Ibid*.
[9] *Ibid* at 538.

information is for "determining, providing, monitoring or verifying payment or funding."

7. When this type of health information is collected by MCCSS for the purposes of determining disability, there is a risk that they may obtain incomplete information. This may occur because a patient is receiving care from another health information custodian, which MCCSS may not be aware of, or because their health condition has worsened or become more complicated, requiring more specialized care.
8. Terminating enrollment in ODSP simply based on information obtained from a health information custodian under s. 46 of PHIPA would potentially place many disabled individuals in a dire situation. Instead, MCCSS should notify any recipients of ODSP that they are requesting this information, and also request an update to their file as to any other health care providers they may be seeking care from.
9. If implemented in this manner, DCLC would support this regulatory reform as one that will improve the efficiency of ODSP, but also assist many of the clients who have difficulty collecting and maintaining all of their health information. However, the proposed amendment to the regulation as it is currently drafted creates other challenges around how exemptions are created under PHIPA.

Background

10. ODSP is a means-tested last resort income support in Ontario, which has been in place since 1997. This was part of a broader initiative to help move people from

facilities, which is expensive and often ineffective in promoting independence, back into the community, where they could be better supported. ODSP is therefore an essential part of ensuring that community supports are provided in a cost-effective manner, keeping recipients in their communities, and encouraging their participation and promoting their dignity.

11. Prior to this time, much of the government assistance to individuals with disabilities was in government facilities. One of the earliest versions of this was *An Act to Authorise the Erection of an Asylum within this Province for the Reception of Insane and Lunatic Persons*[10] in 1839, which established the first provincial asylum. This was considered a progressive measure at the time, as it alleviated family members of the responsibility for supporting these individuals. By 1960, over 6,000 people lived in these institutions.[11]

12. This approach began to change in 1971, with the Williston Report,[12] which recommended that institutions be phased out, and that supports be provided in the community instead. This report went a long way to promote the normalization of individuals with disabilities, with the understanding that they would be better able

[10] 1839, 2 Vic, c 11 (Upper Canada). See also, Thomas E. Brown, "The origins of the asylum in Upper Canada. 1830-1839: Towards an interpretation," University of Toronto Press, 1984, (1:1), available at: <https://www.utpjournals.press/doi/pdf/10.3138/cbmh.1.1.27>.
[11] Ministry of Children, Community and Social Services, "The evolution of government policy and legislation: 1839 – 1960," available at: <https://www.mcss.gov.on.ca/en/dshistory/legislation/1839-1960.aspx>.
[12] Walter B. Williston, "Present Arrangements for the Care and Supervision of Mentally Retarded Persons in Ontario," Ontario Department of Health, August 1971, available at: <https://www.mcss.gov.on.ca/documents/en/mcss/dshistory/legislation/Williston%20Report.pdf>.

to develop relationships with others in the community through this approach. The first of these plans was implemented in 1977.[13]

13. The government continued to close facilities and move people back into the community, culminating in the "Making Services Work for People" framework of allocating resources to those in need and providing them in the community in which they live.[14] The ODSP program currently administered by MCCSS is a continuation of that policy, and remains the most cost-effective means to support individuals with disability, and the best way to promote their greatest participation in the community. The alternative, of providing this support within various institutions, would be cost prohibitive and directly contrary to this government's policy and objectives, as statement elsewhere.[15]

Recent Changes to ODSP

14. Despite this policy approach towards disability being a significant improvement from the historic approaches taken in Ontario, there are a number of enhancements which have been made since the Auditor General's 2019 report. A few of these changes are briefly reviewed below.

[13] Ministry of Children, Community and Social Services, "The evolution of government policy and legislation: the 1970s," available at: <https://www.mcss.gov.on.ca/en/dshistory/legislation/1970s.aspx>.
[14] Ministry of Children, Community and Social Services, "The evolution of government policy and legislation: The 1990s," available at: <https://www.mcss.gov.on.ca/en/dshistory/legislation/1990s.aspx>.
[15] Hon. Vic Fedeli, "2019 Budget: Protecting What Matters Most," April 11, 2019, at 112, available at: <https://budget.ontario.ca/pdf/2019/2019-ontario-budget-en.pdf>. See also, Rueben Devlin, "Hallway Health Care: A System Under Strain," 1st Interim Report from the Premier's Council on Improving Healthcare and Ending Hallway Medicine, January 2019, available at: <http://www.health.gov.on.ca/en/public/publications/premiers_council/docs/premiers_council_report.pdf>.

15. As of December 2020, the MCCSS target of analyzing data obtained through the Ministry of Health and Long-Term Care to identify health care professionals completing a disproportionate number of disability forms was behind schedule. The 2019 Auditor General's report had a target of September 2020, but this work appears to be ongoing.

Recovery and Renewal Plan

16. The MCCSS' Recovery and Renewal Plan for social assistance, announced on Sept. 30, 2020, intended to make the system more responsive and efficient.[16] Specific elements of this plan include accelerated digital delivery solutions, centralized and automated deliver, risk-based eligibility review, and access to employment and training.[17] The transition to digital disability forms, e-document management, centralized intake, and centralized key ODSP health benefits in this strategy are all implicated in the PHIPA regulation amendments contemplated here.

17. A new online application process for Ontario Works (OW), the Social Assistance Digital Application (SADA), has been launched for specific locations, including Durham Region. This SADA uses a risk-based algorithm to stratify risk. A similar Digital DDP system was introduced in December 2020, similar to the Part "B" of

[16] Government of Ontario, "Ontario Modernizes Social Assistance to Help More People Re-enter the Workforce," Sept. 30, 2020, available at: <https://news.ontario.ca/en/release/58607/ontario-modernizes-social-assistance-to-help-more-people-re-enter-the-workforce>.
[17] Keith Palmer and Nelson Loureiro, "Memorandum to Disability Organizations, re Social Assistance Recovery and Renewal Update," Ministry of Children, Community and Social Services, Social Assistance Operations Division, Sept. 30, 2020.

the Medical Review Package. This section of the package identifies medical conditions not included in the original ODSP disability decision, and requires a Health Status Report and Activities of Daily Living report. Examples of sections from this form can be found in Appendix "A."

18. A medical review is not a reapplication, but rather an administrative review to ensure that a person continues to meet the definition of a person with a disability. This process is therefore directly connected to the issues raised in the Auditor General's report.

19. The vast majority of medical reviews are granted on an initial adjudication, or subsequently granted on an internal review. Very few medical review appeals are ever filed. Only a small fraction of ODSP appeals at the Social Benefits Tribunal are medical review appeals, approximately 1.4% in 2018-2019.[18]

20. The two main sections of Medical Form Part B are the Health Status Report (HSR) and the Activities of Daily Living (ADL). The HSR may be completed by a registered nurse, physician, psychologist, nurse practitioner, psychological associate, or optometrist. The ADL may be completed by a physician, psychologist, nurse practitioner, optometrist, psychological associate, chiropractor, physiotherapist, occupational therapist, registered nurse, social worker, audiologist, speech language pathologist.

[18] Tribunals Ontario, "SBT – Appeals Received," March 31, 2019, available at: <https://tribunalsontario.ca/documents/sjto/reports/16%207%202019-03-31%20SBT%20-%20Appeals%20Received.xlsx>

21. Given the nature of these health care professions, the information provided in Medical Form Part B would be covered by PHIPA. The proposed changes to the regulation would allow the health care provider to share this information directly with MCCSS.

Digital First Shift

22. MCCSS is also undergoing a Digital First Shift plan, which has an effect on ODSP services. The ministry has implemented an Electronic Document Management (EDM) system to reduce the use of paper records, and digitizing all mail, including client documents.
23. On Oct. 25, 2019, the Ministry introduced a new regulation to the *Ministry of Government Services Act.*[19] This new regulation allows ServiceOntario to provide additional services on behalf of the government.[20] This includes services around ODSP on behalf of MCCSS, although this has only been piloted to date in Cambridge and Kitchener. As of November 2020, this is being expanded to Mississauga, Brampton, Hamilton, Bracebridge, Peterborough, Simcoe, and Brantford.
24. This means that the amendments to the PHIPA regulation, making MCCSS a health information custodian, may also extend to ServiceOntario. Given this new role, it's unlikely that ServiceOntario have proper training and understanding on

[19] RSO 1990, c M.25.
[20] Service Provider Organizations - Serviceontario, O Reg 475/07.

how to properly handle health information, but this should be a priority following the amendment to the regulation.

COVID-19 Action Plan

25. The COVID-19 pandemic also created new changes and innovation to the delivery of ODSP services. The COVID-19 Action Plan includes numerous modernization projects, including making government services more digitally accessible, and reducing red tape and simplifying processes.[21]
26. Elements of this action plan include verified, digital identity that can be securely stored on a smartphone, and a new and improved digital health solution for health records. The proposed PHIPA regulation amendment would help with the information sharing in this context, as they would fall under the exceptions for disclosure under PHIPA. However, even these exceptions are subject to limitations and controls, which are important to emphasize in this context of ODSP.

Privacy Considerations

27. Health information custodians are required to treat personal health information in a manner consistent with PHIPA.[22] Any collection, use or disclosure of personal health information must be for the purposes of assisting the individual to whom the information relates.

[21] Government of Ontario, "Ontario Onwards: Action Plan," Treasury Board Secretariat, Oct. 19, 2020, available at: <https://files.ontario.ca/tbs-ontario-onwards-action-plan-en-2020-10-18.pdf>.
[22] Much of these principles can be found in the document, Information and Privacy Commissioner of Ontario, "Frequently Asked Questions: *Personal Health Information Protection Act*," September 2015, available at: <https://www.ipc.on.ca/wp-content/uploads/2015/11/phipa-faq.pdf>.

28. Several ministries, specifically the Ministry of Health and Long-Term Care and Ministry of Health Promotion, are already considered health information custodians under the PHIPA regulation, but have certain exemptions.[23]

29. These ministries are not treated in the same way as other health information custodians, such as health care practitioners, long-term care homes, community care access centres and hospitals. These differences should not necessarily extend to MCCSS, and give rise to special considerations as to whether the proposed regulation amendment is the appropriate mechanism for information sharing, specifically in consideration of ODSP benefits.

30. Personal health information should only be collected, used or disclosed by a health information custodian as between the individual, their substitution decision maker, or another health information custodian. This is typically described as the "circle of care," even though the term is not defined in PHIPA itself.[24]

31. Ministries are not directly involved in the care of an individual, but the exceptions relating to them and others is specifically tied to the provision of health care services, and the planning and management of the health system.[25]

32. Disclosure to the Ministry of Health Promotion and Ministry of Long-Term Care, who are deemed as health information custodians under O Reg 329/04, is still contextual as required for the function of these ministries. For example, the Ministry of Health

[23] O Reg 329/04, *supra* note 2, ss. 3(4),(9).
[24] Information and Privacy Commissioner of Ontario, "Circle of Care Sharing Personal Health Information for Health-Care Purposes," August 2015, available at: <https://www.ipc.on.ca/wp-content/uploads/resources/circle-of-care.pdf>.
[25] See also, PHIPA, s. 45.

and Long-Term Care is permitted to disclose personal health information without consent if it is necessary to provide funding to a custodian for the provision of health care.[26] Related disclosures, including to a regulatory college under the *Regulated Health Professions Act*,[27] are directly related to the provision of health care services.

33. Although there are 308 transfer payment agreements between MOHLTC and MCCSS, the function of these two ministries remain different and distinct. MCCSS does not provide health care services.

34. The proposed amendment to the regulation is still grounded in s. 46 of PHIPA, which states,

> **Health care payments**
>
> **46** (1) If requested by the Minister or the minister of a prescribed ministry, a health information custodian shall disclose personal health information to the minister who made the request for the purpose of determining, providing, monitoring or verifying payment or funding for health care funded wholly or in part by the Ministry, the prescribed ministry, a local health integration network or the Agency or for goods used for health care funded wholly or in part by one or more of them.
> [emphasis added]

35. ODSP and the decision to grant the benefit or not is based on personal health information, but this disclosure of personal health information to MCCSS is not necessary for determining, providing, monitoring or verifying payment or funding for health care. As such, the proposed amendment to the regulation likely requires an amendment to PHIPA for disclosures to be made in the context of ODSP, and likely

[26] Information and Privacy Commission of Ontario, "Disclosure," available at: <https://www.ipc.on.ca/health-organizations/collection-use-and-disclosure-of-personal-health-information/disclosure/>.
[27] 1991, SO 1991, c 18.

for other services provided by MCCSS as well. Transfer payments are not the same as funding health care directly.

Conclusions

36. Although the proposed amendment to the regulation would deem MCCSS a prescribed Ministry for the purposes of s. 46(1) of PHIPA, this amendment directly contradicts the text and the purpose of PHIPA itself. MCCSS is not the provider of health services, and should not be provided a blanked exemption from the requirements of how to handle personal health information.
37. Information collected from ODSP recipients for the use of a medial review should not be used for any other purpose, without the explicit consent of the individual. Any collection, use or disclosure of personal health information must be for the purposes of assisting the individual to whom the information relates.
38. MCCSS should affirmatively obtain informed consent from ODSP recipients in order to collect, use and disclose a person's personal health information, even if it is connected to the ODSP benefits they receive. To the extent that ServiceOntario staff may be involved in the collection, use or disclosure of this same information, it will be important to clarify whether they are also included under the exemption and will be considered a health information custodian.
39. In order to ensure that this consent is freely provided and fully informed, DCLC suggests that MCCSS utilize Community Legal Clinics (CLCs) across Ontario to review this information and explain it to them, which is done free of charge. CLCs

typically obtain much of this information already on behalf of the ODSP recipient, and then provide on their behalf during a medical review, so they are already involved in this process for most recipients.

40. Some ODSP recipients may not want their health care provider to automatically share sensitive health information with MCCSS, even if it is connected to the benefits they receive. There are many privacy interests implicated in personal health information which may be entirely independent of a claim for ODSP benefits, including sexual or reproductive health, health information related to gender identity or transitioning, or other grounds protected under the *Human Rights Code*.[28] For those recipients who do not provide affirmative informed consent, MCCSS should still maintain a paper/digital system that allows this information to be shared manually, even if this is done on their behalf by a legal representative.

41. While DCLC supports many of the initiatives underway by MCCSS, including the digitization of services, and improving the effectiveness and efficiency of the ODSP program, this proposed amendment to the regulation is inconsistent with the intent and purpose of PHIPA itself.

[28] RSO 1990, c H.19.

Appendix "A"

Excerpts from ODSP Medical Form Part B

Medical Condition 2	Prognosis of condition is likely to
A	☐ improve ☐ remain same ☐ deteriorate ☐ unknown B
Impairments	
C	**Duration of Impairments** D Expected to last ▼ And are ▼ ☐ less than 1 year ☐ recurrent/episodic ☐ 1 year or more ☐ continuous
Restrictions	
E	

Section 2.		
2.1. **Are any of the medical conditions you reported in Section 1 of Part B listed below?**		
Mental health condition	☐ Yes	☐ No
Substance-related or addictive disorder	☐ Yes	☐ No
Neurodevelopmental disorder (e.g. intellectual disability)	☐ Yes	☐ No
Other medical condition presenting with a mental impairment (e.g. head injury)	☐ Yes	☐ No

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3.2. **Have any consultations or assessments been completed by another health care professional?** ☐ Yes ☐ No

If **No**, please comment (e.g. pending or waiting list, not available, etc.)

If **Yes** please select the type

☐ Diagnostic tests or investigations (e.g. laboratory, biopsy, sleep study, ultrasound, imaging, stress test, etc.)

Specify _____

☐ Specialist consults (e.g. cardiology, neurology, rheumatology, oncology, etc.)

Specify _____

☐ Other assessments or reports

Specify _____

Please **describe below** relevant findings **or attach** copies of the available report

☐ See Attached

Note: Do not send actual x-rays or an original report. The cost of photocopying has been included in the fee.

Section 6. Intervention and treatment

6.1 **Is the patient receiving any interventions and treatments for conditions and impairments listed in Part B?**

☐ Yes ☐ No

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3.2. **Have any consultations or assessments been completed by another health care professional?** ☐ Yes ☐ No

If **No**, please comment (e.g. pending or waiting list, not available, etc.)

If **Yes** please select the type

☐ Diagnostic tests or investigations (e.g. laboratory, biopsy, sleep study, ultrasound, imaging, stress test, etc.)

Specify _____

☐ Specialist consults (e.g. cardiology, neurology, rheumatology, oncology, etc.)

Specify _____

☐ Other assessments or reports

Specify _____

Please **describe below** relevant findings **or attach** copies of the available report

☐ See Attached

Note: Do not send actual x-rays or an original report. The cost of photocopying has been included in the fee.