THE FIRST NATIONS SOCIAL DATA LANDSCAPE IN ONTARIO

Research and Data
Management Sector

CHIEFS
OF ONTARIO

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Contents

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List of Acronyms

Acronym	Meaning
ACSD	Assistance for Children with Severe Disabilities
ADM	Assistant Deputy Minister
AFN	Assembly of First Nations
AHSOR	Aboriginal Head Start On Reserve
AHSUNC	Aboriginal Head Start in Urban and Northern Communities
ANCFSAO	Association of Native Child and Family Service Agencies of Ontario
ATIP	Access to Information and Privacy
BIPD	Business Intelligence and Practice Division, Ministry of Children, Community and Social Services
CCWIS	Canadian Child Welfare Information System
COO	Chiefs of Ontario
CPIN	Child Protection Information Network
CYFSA	Child, Youth, and Family Services Act
DCI	Data Collection Instrument
ESDC	Employment and Social Development Canada
FIPPA	Freedom of Information and Privacy Protection Act
FNICCI	First Nations and Inuit Childcare Initiative

FNIGC	First Nations Information Governance Centre
FNIM	First Nations, Inuit, Métis
FNREEES	First Nations Regional Early Childhood, Education and Employment Survey
ICFWBA	Indigenous Child and Family Wellbeing Agencies
IDbD	Identity Based Data Standard
IPC	Information and Privacy Commissioner of Ontario
IRS	Indian Registry System
ISC	Indigenous Services Canada
MCCSS	Ministry of Children, Community, and Social Services
NIHB	Non-Insured Health Benefit
OACAS	Ontario Association of Children's Aid Societies
OCAP®	Ownership, Control, Access, Possession
ODSP	Ontario Disability Support Program
OGL-C	Open Government License Canada
ONWAA	The Ontario Native Welfare Administrators' Association
PHAC	Public Health Agency of Canada
RHS	First Nation Regional Health Survey
SAMS	Social Assistance Management System

SOR-RL	Serious Occurrence Reports and Residential Licensing
SQIP	Standard Quality Improvement Plan
TRC	Truth and Reconciliation Committee of Canada
UNDRIP	United Nations Declaration of the Rights of Indigenous Peoples

Executive Summary

The purpose of this report is to provide an environmental scan on the status of First Nations social data in Ontario, and to assess the barriers and opportunities to advance OCAP® discovered in this scan. The focus is on data arising from the administration and provision of the major social assistance programs in Ontario, programs aimed at early learning and childcare, and from child protection services. Information was gathered through literature reviews, exploring data available online, and interviews with key stakeholders (see appendix A for a list of organizations consulted).

OCAP® was created by the First Nations Information Governance Centre (FNIGC). The acronym stands for "Ownership, Control, Access, and Possession". These principles are an inseparable whole and must be interpreted in dialogue with appropriate First Nations representatives. The First Nations Data Governance Strategy, developed by FNIGC and endorsed by the Chiefs in Assembly, clearly lays out that rights holders are the appropriate authorities for exercising First Nation control over data. **Rights holders are the First Nations governments, and through them First Nations citizens themselves.**

The social data landscape is quite complex, with a variety of organizations that collect First Nations social data in Ontario. This includes the provincial and federal governments, along with First Nations themselves, various organizations that provide services to First Nations, and researchers.

The goal of OCAP® is for governance systems to centrally involve First Nations rights holders in decision making and approval for the uses of First Nations data. Community level data should be treated as deserving significant privacy protections, and access should be restricted to those who have appropriate permission from the rights holders themselves. Efforts should be made to ensure that First Nations rights holders have access to meaningful and relevant data they can use for governance and advocacy. The organizations collecting First Nations social data display a wide range in terms of their knowledge of and commitment to these requirements of OCAP®.

The First Nations Information Governance Centre (FNIGC) provides an example of strong; First Nations lead data governance. The FNIGC has a national mandate from an Assembly of First Nations (AFN) resolution to gather and authorize the sharing of the data that they collect. The information is all de-identified, and there are permissions on the files so only analysts who need the data can access data. Data is collected only with community consent as well as individual level consent and provided back to First Nations to aid in governance. The entire process is designed to realize the values of OCAP®.

In some cases, such as Statistics Canada and Indigenous Services Canada, there are legal barriers to the full realization of OCAP®. These include the access to information laws that give access to First Nations data without rights holder permission, and Statistics Canada's legislative mandate to make data available.

In other cases, the design of important information systems makes OCAP® compliance a challenge. For example, the Child Protection Information Network, or CPIN, is designed to allow employees at any child welfare agency that uses it to access data from any other child welfare agency that also uses CPIN. This makes First Nations control over the data, and who can access it, effectively impossible at present. While suggestions have been made for how to improve CPIN in this regard, they have not been acted on for many years.

The design and implementation of CPIN presents one of the barriers to OCAP® discovered during the scan. One thing that can be done to help address this issue is to support Indigenous child and family well-being agencies in remaining independent of CPIN. All but three Indigenous child and family well-being agencies use systems other than CPIN. However, adopting CPIN has been made a condition of new Indigenous agencies being designated, and the systems being used in place of CPIN are at or near end-of-life for the technology being used. These organizations could remain independent of CPIN either through the creation of a centralized Indigenous information system, as proposed by the Association of Native Child and Family Service Agencies of Ontario (ANCFSAO), or by independently adopting newer systems. Whichever approach is taken, there will still be a need to improve the OCAP® compliance of CPIN, since 40% of Indigenous children are served by a mainstream agency rather than an Indigenous agency.

Another barrier to OCAP® is data that is being collected without rights holders approval. A great deal of data is gathered across the social sector, and rights holders are often only consulted about particular uses of the data, if they are consulted at all. Collection of data is often justified by reference to privacy laws or other legislation that permits or requires the data collection but fails to account for OCAP®. One way to address this issue is to emphasize existing commitments on the part of the government to respect OCAP® and First Nation data sovereignty.

A third barrier to OCAP® is the underfunding of First Nations to provide their own services. First Nations providing their own services is the best way for the data collected to be OCAP® complaint, since it gives the First Nation direct control over and possession of the data. However, due to discriminatory underfunding of First Nations, some First Nations must rely on nearby municipalities to administer their social support programs. This raises OCAP® worries over the data gathered in administering these programs. Thus, data sovereignty provides a further reason to advocate for sufficient and fair funding for First Nations to provide their own services.

Finally, there is the issue of First Nations being excluded from certain data analysis projects. An example of this approach is the decision by the Business Intelligence and Practice Division (BIPD) of the Ministry of Children, Community and Social Services (MCCSS) to screen out First Nation data from their analysis of educational results for children in care. This means that the data from this project will exclude First Nations data. This is being done due to concerns that using First Nations data would potentially violate First Nations data sovereignty.

The problem is that policy and funding decisions will be made on the basis of the results of this project. Since First Nations data has been excluded, that means that the needs of First Nations children will not be accounted for in these decisions. Furthermore, First Nations as a whole will lack the ability to make decisions and advocate for themselves on the basis of the data. The access component of OCAP® includes First Nations having access to the data they need, and excluding First Nations data from important projects exacerbates this problem. It is crucial to educate data holders that making decisions that will affect First Nations without including them in the data is not a way of respecting OCAP®, and deprives First Nations of the ability to use data effectively for governance.

1. Introduction

The social services sector deals with a huge amount of sensitive data, and often comes into contact with individuals at their most vulnerable. Alongside other personal data collected, some of these programs collect sociodemographic data that can identify First Nations individuals in the datasets, while other programs are targeted specifically at First Nations and thus all the data they collect is First Nations data by default. While there are various legal protections around personal information, such as the Freedom of Information and Protection of Privacy act (FIPPA), these legal protections do not extend to community level information.

First Nations have a fundamental right to sovereignty over their data. First Nation data refers to any facts, knowledge, or information about the nation and about its citizens, lands, resources, programs, and communities. This includes both data that is about First Nations, such as demographic, socio-economic, and health, housing infrastructure, and other services, as well as data from First Nations, such as traditional knowledge and languages.[1] Data sovereignty can be defined as "managing information in a way that is consistent with the laws, practices and customs of the Nation or State in which it is located".[2] First Nation data sovereignty, then, is just the fact that First Nations, as nations, have the right to exercise their own jurisdiction over data about their citizens and lands.

First Nations data sovereignty requires that social data collected in Ontario must be subject to the OCAP® principles. The OCAP® principles were first formulated in 1998, and ever since have provided a firm statement of the rights First Nations have over their data. It stands for Ownership, Control, Access, and Possession. In other words, First Nations own their own data, including community level data; they have a right to control this data and how it is governed; they must have the ability to access their own data and dictate who else has access to this data; and they should possess their own data. This report aims to support First Nations in their assertion of their OCAP® rights over social data in Ontario.

1.1 Purpose and scope of the report

This report focuses on social data collected from First Nations in Ontario, especially data that contains First Nation identifiers and thus can be identified as First Nations data. This includes both personally identifying information, but also aggregate[3] or deidentified[4] data in which First Nations community data can be identified. For the purposes of this landscape scan, social data will be defined as data arising from the administration and provision of the major social assistance programs in Ontario,

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[1] Rainie, Rodriguez-Lonebear & Martinez, 2017

[2] Snip, 2016

[3] Aggregate data is defined as data that has been collected and combined from multiple individuals from a population and then is used to create a statistical report that makes inferences about the population.

[4] Deidentified data is data that has had personally identifying information removed so as to make it more difficult to identify any specific individuals within the dataset.

programs aimed at early learning and childcare, and from child protection services. For social assistance programs, this would include Ontario Works, Ontario Disability Support Program (ODSP), and Assistance for Children with Severe Disabilities (ACSD). For early learning and childcare, this will include both programs at the federal level, such as the First Nations and Inuit Child Care Initiative (FNICCI), and at the provincial level through the Ministry of Education. For child protective services this will include all the information generated by Children's Aid societies, including prevention and support for families where these are provided.

This report is not exhaustive of all the social data on First Nations in Ontario. A notable omission is the data that was collected by residential schools in Ontario. Looking into the location and management of these data will need to await future work.

This report also look at the degree to which this data collection, sharing, and use is done in accordance with OCAP®, the First Nations data sovereignty principles that identify the appropriate relation between First Nations and their data—namely, that First Nations own, control, can access, and possess their own data.

The overall aim of this report is to provide First Nations and their allies who seek to assert First Nations data sovereignty rights in Ontario with a clearer picture of the data landscape. This includes what data is being collected from First Nations, who collects this data, and how this data is governed. The report also aims to identify some of the major barriers and opportunities to promote OCAP® within the field of social data collection, which should support First Nations seeking to assert their rights under OCAP®.

1.2 Approach

The approach to this data scan was a mixture of interviews, most of which were conducted over zoom and lasted between 30-60 minutes, and a literature review of existing literature discussing social data collection in Ontario. Interviews were carried out with individuals from a range of organizations, including provincial and federal government sources and organizations that provide or fund social services for First Nations in Ontario. See appendix A for a list of organizations contacted. These interviews sought to identify whether First Nations social data was held by these organizations, and if so how it was managed. This included what security procedures were in place around the data, if there were any special procedures for handling First Nations health data, who had access to the data both within the organizations and who if anyone it was shared with externally, and how the interview respondent saw the data handling as being in accord with OCAP®. Interviewees were identified both by the results of the literature search and via a snowball sampling approach, whereby early interviewees identified additional people to contact.

2. Background

This landscape report considers the First Nations social data landscape through the lens of First Nations data sovereignty. This section will provide an overview of what First Nation data sovereignty is, focusing on the OCAP® principles.

2.1 OCAP® principles

The OCAP® principles assert First Nations data sovereignty rights and provide the standard for how First Nations data should be treated. The acronym stands for “Ownership, Control, Access, and Possession”. Ownership refers to the relation between First Nations rights holders and their data; it asserts that First Nations rights holders own data about them in the same way that individuals own data about themselves. Control states that First Nation rights holders have the right to control all aspects of the research and information management processes that involve them. This includes the collection, use, disclosure, and destruction of First Nations data. Access holds that First Nations must have access to their information, wherever it is held. It also covers the right of First Nations rights holders to decide who else should have access to the data. Finally, possession is the mechanism whereby ownership can be asserted and protected. This refers to the physical control over the data. [5] The national First Nations Data Governance Strategy, developed by the First Nations Information Governance Centre and endorsed by the Chiefs in Assembly, clearly lays out that rights holders are the appropriate authorities for exercising First Nation control over data.[6] Rights holders are the First Nations governments, and through them First Nations citizens themselves. Thus, for the collection or use of data about a specific community, a band council resolution would be an appropriate way to ensure First Nation control over their data, while for province wide data use, a resolution from the Chiefs in Assembly would be an appropriate form of control. An example of rights holders’ permission for province wide data use is the First Nations cancer surveillance initiative resolution obtained in 2009. The Chiefs in Assembly is the provincial level decision making body for First Nations in Ontario, where the leadership from First Nations communities across Ontario assemble to discuss issues and come to collective decisions.

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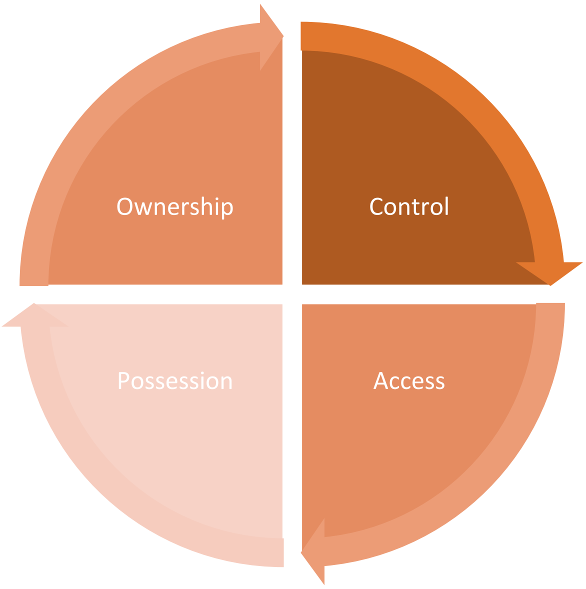
[5] First Nations Information Governance Centre, 2019a

[6] First Nations Information Governance Centre, 2020



While we can outline what each of these principles mean, OCAP® itself outstrips the definition of each individual word in the acronym. It represents First Nations principles and values of data sovereignty, and the four elements are part of an inseparable whole, where no one of the elements can exist without the others. As Bonnie Healey put it, "We cannot ignore 'ownership' or 'possession' any more than the Four Directions can omit the East or the North."[7]

The principles were first created in 1998 during a brainstorming session of the Regional Health Survey Steering Committee (now the First Nations Information Governance Centre, or FNIGC). They were originally called 'access, control and ownership', with Cathryn George of the Association of Iroquois and Allied Indians credited with arranging the original concepts into 'OCA'. Possession was added, arriving at the current OCAP®, when the FNIGC recognized the importance of physical control of First Nations data.[8] In 2014 FNIGC's Board of Directors started the process of pursuing trademark protection for OCAP®. This trademark was sought due to incidents of misuse, misapplication, or improper interpretation of the OCAP® name, logo, and principles. This trademark was granted in August of 2015, for both OCAP® and its French equivalent PCAP®.[9]

2.2 First Nations data misuse and challenges

First Nations data sovereignty is a fundamental right, recognized by the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). It is supported by multiple articles of UNDRIP. This includes article 18 that states that Indigenous peoples have the right to participate in decision-making in matters which would affect their rights in accordance with their own procedures. It also receives support from article 19, which holds that States should obtain free, prior and informed consent from Indigenous peoples before adopting and implementing legislative or administrative measures that may affect them. Article 23 also supports data sovereignty, holding that Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. Finally article 31 also supports First Nation data sovereignty, stating that Indigenous peoples have the right to maintain, control, protect and develop

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[7] First Nations Information Governance Centre, 2016
[8] First Nations Information Governance Centre, 2016
[9] First Nations Information Governance Centre, 2019a

their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures.[10]

First Nations data sovereignty also receives support from the Truth and Reconciliation Commission of Canada's (TRC) calls to action. Particularly relevant to the social data case is call to action number 2, which states "We call upon the federal government, in collaboration with the provinces and territories, to prepare and publish annual reports on the number of Aboriginal children (First Nations, Inuit, and Métis) who are in care, compared with non-Aboriginal children, as well as the reasons for apprehension, the total spending on preventive and care services by child-welfare agencies, and the effectiveness of various interventions." Call to action number 9 also provides support for data sovereignty, stating, "We call upon the federal government to prepare and publish annual reports comparing funding for the education of First Nations children on and off reserves, as well as educational and income attainments of Aboriginal peoples in Canada compared with non-Aboriginal people".[11] Both of these calls to action speak to the need to gather appropriate social data, which must be made available to First Nations.

In addition, First Nation data sovereignty over child protection data is supported by the Child, Youth, and Family Services Act (CYFSA), sections 72 and 73. The sections hold that "a society, person or entity that provides services or exercises powers under this Act with respect to First Nations, Inuit or Métis children or young persons shall regularly consult with their bands and First Nations, Inuit or Métis communities about the provision of the services or the exercise of the powers and about matters affecting the children or young persons."[12] Data collection, use, and sharing affects the children or young persons involved, and so should require consultation, although this is not universally recognized in practice.

Data Sovereignty is needed to address harms caused by the historic and current management of First Nations data. An example is what Maggie Walter describes as 5D data, which refers to when data gathered about Indigenous people focuses on difference, disparity, disadvantage, dysfunction and deprivation.[13] This form of data collection can foster stereotypes about First Nations people, and ignores the strengths of First Nations.

Information collected about First Nations rights holders is also collected and shared without the consent of the rights holders themselves, in violation of OCAP®. As an example, information from the Non-Insured Health Benefits (NIHB) database controlled by Health Canada, which records a vast amount of information about First Nations' use of health services and goods, was released without consent to a health consulting and

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[10] UNDRIP, 2007

[11] TRC, 2015

[12] Child, Youth and Family Services Act, 2017

[13] Walter 2016, 2017

analysis firm that then offered the data for sale to pharmaceutical companies. The data was anonymized, but First Nation identifiers remained.[14]

There are legislative challenges to the full realization of First Nations data sovereignty. The Access to Information Act allows for public access to government information via an access to information and privacy (ATIP) request.[15] There are exceptions for, among other things, personal information and information obtained in confidence from another government. However, neither of these exceptions cover the majority of First Nations information. Most First Nations, with the exceptions of those that have entered into self-government agreements with Canada, and participating First Nations under the *First Nations Jurisdiction over Education in British Columbia Act* (2006), are not recognized as governments for the purpose of the Access to Information Act, and so information they share is not treated as exempt from disclosure.[16] In addition, while personal information is protected, community information is not, such as survey and demographic data. Indeed, huge amounts of First Nations data is available upon request as long as it can be stripped of personally identifying information, a task that is easier than ever due to the digitization of most data.

A further challenge lies in the fact that often the data collected is not adequate to the needs of First Nations rights holders and does not reflect First Nations worldviews. For example, the 2018 Spring Report of the Auditor General of Canada to the Parliament of Canada found that “Indigenous Services Canada’s main measure of socio-economic well-being on reserves, the Community Well-Being index, was not comprehensive. While the index included Statistics Canada data on education, employment, income, and housing, it omitted several aspects of well-being that are also important to First Nations people—such as health, environment, language, and culture.”[17]

There are serious gaps in the data collected about First Nations.[18] For example, the national census does allow people to self-identify as First Nation. However, the census is known to be less accurate for the homeless and those who move frequently, both groups in which First Nations people are over-represented.[19] In addition, a number of band councils have refused to allow the census access to their territory, meaning these reserves are not counted in the census numbers. Overall, First Nations individuals in Ontario had a 27.7% non-response rate to the long form census[20] as compared to a non-response rate of 4.2% for the province as a whole.[21]

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[14] First Nations Information Governance Centre, 2016

[15] Government of Canada, 1985a

[16] First Nations Information Governance Centre, 2014

[17] Office of the Auditor General of Canada, 2018

[18] Smylie and Firestone, 2015

[19] Smylie and Firestone, 2015, pg.75

[20] Indigenous Peoples Reference Guide, Census of Population, 2021

[21] Guide to the Census of Population, 2021. I am using the unweighted non-response rate here, the weighted non-response rate was slightly lower.

The move towards open data creates its own challenges for First Nations data governance. Open data is data that "*can be freely used, re-used and redistributed by anyone - subject only, at most, to the requirement to attribute and share alike.*"[22] There has been a move, as part of Canada's Open Government initiative, to make more federal government data open data.[23] This includes an open government licence-Canada (OGL-C); a license for open data that allows users to "copy, modify, publish, translate, adapt, distribute or otherwise use the information in any medium, mode, or format for any lawful purpose", subject to the condition that they acknowledge the source of the information.[24] Ontario is similarly seeking to make data open by default, except where exempted by specific circumstances, which do not specifically include First Nations data.[25]

Open data, and open data licenses such as OGL-C in particular, run the risk of violating OCAP® in a number of ways.[26] Open data licenses can take the decision about who accesses data out of the hands of First Nations, violating the access principle. In addition, lack of access to internet and digital technologies can leave First Nations without easy access to their own data when it is distributed online through an open data license. OGL-C also undermines control, since it explicitly allows users to copy, modify, translate, adapt, or distribute the data. Possession is also hindered, since under an OGL-C license anyone can take possession of the data and even distribute it onwards, subject only to the need to credit the original source.[27]

Another reason to be cautious of open data in the context of First Nations is the risk that data will be misinterpreted or taken out of context to the detriment of First Nations. As Rainie et al. (2019) point out "one of the key challenges to open data is the risk of interpreting results in the absence of historical, cultural, political, and social contexts. This risk could even further marginalise and stigmatise Indigenous peoples, ostensibly the opposite of what is intended. There will be unintended and pejorative consequences for Indigenous peoples if open data movements do not acknowledge the bias and values inherent in all data."[28] Proponents of open data, and governments who try to implement these principles, must be aware of these risks.

2.3 Data being put to good use in Ontario under OCAP®

OCAP® has led to some notable successes in securing data sovereignty for First Nations. One example is the agreement between the Chiefs of Ontario (COO), ICES, and Indigenous Services Canada (ISC). This agreement was for ISC to provide ICES with a copy of the Indian Registry System (IRS) that could then be linked to the health administrative data in ICES possession. This linkage allows for the identification of First

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[22] Open Data Handbook
[23] Government of Canada, 2018
[24] Government of Canada 2017
[25] Government of Ontario, 2021
[26] Hackett et al. 2019
[27] Hackett et al. 2019
[28] Rainie et al. 2019, pp. 309

Nations data within these datasets much more accurately than previous methods, by allowing researchers to distinguish First Nations populations in health data. This opens the door to a great deal of research that is highly beneficial to First Nations.

This kind of data linkage clearly involves a great deal of First Nations information, and so it is crucial that OCAP® be respected in the way the agreement is set up. The agreement signed between the Chiefs of Ontario and ICES is an example of how OCAP® can be implemented in practice, and lead to beneficial results. The agreement specifies that all First Nations identifying data will be treated as personal health information even if it does not in itself allow for the identification of any specific individual. In other words, it treats community level privacy with the same seriousness as has traditionally been applied to individual privacy. This is true both for the direct First Nations identifiers found in the data linked to the IRS, but also for indirect First Nations identifiers such as geographic location, where this might reveal First Nations status by indicating who lives on a reserve for example. All access to, and use of, data with First Nation identifiers is required to go through an approval process. One of these processes used for approving projects is approval by a data governance committee populated by relevant First Nations representatives. As part of this approval, researchers are required to discuss their projects with First Nation community representatives, who may participate in the planning, conduct, and reporting of the studies. In addition, one of the goals of the agreement is to have communities involved in the interpretation of study results and have a significant role in deciding how these results will be shared more widely.[29]

The agreement with ICES has made possible work that addresses data gaps for First Nations while ensuring that this research is conducted in accordance with OCAP®. As an example, we can look at an Ontario-wide First Nations diabetes research project, which drew on the ICES linked data and culminated in a report published on the Chiefs of Ontario website in February of 2019.[30] This project included several layers of patient and community engagement. For a start, members of the research team were also First Nations people with diabetes or family members of people with diabetes. They also established a six member patient advisory group of First Nations individuals with lived experience of type 2 diabetes to work with them through all phases of the research project. The members of the advisory group were selected to represent a range of perspectives and geographical regions. The advisory group provided feedback on approaches, qualitative interview questions, analysis and interpretation of data, and important context that informed the way they presented and shared the knowledge from the project. Community engagement was also a key component of the research design, and once the individual communities were determined, they worked closely with each one to obtain permission for the project and conduct the interviews in ways that were specific to that community. This included attending community meetings and fairs to

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[29] Walker et al. 2017

[30] Walker, Rowe and Jones, 2018

share information with community members. The project also served as one of the first applications to the then newly created First Nations Data Governance Committee that was appointed by the Ontario Chiefs Committee on Health to oversee researcher requests to access the First Nations data at ICES.

Another success story is the Ontario Population Trends in Improved Mortality: Informing Sustainability & Equity of the health care system (OPTIMISE) study. This study was a joint effort between the Chiefs of Ontario, the Population Health Analytics Laboratory at the Dalla Lana School of Public Health, University of Toronto, and ICES. It looks at Chronic Disease and Mortality Trends among First Nations People in Ontario over the period 1992-2014. It aimed to analyze all-cause and cause-specific, age-standardized mortality trends among First Nations populations across sex, chronic disease status and age to identify the trends in overall, cause specific, and preventable mortality over the past 25 years, and to measure chronic disease burden and disease-specific mortality trends among First Nations populations over time. The project linked data from the Indian Registry System (IRS), the Ontario Registered Persons Database (RPDB), Health claims utilization data, disease specific registries, and Ontario Registrar General's Death file. This information can be used for health services planning and chronic disease prevention strategies.

2.4 Chapter summary

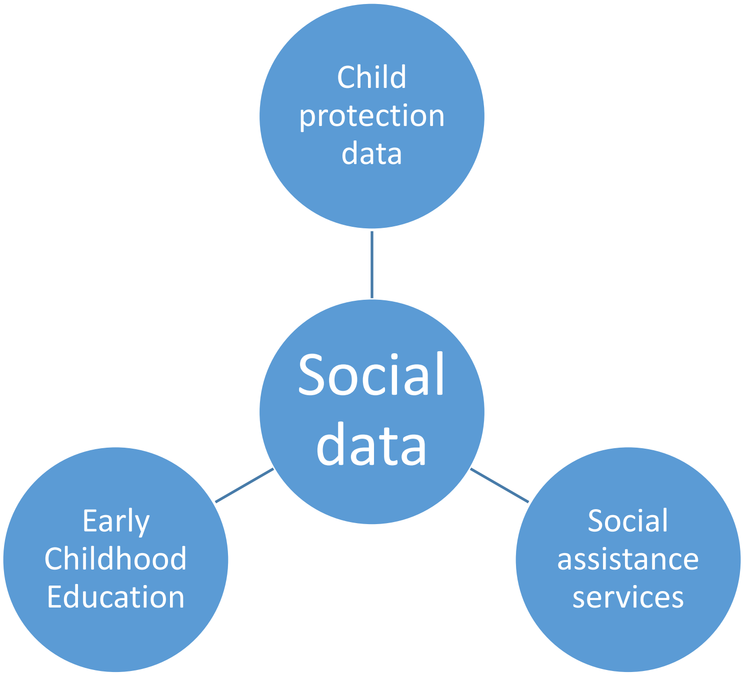
First Nations have suffered historical and ongoing harms as a result of the misuse of their data, and the barriers erected to accessing quality data needed for governance and advocacy. Unfortunately, some of this misuse will require legal change to correct, since current privacy laws do not recognize the importance of community privacy. As a response to these harms, First Nations developed the principles of OCAP®; ownership, control, access, and possession. These principles encapsulate the necessary conditions for First Nation data sovereignty. They are an inseparable whole, and must be interpreted in dialogue with appropriate First Nations representatives.

The agreement between the Chiefs of Ontario, ISC, and ICES provides an example of how to realize data sovereignty in practice. It has seen First Nations able to access important health data by linking ICES store of health data to the Indian registry (IRS). This data linkage comes with strong governance agreements that ensure that the access to and use of this data is firmly under First Nations control. The data from this project has been successfully used for a number of important health research projects, and demonstrates the power of First Nations data sovereignty in action.

3. Social Data Collected in Ontario

This chapter will look at what social data is being collected in Ontario. It will break down what organizations collect social data and what data they collect. The governance of this data will be discussed in the next section. This section focuses on data that can be identified as being from First Nations. This could be because of sociodemographic data collection, or due to the fact that a program is targeted at First Nations or Indigenous individuals exclusively. It also includes data where it is possible to identify First Nations in other ways through the data being collected, such as by sexual orientation including an option for “two spirited”, or where a primary language might be listed as a First Nations language, or where geographic data might identify an individual as living on reserve.

For purposes of this scan, we will divide the social data landscape into three principle areas. The first is data collected in connection with child protection services, as provided by both “mainstream” children’s aid societies and by Indigenous child and family services organizations. The second is early childhood education data collected in Ontario. The third is the provision of major social programs, such as Ontario Works, Ontario Disability Support Program (ODSP), and Assistance for Children with Severe Disabilities (ACSD).



1.1 Child Protection Data

Child protection services collect a huge amount of First Nations data. This includes both Indigenous child and family services organizations and non-Indigenous children’s aid societies. These data are very sensitive, collected from some of the most vulnerable members of the population, and so it is particularly crucial that OCAP® be asserted with respect to them.

3.1.1 Child Protection Information Network (CPIN)

The largest collection of child protection data is held in the Child Protection Information Network (CPIN). CPIN is a case-management software run by the Ministry of Children, Community, and Social Services (MCCSS). Alongside case management CPIN also contains a finance module and a module used for generating reports, but the case management side is where the relevant First Nations data is gathered. CPIN is used by all of the non-Indigenous children's aid societies, and by three of the Indigenous Child and Family Wellbeing Agencies (ICFWBA).

CPIN is a centralized system run by MCCSS. All of the different agencies that use CPIN enter their data into the system, where it is uploaded to servers run by the Ministry. Any authorized user at any of the agencies using CPIN can look up information uploaded to CPIN by any agency. This ability to access data across different agencies is a major reason why CPIN was designed in the first place. CPIN was brought about following the inquests into two highly publicized deaths of children, the 2002 death of Jeffrey Baldwin inquiry and 2008 death of Katelynn Sampson inquiry. The inquests pointed out the need for communication between agencies, and the danger of having files on the same children held by different agencies without proper communication between these agencies.

CPIN is a person-based system, meaning files are organized by people rather than by incidents. Every person involved in a child protection case will have their own person file. This obviously includes the child, but also the caregivers of the child, which will include anyone with a substantial caregiving role, including for example grandparents who live in the same house as the child. Foster home caregivers and volunteers who have worked with the agency would also have person files in CPIN.

The person files on CPIN contain a great deal of information. There is extensive sociodemographic data collected, and many of these fields can reveal First Nations status. MCCSS uses five fields to identify First Nations data that they hold. These are Ethnic Origin, Population Group, Status under the Indian Act, FN Band/FNIM[31] Community, and FNIM identity. However, there are other fields that could also potentially reveal First Nation status. These include sexual orientation, if it is marked as two-spirited, primary language, if this is an Indigenous language, and religion, if a First Nations religion is selected.

Alongside the sociodemographic data fields in CPIN, there is also an accompanying module called the identity based data standard (IDbD). The IDbD is a consent-based collection, where the person is asked if they would fill out the accompanying sociodemographic information. If they refuse, then no data is collected for this module. If

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[31] FNIM stands for First Nation, Inuit or Métis

they consent, then they are asked questions on fifteen different sociodemographic categories, which includes Indigenous identity, race, age, gender identity, disability, religious/spiritual affiliation, language, sexual orientation, and more. The IDbD is not used by the Indigenous child and family wellbeing agencies, even those that are on CPIN.

Alongside this sociodemographic data, CPIN also collects a range of other data on people who have a person record in the system. There is a huge quantity of sensitive data collected via CPIN, especially for children in care. It includes information on every interaction between the person and child protective services, including narrative information about the process, any legal processes initiated, records of each contact by the child protection worker, a list of allegations of mistreatment for the child, and placement information for children who have been put into care. In addition, CPIN includes medical information on children who are in care, such as what medical conditions they have, what medications they take, and so on. There is also extensive educational data captured in the person record, such as the Ontario student number.

Not all the data that has been collected historically by child protection agencies has been uploaded to CPIN. For files created before the adoption of CPIN, it will depend on the data migration policies of the particular agency—there might be many data that was never transferred to CPIN, and so would not be accessible. In those cases, there would usually be a note included in the file, so that if another agency needed access to the information they would know to contact the agency for more information.

While most Indigenous agencies do not use CPIN, there is still a great deal of First Nations information in CPIN. The Association of Native Child and Family Service Agencies of Ontario (ANCFSAO) estimates that 60% of FNIM clients are served by a non-Indigenous agency. It is hard to be sure, however, because markers of Indigenous identity are often not filled out in CPIN, and thus there are gaps in the data. 40% of files in CPIN are missing identifiable information that a family or child is Indigenous. In addition, many pieces of information that might be relevant to First Nations children in care as they grow up, such as nation, are not captured. People who later go to see their file to learn more about their First Nations background are missing this important information.

The data within CPIN is used in the day-to-day operations of child protection agencies. It is also used for administrative purposes by each agency, and for generating reports that each agency provides to MCCSS.

3.1.2 Fast Track

As was mentioned previously, the impetus to create CPIN came from the need to share data between agencies. However, not all agencies are on CPIN; nine Indigenous agencies continue to use other systems. Fast Track is a system that ensures that information is shared between all agencies, including those not on CPIN. Basic information from all child protection agencies is uploaded to Fast Track nightly, which can then be searched to identify whether a person has had previous contact with a child protection agency. The original intent was that fast track would be retired once all the agencies had migrated to CPIN, but since some Indigenous agencies continue to use other systems, Fast Track has remained in place. It contains basic data about the child welfare history of individuals, including their name, personal information, family connections, and reason for previous service. The agency that uploaded the data can then be contacted if more information is needed.

3.1.3 Indigenous Child and Family Well Being Agencies (ICFWBA)

As mentioned in 3.1.1, three of the twelve ICFWBA's use CPIN, and so their data collection is covered under the discussion above. The remaining nine, however, have not switched to CPIN and continue to use other systems. The most common system is called Penlieu, with one organization on Coyote, and one on Matrix. These systems will collect much of the same information as is stored in CPIN, including sociodemographic data, personally identifying information such as name, address, and so on, and details of incidences that have occurred and about each past contact with the agency.

One use of the data is to report to ISC for the cost-sharing program. They provide quarterly reports that include identifying information on clients, days of care provided, and other information relevant to determining eligibility for the cost-sharing program.

MCCSS also receives regular reports from all the agencies, including those not on CPIN. One form of report back is information on Standard Quality Improvement Plan, or SQIP. This data reporting was put on hold during COVID but has been restarted. Indigenous agencies have decided collectively to refuse to provide this information at the moment, due to data sovereignty concerns. There are also concerns that the SQIPs are poorly designed for Indigenous agencies. For example, one measure is whether there is a seven-day check from a protection agent. In some northern communities, they are almost guaranteed to miss the seven-day check requirement, since some of the communities they serve are fly in with only monthly accessibility. At the same time, it has been argued that non-Indigenous agencies should have SQIPs that reflect the requirement in the Child and Youth Family Service Act (CYFSA) that when working with FNIM clients, they must engage with the community to which the client belongs.

Many agencies also provides statistics to the First Nations themselves, and to their board of directors. If First Nations want additional information, they can informally request it by email. Personally identifying information would not be provided, however.

In addition to this information, many ICFWBA's offer preventative services alongside their child protection services. These might include things like parenting supports, pre and post-natal supports, and programs for early childhood education such as daycare. All of these programs would gather some forms of data on the clients they serve. This data could not be stored in CPIN, since it is designed exclusively for child protection data. This requires CPIN agencies to have a separate system to track prevention data, limiting integration between these services.

Prevention services are not funded by MCCSS. Instead, they might receive funding from ISC, municipalities, and Public Health, among others. There is some data that is reported back to funders. This would be basic usage and client numbers, along with some outcome measures, but no personally identifying information.

In addition to the data collected by its member organizations, the Association of Native Child and Family Service Association of Ontario (ANCFSAO) does some of their own research, most notably the First Nation Ontario Incidence Study of reported child abuse and neglect (FNOIS). This was last done in 2018, and is done every 5 years, so this year another one is being prepared. Information was accessed from both Indigenous and non-Indigenous agencies for the incidence study, in order to be able to compare the two.

3.1.4 The Ministry of Children, Community, and Social Services (MCCSS)

The Ministry of Children, Community, and Social Services was contacted early on in the process of preparing this report. They indicated that they would collect information on the First Nations data gathered by the Ministry, including in the area of child protection, and send it for use in this scan. Follow up emails were sent to check on the progress of this information gathering over the next six months, but at the time of publishing this report the information has still not been shared. Thus, this section had to be prepared without direct input from the Ministry, and data was instead gathered from other sources. Some sources of information may be missing as a result.

MCCSS has access to much of the child welfare data collected across the province. As the administrators of CPIN, they can in theory access any of the data stored in CPIN. See section 3.1.1 for more information on the data stored in CPIN. One of the purposes for which MCCSS uses their access to CPIN is to provide technical support and data corrections to the agencies using CPIN. In the case of an error in the data uploaded to CPIN, there are some corrections that can be done by the agency but others require a ticket be submitted to MCCSS. For example, if a child is accidentally discharged from a case, a request must be made to MCCSS to fix this error.

Another source of data for MCCSS is the Serious Occurrence Reporting and Residential Licensing (SOR-RL) tool. As the name implies, this digital tool has two parts; it collects information on serious occurrences and information relating to residential licensing for children in care. For serious occurrences, the system records the name of the person involved, the type of incident, who has been notified, a description of the incident, and individual’s own perspective on the incident, along with any supporting documents. The residential licensing component of the system would include information on people operating group homes and other licensed residences for children in care, including customary care.

The Business Intelligence and Practice Division (BIPD) has been designated in the Freedom of Information and Protection of Privacy Act (FIPPA) as an inter-ministerial data integration unit. There are only three such inter-ministerial data integration units currently recognized by FIPPA, with the other two being The Ontario Statistics Office of the Ministry of Finance and the Capacity Planning and Analytics Division of the Ministry of Health. This designation allows them to integrate the data they hold with data from other Ministries. At the moment, they are still awaiting review of their processes by the Information and Privacy Commissioner (IPC) before they can begin to integrate data.

The first project planned by BIPD is to look at the educational results from children in care. This will involve taking data from CPIN on children in care, and matching that data with data from the Ministry of Education. The plan is to compare children in care with the wider population across a range of indicators, including grade level enrollment, receipt of special education program and/or services, school attendance, suspensions, EQAO results, and more. They will also look at whether there are significant differences in their outcomes based on society, school board, race, placement type, country of birth, and other factors.

The Ministry acknowledges that a project like this raises important issues of Indigenous data governance. They do not currently have a framework in place to address these issues, so their plan is to instead omit Indigenous data from the analysis. They will do this by looking at five CPIN fields to identify indigeneity. These fields are Ethnic Origin, Population Group, Status under the Indian Act, FN Band/FNIM Community, and FNIM identity. Any records identified as belonging to an Indigenous child will be omitted from the analysis. However, there are other fields that can also be used to potentially identify First Nations, such as first language, religion, or sexual orientation (if two-spirited is chosen, for example). These fields are not used to filter FNIM data, so some identifiably FNIM data will not be flagged correctly. In addition, known data quality issues results in First Nations individuals being incorrectly identified by these fields. The Ministry also has a separate plan to work with any Indigenous communities that would like to be part of the project and plans to work with these communities to develop what research questions would be most useful for these communities and how to handle the data. However, as of right now no communities have indicated their interest in participating.

Alongside the data in CPIN, MCCSS also receives reports from the non-CPIN agencies, as discussed in section 3.1.3.

3.1.5 Indigenous Services Canada (ISC)

The First Nations Child and Family Services (FNCFS) program oversees, administers, and provides contribution funding for the ongoing provision of culturally appropriate prevention for First Nations children, youth and families ordinarily living on reserve or in the Yukon. This includes early intervention, least intrusive measures, legislated protection services to respond to children at risk of harm or maltreatment, and support for family preservation and well-being.

Data gathered through funding agreements is governed through a data collection instrument (DCI). Each DCI in the department has a data steward that coordinates the program area’s data needs and a Director General and Assistant Deputy Minister that approves them. The DCI is vetted through access to information and privacy (ATIP) to ensure that privacy of individuals is acknowledged and protected. An assessment is put forward for what the data will be used for. The DCI is clear on what can and cannot be done with the data. Data can only be used for the purpose for which it was collected; if it is collected for operational purposes, this does not necessarily mean it can be used for analytical purposes.

3.1.6 Canadian Child Welfare Information System (CCWIS)

The Public Health Agency of Canada (PHAC) has begun work to explore the creation of a national child welfare information system. This effort is still in the early stages. They have developed a first report which aims to estimate the rates of out-of-home care among children in Canada. This report is based on existing administrative data from the various provincial level organizations. The results from the first analysis of CCWIS data was published on February 14, 2024 in the journal Health Promotion and Chronic Disease Prevention in Canada.

The data they accessed from Ontario excluded information from First Nation agencies, as did the data from several other provinces. To compensate for this, they accessed data from ISC on number of indigenous children in care. While this data was not itself broken down by province, it was used to estimate the number of additional children in out of home care for the missing data from First Nation agencies. The data accessed was restricted to the information made publicly available on the ISC website. They did not analyze the data they gathered according to indigeneity or race, although they did do some analysis by gender, age, and placement type.

The plan is to continue efforts to gather data on out of home care in Canada, and make this data available for use by those working in this sector. This could also include analyses of First Nations data; PHAC is looking to establish data governance frameworks with First Nations partners for this work.

3.1.7 Ontario Looking After Children (OnLAC)

Ontario Looking After Children, or OnLAC, is a program for monitoring the wellbeing of children and youth in society care, either by court order or agreement, or subject to a customary care agreement, for a continuous period of 12 months or longer.

OnLAC includes an assessment tool, the Assessment and Action Record (AAR), for assessing the child’s needs, planning their care and monitoring their outcomes. This assessment tool is used by societies with all children and youth who have been in care for one year or longer. The AAR is completed annually in conversational interviews by the child welfare worker, the child or youth (if age 10 or over) and the caregiver. The AAR tracks a child’s progress in seven life dimensions: health, identity, family and social relationships, emotional and behavioral development, self-care skills, and education.

OnLAC was established by a policy directive issued on December 3rd of 2007 by the Ministry of Children, Community and Social Services (MCCSS) under the authority of the Child, Youth, and Family Services Act (CYFSA). This policy directive directed

Children's Aid Societies to deliver the AAR for children who have been in care for a year, and to administer it on an annual basis, for the purpose of informing the development of the Plan of Care.

The AAR is used at the case level to develop an individual child's Plan of Care, at the management level to provide outcome data that can assist a society in developing needed services and programs for all children in care; and at the Ministry level providing key marker outcome data to support continuous improvement in policy and program design. The Ontario Association of Children's Aid Societies (OCAS) subcontracts with the University of Ottawa to provide data aggregation and research support for the OnLAC program. As such, each society sends the results of their AAR's to the University of Ottawa. This data includes CPIN number, band number, full name, date of birth, and community, and so clearly identifies individuals as indigenous.

The University of Ottawa has used this data for research purposes. They have also provided the raw data to other researchers around the country. Only aggregate data has been shared, but it is still indigenous data. A book entitled "Young people in out of home care: findings from the Ontario Looking After Children program" was published in 2023 by the University of Ottawa press on the results of research using this data.

3.2 Early Childhood Education Data

Early childhood education is an area in which there are a number of programs that are aimed at First Nations or Indigenous people specifically, and so the data collected will be readily identifiable as First Nation data. There are also a number of surveys and studies that collect relevant data and publish the results, including First Nations data.

3.2.1 First Nations and Inuit Childcare Initiative (FINICCI)

The First Nations and Inuit Childcare Initiative (FNICCI) is an Indigenous child care funding program run by Employment and Social Development Canada (ESDC). It mostly serves off reserve populations. It funds childcare centers that provide service to First Nations, Inuit, and Metis children. It began in 1995, and started as part of skills training—the idea being to allow parents to pursue work or education by providing child care. The program collects only administrative level program data, not personally identifiable data. They acknowledge some serious quality issues and gaps in this data, and it is not presently possible to disaggregate different Indigenous groups within the data.

They are currently in the process of co-developing with the national expert working group of the Assembly of First Nations (AFN) a results framework to make data higher quality and more readily available. The results framework is likely to include elements such as spaces, how culturally relevant programming is, and high-level indicators of infrastructure built.

3.2.2 Aboriginal Head Start in Urban and Northern Communities (AHSUNC)

The Aboriginal Head Start in Urban and Northern Communities (AHSUNC) is a program run by the Public Health Agency of Canada (PHAC), providing funding for preschool programs for children living off reserve. Indigenous Services Canada (ISC) runs a parallel program on reserves that will be discussed in section 3.2.3. This program does not gather much data. It has an annual reporting template that each service site is required to fill out. This captures basic information on the number of children in the program, the number on the waitlist, and some qualitative data on things like whether cultural education is provided and whether, and which, languages are taught. They also gather information on the breakdown between First Nations, Inuit, and Métis children at each site. They used to collect information on special needs in children attending the program, but this could raise privacy issues in smaller centers, and they did not make use of this data so they have stopped collecting it.

The data is generally not broken down into site-level data but is instead amalgamated at the provincial or national level. Thus, PHAC only reports on the number of children who are enrolled in the program nationally. With a sites permission, then they might pull data on number of children for a report to a Minister. Much of the data is available publicly from the centers themselves, who often say how many children they enroll on their websites. The data collected is used for reporting to the Treasury board. There is an effort made not to collect data that is not being used.

There was a mapping project carried out that used census data and other data from Statistics Canada to identify where Indigenous children are across Canada, correlated with availability of AHSUNC services, identifying gaps. This mapping exercise is now out of date.

3.2.3 Aboriginal Head Start on Reserve (AHSOR)

The Aboriginal Head Start on Reserve (AHSOR) program provides funding to enhance child development and school readiness for children living in First Nations communities on reserve. The data collected by this program would be in the form of report backs from organizations receiving funding. Most funding goes to First Nations directly, or through tribal councils or another organization. All the data would be aggregate data, with none of it personally identifying.

The data is used to monitor the success of the program, and to demonstrate efficacy to secure funding for AHSOR. The person I spoke with was unsure on the process for external requests for data, however they indicated that if there was a request from a specific First Nation for their own data it should be simple enough to provide it. The data would also be potentially available to anyone through access to information requests, as long as it did not contain any personally identifying information.

3.2.4 Statistics Canada

Statistics Canada collects early childhood education data from First Nations via a number of surveys. The largest survey they run is the census, which was last held in 2021. The long form census asked whether respondents had paid for childcare in order to work, and how much they had paid. These were the only early childhood education questions asked, and they are limited. For instance, they do not capture childcare that was for purposes other than work, or for childcare that was not paid for such as that provided by a relative. The census is the only survey run by Statistics Canada that gathers data from people on reserve. Some reserves have refused to allow access to Statistics Canada for the census, and in the last census there were 63 census subdivisions identified as being on reserve that were incompletely enumerated by the census. This does not necessarily correspond to 63 reserves; many reserves contain more than one census subdivision.

The Indigenous Peoples Survey uses the census data as its frame, selecting from people who have self-identified as Indigenous on the census to invite to complete the Indigenous peoples survey. The most recent such survey included questions on children's educational experience, and a section on childcare impact on employment, which asked if parents currently use child care, what type of child care they use, whether this care is delivered in the home or outside of it, and whether in the past 12 months childcare responsibilities have impacted their employment.

The Aboriginal Children's Survey collected a wealth of data on childcare and early education from First Nations, but this data is now mostly out of date since the survey was last run in 2006. The data from this survey was collected exclusively off reserve.

There are a number of other surveys that, while not focused on Indigenous peoples, nonetheless contain questions about Indigenous identity and collect data on early childhood education. Examples include the Canadian Survey on Early Learning and Childcare, which was conducted in 2023, the Survey on Early Learning and Child Care Arrangements, also conducted in 2023 the Survey on Before and After School Care in Canada, which was conducted in 2022, and the Canadian Health Survey of Children and Youth, which was conducted in 2019 with a follow up survey in 2023. All of these were conducted exclusively off reserve. The number of First Nations respondents in these surveys tend to be too small to allow for anything but national level data, and in some cases are small enough that they cannot separate out First Nations from Inuit and Métis data, restricting them to taking a pan-Indigenous approach to analyzing the data.

3.2.5 The Ministry of Education

The Ontario Ministry of Education collects data on First Nations early childhood education through a number of routes. They conduct an annual Licensed Child Care Survey through which statistical information is collected from licensed childcare centers and home childcare agencies, including those operated by First Nations. The survey collects information about childcare program operations, such as hours of operation, enrolment, parent fees, staff wages, and fee subsidies. Some of the data, in aggregate form, from this survey is reported in Ontario's Early Years and Child Care Annual Report. This data is used to monitor and report on childcare in the province of Ontario.

The Ministry also provides funding to ninety-six First Nations and three transfer payment agencies for childcare and child and family programs. Under financial reporting, First Nations and transfer payment agencies are required to report financial and service data to the Ministry related to licensed childcare and/or child and family programs. Examples of the information reported include average monthly number of children served by age group, number of fee subsidies provided broken down by family income level, and required parent contribution and other offsetting revenues by age group. This data is used for financial accountability.

Through the Child Care Licensing System (CCLS), the Ministry collects information about licensed childcare programs, including those that are operated by a First Nation. The data that would identify First Nations organizations would be the licensee type (i.e., individual, corporation, or First Nation,) First Nation name, and whether the childcare program operates on- or off-reserve. CCLS does not capture information about children enrolled in childcare programs and their family's contact information. This data is used to track licensed childcare organizations and maintain contact information for them.

3.2.6 First Nations Information Governance Centre (FNIGC)

FNIGC is an independent, non-profit organization that was incorporated in 2010, and it operates under a mandate from the Assembly of First Nations (AFN) Chiefs Assembly. It developed out of the National Steering Committee formed in 1996 by the AFN to design a new national First Nations health survey in response to a decision from the Federal Government to exclude First Nations people living on reserve from three major population surveys. FNIGC continues to run the First Nations Regional Health Survey (RHS), along with a number of other surveys and research activities to support First Nations data needs.

Several of the surveys that FNIGC has conducted have collected data on early childhood education. The RHS itself focuses on a holistic understanding of health, and thus includes some questions on early childhood education. The RHS phase 3, the most recent iteration that was conducted in 2015-2016, had six questions on education. The education questions focused on participation in preschool programs, specifically the Aboriginal Head Start program. Other education questions focused on current grade level and questions about whether the child had skipped or repeated a grade. The childcare section contained two questions: the first about type of arrangement and the second about the number of hours per week in child care.[32]

Another survey more directly relevant to early childhood education is the First Nations Regional Early Childhood, Education & Employment Survey (FNREEES). FNREEES was carried out between 2013 and 2015. The survey looked at early experiences of children between 0 and 11 years of age living in First Nations reserves and northern communities across Canada. The survey asked a variety of questions around children's care and learning experiences, including questions on childcare set ups, educational experiences, culture, and traditional languages.

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[32] Greenwood et al. 2020

Through these two surveys, there is a wealth of data on the subset of First Nations living on reserve and in northern communities. The FNIGC works to make this data available to First Nations that would like to access it.

3.3 Social Assistance Services Data

Social Assistance includes programs such as Ontario Works, Ontario Disability Support Program (ODSP), and Assistance for Children with Severe Disabilities (ACSD). It also includes home care services. Most of this data is administrative data collected in the process of providing these services, or data submitted to Government for funding purposes.

3.3.1 Indigenous Services Canada (ISC)

Indigenous Services Canada (ISC) receives copies of forms submitted to the province for Ontario Works. These forms are submitted monthly by the First Nations that administer Ontario Works for their members. The do not contain any individual level data or identifying information. They merely list the total number of cases receiving income assistance that month, broken down into single individual or family.

This data is used for determining allocations, by estimating the cost of services being provided, and for internal resource planning. The social team has access to this data, which is housed on its information management site. If anyone outside of this team wanted to access the data, they would need to make a request and receive permission from the director of the department. The procedure for requesting such access is to send an email to the director. This access has been requested in the past for system upgrades, where the IT team needed access to the data. The data is shared in aggregate form with the Indian Government Support Program, while the Capital Program gets aggregate data on how much is being spent on shelter costs.

In addition, ISC gets copies of the assisted living forms from the in home care program, which is called the homemakers program on the provincial side. This program provides money for services such as housekeeping, meal prep, laundry, and other such services. Again, the First Nation will submit a form to the province as part of the program and send a copy to ISC at the same time. The data does not contain personally identifying information, but is divided up into individual cases, which each case giving the number of hours of service provided. The data is also broken down in terms of age, noting who is a senior (60+ years old), and whether any children under 16 live in the household requiring the homemakers program.

3.3.2 Ministry of Children, Community and Social Services (MCCSS)

As stated above in section 3.1.4, the Ministry of Children, Community, and Social Services (MCCSS) had said they would provide information on the First Nations data gathered by the Ministry in this area. However, while follow up emails were sent over the next six months, at the time of publishing this report the information has still not been shared. Therefore, it has not been possible to learn any details about the First Nations data gathered by the Ministry through social assistance services.

3.3.3 The Ontario Native Welfare Administrators' Association (ONWAA)

The Ontario Native Welfare Administrators’ Association (ONWAA) gathers data to use in research and advocacy. This is a relatively new component of ONWAA and is funded for at least the next two years. Datasets gathered by ONWAA are membership driven, anonymized, held for 10 years and then destroyed. As soon as the project is done, any identifying information, such as dates of birth and so on, is deleted. They have noted that some information is very difficult or impossible to access. For instance, they asked recently how many Ontario Disability Support Program (ODSP) clients have child welfare issues, but this information could not be pulled from the systems as they are now designed. In general, it is difficult to access data on poverty in First Nations communities, information that is sorely needed for advocacy.

ONWAA frequently has to rely on members within the organization to provide them with the information they require. These members are generally very helpful, but busy and can find it difficult to find the time to provide information. In addition, it is difficult to go to each community individually to gather aggregate data.

ONWAA uses the data to write reports on topics such as the cost of providing services, Indigenous look at market basket measure/inflation, and costs of administration assisted living. They also do primary research via interviews and surveys.

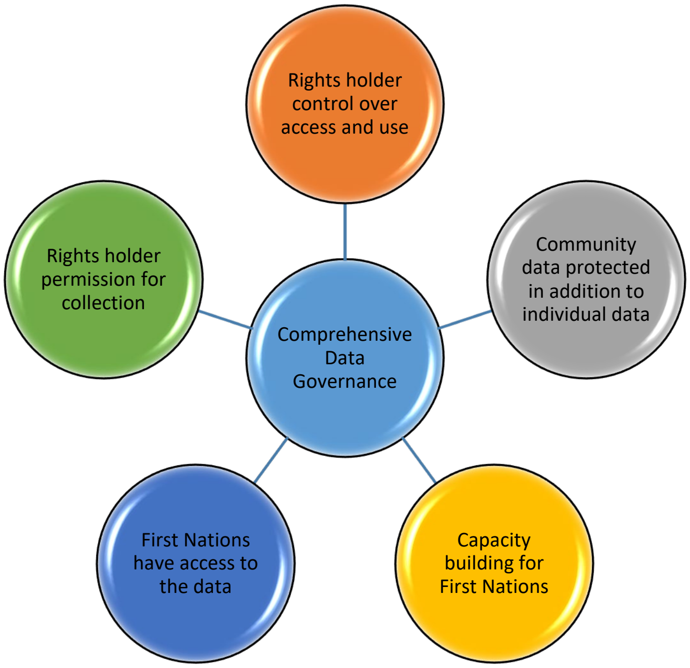
3.3.4 Individual First Nations or Municipalities

The bulk of the data collected in administering social assistance programs will be collected by those directly providing those services. In most cases, this will be the First Nation themselves. They will collect and store the personal information and eligibility information of those receiving social assistance, and since this data is being gathered by the First Nation about its citizens, this data will all be First Nations data.

Different communities use different computer systems to collect and store data. Some communities use a system provided by A.D. Morrison, some use the Social Assistance Management System (SAMS), and a small number are on other systems, with some communities continuing to do things by hand, without a computer system to gather and store data. Five communities do not administer their own social services, allowing municipalities to administer these services. Some communities are considering transitioning away from providing their own services to allowing municipalities to deliver these services, due to resource constraints—some of the administrators are paid minimum wage, and it is difficult to recruit or retain staff. When a municipality is providing the services then the information of whether a client is on reserve or not is no longer captured, and so it can be difficult to determine what portion of the data is First Nation data.

4. Management and Access to First Nation Data

This section will look at the governance of First Nations data in the various locations that have been identified above in section 3. The focus will be on the OCAP® compliance of the data governance systems identified. The ideal will be to achieve comprehensive data governance for all First Nations data gathered. This involves rights holders giving permission for the collection of the data in the first place. This goes beyond merely being consulted, and includes a positive affirmation from the rights holders, such as a Band Council resolution or a resolution from the Chiefs in Assembly. Rights holders should also have control over who has access to the data and how it used once it is gathered. This includes the First Nation itself having access to the data for their own use. It is crucial that community level data be protected in addition to individual data; this requires policies that go beyond what is required by legislation, since privacy legislation in Canada is focused on the individual. Finally, ideally there would be opportunities for capacity building for First Nations, so that they can over time take greater ownership and make better use of the data that is collected.



4.1 Child Protection Data

4.1.1 Child Protection Information Network (CPIN)

The Child Protection Information Network (CPIN) system is probably the largest collection of First Nation child protection data. Thus, the governance of this system is of great importance in assessing the overall child protection data landscape.

CPIN is a role-based system. Each user has a role assigned to them in the system, and what data they can access depends on their role. Any caseworker of a child protection agency can access any of the records for active cases within CPIN, not just those they have worked on directly. This access is tracked, and if there are allegations of wrongdoing then the records can be audited to see whether an individual has improperly accessed information, which would be a cause for disciplinary action. However, there is little capacity to do this kind of audit outside of a specific complaint that has been made. The system does contain some role-based security protections. For example, if you are not an adoption worker, you cannot access adoption records. However, a great deal of sensitive information is available to all users of the system.

There are numerous OCAP® issues raised by CPIN. The data is accessible to MCCSS and to caseworkers at other agencies without First Nation permission. Even if an agency has a data sharing agreement with a First Nation, and thus has received permission to collect data from that First Nation, they cannot control who else has access to this data. Another agency or MCCSS could still access this information without permission from the agency that originally collected the data, and without permission from the First Nation whose data it is. One solution for this would be an Indigenous restriction added to First Nations files, so that only certain people would be able to see the information. This could be implemented via a check box to indicate Indigenous cases, and if it were to be checked then this would limit the number of people who could access the file. This has been requested by Indigenous agencies and ANCFSAO since 2018, but nothing has happened to date. Furthermore, First Nations were not adequately consulted during the design and rollout of CPIN, and to this day CPIN does not reflect First Nations feedback and recommendations. For example, a recommendation has been that CPIN needs more information on reasons why children are brought into care. The most common code is “caregiver with a problem” but it does not specify what kind of problem. Furthermore, 40% of files in CPIN are missing identifiable information that a family or child is Indigenous. In addition, many pieces of information that might be relevant to First Nations children in care as they grow up, such as nation, are not captured.

There are also worries expressed that systems like CPIN are inherently assimilationist, in virtue of homogenizing the information collected. The system is designed for use across Ontario, and this makes it difficult for it to be customized to take account of the specific needs of First Nations. As an example, First Nations developed their own assessment tool for use in assessing children’s needs, and had this assessment tool approved. However, they have not yet made inroads to change CPIN to allow agencies using this tool to enter information, so this data cannot currently be inputted to CPIN. CPIN can also collect the wrong information, with much of the data collected having nothing to do with outcomes. Instead, much of the information tracked has to do with whether meetings occurred at specific intervals, for example.

There was a resolution passed by the Chiefs in Assembly on November 25th, 2015, that stated that Ontario First Nations had not been adequately consulted or given consent for CPIN, and directing the Ontario Regional Chief to meet with the Ministry of Children and Youth Services and report within three months. Almost two years later, a second resolution was passed on October 25th, 2017, during the rollout of CPIN. This resolution noted several concerns First Nations had about the design and implementation of CPIN. These included a lack of checks and balances to ensure First Nations children and families were not further stigmatized by the system, how cultural considerations from Indigenous child wellbeing agencies and First Nations communities would be incorporated into CPIN, and whether CPIN would accord with the OCAP® principles. In light of these concerns, the resolution called on the Minister of Children and Youth Services to engage with First Nations communities and Indigenous child and family wellbeing agencies on the implementation of OCAP®. It also directed the Ontario Regional Chief and Social portfolio holder to meet with the Minister to develop a proper engagement process, and directed the Chiefs of Ontario to report to the Chiefs Committee on Social Services (CCSS) to report on the status of CPIN and identify next steps. To date these resolutions have not been adequately addressed by the Ministry.

ANCFSAO has also expressed their concerns over the data sovereignty issues with CPIN. In November of 2019, the ANCFSAO Board of Directors passed a motion declaring that no additional Indigenous agencies or their First Nations will deploy the Child Protection and Information Network (CPIN). In August of 2020, in line with the 2015 COO resolution, ANCFSAO provided written notice to the Ministry of Children, Community and Social Services (MCCSS) that no further ANCFSAO member agencies would deploy CPIN.

The amount of access First Nations have to their own data, and to a degree the control they have over this data as well, depends on the specific agency that holds the data. Some agencies make an effort to reach out to First Nations communities, especially those that might fall within their catchment area. This can involve building trust with these communities, establishing data sharing agreements, and providing access to the data that is collected about the First Nation. Some agencies also consult with First Nations before collecting some forms of data. For example, the board of Family and Children's Services of the Waterloo Region voted not to send First Nations data to MCCSS as part of their reporting unless they had permission form the First Nation itself. However, they have received some push back from MCCSS about this decision.

Sections 72 and 73 of the Child, Youth, and Family Services act support the need for agencies to consult with First Nations before collecting or sharing their data. These sections state that "a society, person or entity that provides services or exercises powers under this Act with respect to First Nations, Inuit or Métis children or young persons shall regularly consult with their bands and First Nations, Inuit or Métis communities about the provision of the services or the exercise of the powers and about matters affecting the children or young persons."[33] However, not all agencies prioritize these sections of the act, or recognize their application to First Nation data. Some agencies will instead cite part X of the act, which deals with personal information and what data MCCSS and service providers are permitted and required to collect, as providing authority to collect and share First Nations data without seeking permission.

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[33] Child, Youth and Family Services Act, 2017

The act is not clear on the relation between sections 72 and 73 and Part X. Individual agencies can interpret the law in either way, and this leaves gaps in First Nations data sovereignty.

Overall, CPIN does a poor job of recognizing First Nations ownership over data, gives First Nations little to no control over the data, does not allow for control over access to data, and is not in the possession of First Nations. While some agencies have taken steps to be more OCAP® compliant, this is not universal and is not consistently supported or encouraged centrally by MCCSS. Thus, despite feedback having been provided over the past several years on how to improve the system, CPIN remains far from OCAP® compliant.

4.1.2 Fast Track

The Fast Track system is used exclusively for crosschecking to ensure that agencies providing services to children are aware of any history the child or guardians may have with other child protection agencies. Data is required to be uploaded by both Indigenous and non-Indigenous agencies, and it will therefore contain a great deal of First Nation information. The requirement to upload this data does not depend on the permission of the First Nations whose data is at issue, and this data is accessible to all child protection agencies, as well as MCCSS.

Fast Track, therefore, fails to abide by OCAP®. The data is not controlled, possessed, or owned by First Nations. The data contained in Fast Track cannot be accessed directly by First Nations either, but the original files on which Fast Track data is based may be accessible depending on the child protection agency that holds that data.

4.1.3 Indigenous Child and Family Well Being Agencies

Indigenous child and family well-being agencies must abide by OCAP® as well. Even though these organizations are Indigenous, they are not themselves the rights holders over the data they hold. The rights holders are the First Nations citizens themselves, and by extension their representatives, so the issue of OCAP® compliance still arises for Indigenous agencies.

Security, both in CPIN and in other alternative systems, is role-based. A user’s role within the system determines the data to which they have access. For example, caseworkers would have access to the case data, while finance employees would have access to financial data. All caseworkers would be able to access data about any case, but there are strict rules around only accessing data that is needed for one’s work. All access is logged and can be reviewed to look for unauthorized data access, although this is generally only done if there is a suspicion of unauthorized access or occasionally through a random audit.

Indigenous agencies generally look to build relationships with the First Nations communities they serve. This involves sharing data, seeking permission to collect data and to share data with others, and working with the First Nation on their priorities. Different Indigenous agencies are at different places in pursuing these relationships.

There are complications for urban agencies, such as Native Child and Family Services of Toronto. It is often unclear who to ask about access to data, since some clients are not members of any specific First Nation, while others may have bad relations with their First Nations which may be in part why they left. There is also distrust between these nations and child welfare agencies, which can make relationship building difficult.

Indigenous agencies have refused to provide some information that has been requested by MCCSS when they felt that it was violating First Nations data sovereignty. An example of this is the Standard Quality Improvement Plan, or SQIP, data, which indigenous agencies have collectively declined to share with MCCSS over data sovereignty concerns.

Despite this, Indigenous agencies are still licensed by the government and required to share data in many circumstances. For example, they must upload information to Fast Track, and share information on past interactions with a child or caregiver with other agencies when requested to do so. Once this data is shared, it passes into the possession of the other agency, and thus leaves the control of the Indigenous agency and any data sharing agreements they may have with First Nations communities. Thus, First Nations can lose control of their data in such a situation. It also worth noting that, with the advent of CPIN, non-Indigenous agencies have changed their requests for data when asking about a client who is moving to a new agency. Rather than just requesting specific information, they began to request all the case files and notes.

Indigenous agencies that use CPIN raise this concern even more strongly. Any other agency can access the data that is uploaded to CPIN, so it is difficult or impossible for agencies to control who accesses their data, and thus impossible for them to delegate such control to First Nations. See above for more discussion of the data sovereignty issues with CPIN. Unfortunately, MCCSS has made using CPIN a requirement for new Indigenous agencies to be licensed. Furthermore, the systems being used by the non-CPIN agencies are reaching the end of their lifespan and will need to be replaced. This will make it more difficult for such agencies to continue to operate without using CPIN.

With respect to OCAP®, then, Indigenous agencies are working towards recognizing the ownership of this data by First Nations, and giving them some degree of control and access to this data. However, legal requirements create limits on the degree to which this can be realized. CPIN agencies are also limited by the design of the technology, which as discussed above fails to protect First Nations data.

4.1.4 The Ministry of Children, Community, and Social Services (MCCSS)

The Ministry Children, Community and Social Services (MCCSS) has access to a variety of data, through the reports delivered to them by the child protection agencies, their management of CPIN, and the ability to integrate their data with data from other Ministries. While there are some promising signs of their awareness of OCAP® and efforts to bring their data governance in line with it, there remain a number of major concerns.

As mentioned above in the discussion of CPIN, the management of CPIN by MCCSS has failed to resolve some serious OCAP® issues with the platform. Despite longstanding requests for certain features to be added or changed, there has been little progress. This includes the Indigenous flag for files in CPIN that has been requested since 2018 and is discussed in 4.1.1. This has led to some frustration within the sector, and the feeling that Indigenous data sovereignty is not being prioritized.

The plan to integrate CPIN data with data from the Ministry of Education also raises OCAP® concerns. As discussed in 3.1.4, the plan is to exclude Indigenous data from this analysis, using five specified CPIN fields to identify indigeneity. There are two main OCAP® worries with this project. The first is that, due to the limitations of the five fields used to identify indigeneity and due to data quality issues in CPIN, it is likely that some First Nations individuals will be included in this analysis despite efforts to exclude them. The second, and more serious, issue is that the exclusion of First Nations data has the potential to harm First Nations communities. For one thing, First Nations will be unable to take advantage of this analysis, and so will be deprived of knowledge of how their own children and youths are faring. Furthermore, the plan is to use the results of this analysis to inform funding and planning decisions. If First Nations are excluded from the analysis, then these decisions will not reflect the needs of First Nations.

Another relevant MCCSS initiative under way at the moment is the Data for Equity project. This project aims to reform and improve the ways that identity-based data is collected and used across the Ministry. This includes First Nation and other forms of Indigenous data. It is being run by staff within the Business Intelligence and Practice Division (BIPD).

There is a Data for Equity working group that has been established, which has representatives from various stakeholders including Association of Native Child and Family Services agencies of Ontario (ANCFSAO) and the Chiefs of Ontario (COO). This group has been providing feedback on a proposed engagement plan being developed by MCCSS to consult on updating the identity-based data (IDbD) standard and building the reporting roadmap. One of the goals of the roadmap is distinct Indigenous data governance approaches informed by First Nations, Métis and Inuit perspectives on data.

The current plan is to engage a third-party vendor to conduct engagements with equity-deserving communities, including First Nations. It appears that rights holders will not be directly consulted in this phase of engagement, although it was suggested that elders who were consulted might be able recommend a plan on how to engage with rights holders. Key findings from the engagement process are scheduled to be reported back in August 2024, with MCCSS recommendations for updated IDbD standard and reporting roadmap following in September 2024. Nine engagements are planned with Indigenous partners and communities using surveys, town halls, webinars and talking circles in partnership with MCCSS corporate and program areas. It is not clear whether these engagements will be distinctions based, or how many will involve First Nations specifically.

ANCFSAO has expressed concern with the way that the call for proposals was held for the third-party vendor, since MCCSS did not take on board their recommendations for the process. The worry is that the vendor will not have appropriate experience with OCAP® and First Nations data sovereignty. The lack of commitment to consulting with rights holders is also problematic, since it is rights holders who have the right to decide how First Nations data is collected or used. Consulting other First Nations individuals will not serve as an appropriate engagement, or satisfy OCAP®, and the danger is that this engagement will be taken to constitute sufficient engagement.

There are other examples that came up in the course of this data scan that demonstrate some respect for First Nations data sovereignty on the part of the Ministry, but not a complete commitment. For example, the Ministry wanted to carry out a review of customary care arrangements in First Nations. They were told they needed to receive permission from the First Nation to gather this data. The Ministry did honor those communities who said clearly no to the review of their customary care arrangements, but they also went ahead in cases where they had difficulty getting in touch with the community and so did not receive a clear response.

4.1.5 Indigenous Services Canada (ISC)

Within Indigenous Services Canada (ISC) data governance oversight is shared between the Chief Information Officer (CIO) and Chief Data Officer (CDO). Requests from external requesters undergo a scoping/review process between ISC and the requester, led by the Executive Data Steward(s) in the department who are accountable for data assets under their purview and concerned with data collection, access, use, quality, sharing and protection. These people are senior level officials (Director General or higher) in the role of trustee for departmental data assets. They seek to ensure that the requester either has an Indigenous partner in the research, or that the research will directly benefit indigenous communities. However, there are times where ISC may be legally obligated to share the data without explicit endorsement from Indigenous partners. The data steward would also ensure that sharing the data for this purpose would be consistent with the purpose for which the data was collected.

ISC assesses the data to check whether it contains personal information about individuals or whether it could be considered sensitive. They ensure that the requester has legal authority to receive data, and that ISC has the legal authority to share the data. They also review what the data set will look like, to discern how big the community is, look at how granular the data is, and potentially aggregate small sample sizes to preserve privacy. When the request involves restricted information (e.g., personal or sensitive information), then an Information Sharing Agreement is put in place to determine the terms and conditions around the sharing of the data, and which would cover the lifecycle of the data.

For requests for data from within ISC, “Executive Data Stewards” are responsible for assessing and authorizing the request, which would include ensuring that privacy and other legislative obligations were met. There is also a Data Access and Sharing Review

Board that brings subject matter experts together (e.g. privacy, legal, data experts) to provide advice and recommendations on complex data requests in support of CIO and CDO decision-making. This Review Board can be involved in internal and external data sharing requests.

These procedures apply to all requests for custom datasets from ISC, whether they come from internal or external bodies. However, for data that they already possess, and that would not require a custom dataset, an access to information request could potentially bypass these processes and allow someone access to First Nations data. This would be anonymized, to prevent individuals being identified, but might still allow for identification of groups. Some data is also released publicly under Canada's open data initiative.

ISC is in the process of planning for an engagement with Indigenous partners on the development of a Policy on External Data Sharing. The Policy is intended to streamline and improve data sharing with partners, both Indigenous and other. Importantly, the Policy will reflect the needs and priorities of Indigenous communities, governments, and organizations to the extent possible within the current legislative framework. In addition to policy development work, ISC also participates in an interdepartmental working group on supporting and advancing Indigenous Data Sovereignty.

Overall, ISC has an awareness of OCAP® and is taking steps to improve their Indigenous data governance procedures. However, there are legislative barriers, such as access to information laws, that prevent ISC from being fully OCAP® compliant.

4.1.6 Canadian Child Welfare Information System (CCWIS)

At the moment, the only First Nations data that the Canadian Child Welfare Information System (CCWIS) has used is the data publicly available off ISC's website. However, despite this it would still be preferable had CCWIS sought First Nations approval before making use of this data. A great deal of First Nations data is made publicly available without proper permission, which does not absolve future users of the requirement to get permission from rights holders for use of the data. The fact that the study itself does not disaggregate the data by race or indigeneity makes this less of a violation of OCAP®, but the failure to seek rights holders permission is still a concern in this case.

CCWIS do have plans to use more First Nations data in the future. CCWIS are currently reaching out to First Nations groups to learn more about how to use child welfare data respectfully. The early engagement is a good sign, but the actual OCAP® compliance will depend on how they take this advice, and what data they end up looking to access.

4.1.7 Ontario Looking After Children (OnLAC)

The OnLAC program raises some serious data sovereignty issues. There are concerns over whether the program respects the privacy of the children involved. It has not been reviewed since part X, the section dealing with privacy, of the Children, Youth, and Family Services Act (CYFSA) came into force.

In addition, there are First Nations data sovereignty issues. A briefing note from OACAS gave directions for mainstream agencies to consult with indigenous groups before sending data to the University of Ottawa, but it is unclear if this is being followed in all cases. Indigenous organizations also collect data using the Assessment and Action Record (AAR) tool, but not all of them provide this data to the University of Ottawa.

The University of Ottawa's use of this data for research violates the principles of OCAP®. There is a great deal of First Nations data among the data being analyzed, and the results are compared between Indigenous versus non-Indigenous children. Rights holders have not been consulted about this use of First Nations data, and rights holders also have no control over how this data is being used. Access is being granted to other researchers without First Nations permission. The University of Ottawa's policy is to keep the data indefinitely unless asked to destroy the information by the society that provided the data.

4.2 Early Childhood Education Data

4.2.1 First Nation and Inuit Child Care Initiative (FINICCI)

Employment and Social Development Canada (ESDC) collect some data through their delivery of the First Nation and Inuit Child Care Initiative (FINICCI). They are currently in the process of co-developing with the national expert working group of the Assembly of First Nations (AFN) a results framework to make data higher quality and more readily available. They do not see themselves as owning the data, and acknowledge First Nations ownership of data about First Nations. They would like to be able to report back and provide success stories from the program, which requires better data. The results framework is likely to include elements such as spaces, how culturally relevant programming is, and high-level indicators of infrastructure built.

The person I spoke with was unsure what the procedure would be if a First Nation asked for their own data; it had never happened in her knowledge. It would be difficult since they are not able to effectively disaggregate data, so it would be hard to provide only information belonging to a single First Nation.

Currently, the data collected is not used. It has not been shared or published, and they recognize their inability to effectively make use of the data. Their data only dates back to the adoption of the Indigenous Early Learning and Child Care Framework (IELCC) in 2019, and the pandemic occurred just after this, so they have no baseline for what data looks like in a normal year.

4.2.2 Aboriginal Head Start in Urban and Northern Communities (AHSUNC)

Aboriginal Head Start in Urban and Northern Communities (AHSUNC) gathers minimal data. They make an effort not to collect data that is not going to be used, since they acknowledge the data sovereignty issues raised by First Nation data collection. Much of the data they gather is also publicly available from the childcare centers themselves, and is not of a particularly sensitive nature. Despite this, it would improve the OCAP®

compliance of the program if there was more effort to engage with rights holders directly, and to ensure that permission was sought for all data collection.

4.2.3 Aboriginal Head Start on Reserve (AHSOR)

AHSOR collects minimal data, all of it aggregate, from the organizations it funds. They are in the process of creating new reporting templates, in consultation with First Nations and other Indigenous partners. This work is still in progress, so it remains to be seen how well it will respect data sovereignty, but the increased awareness of the importance of data sovereignty is a good sign. However, the fact that the data would be available through an access to information request is potentially problematic, since this would make First Nations data available without permission from the appropriate First Nation.

4.2.4 Statistics Canada

Statistics Canada holds early education data from a number of off-reserve surveys, as well as limited early education data from the census itself, which is distributed on reserve. Statistics Canada information is available through the research data center, and de-identified data can be accessed via public use microdata files. There are also partners who have data sharing agreements and receive a copy of the data. The data from these surveys is physically located within Statistics Canada servers, and the data that is shared is housed with the partners with which it is shared. The data is on a secure network, and partners need to house the data in similarly secure environments. Statistics Canada shares data with a wide variety of partners, including federal departments/agencies such as Indigenous and Northern Affairs Canada (INAC), provinces and territories such as Ontario Economic Development and Growth, and other organizations, such as CIHI, Universities, and Educational Testing Service Canada Incorporated.

In order to get access to the data internally, a Statistics Canada employee need to submit a request that must be approved by the director of the employee making the request, the chief statistician, and the director of the department responsible for the data. For external applicants looking to access the data, they would need to submit a request with a research proposal through the research data center. For the public microdata file, individuals looking for data can go to a website and submit a request. In addition, some information is made freely available to download from the public Statistics Canada website. None of this data is individually identifiable, and it is all vetted to ensure it cannot be used to re-identify individuals. However, community level data has no such protections.

Statistics Canada makes a number of efforts to comply more fully with OCAP®. For example, they work with Indigenous organizations at the national level, such as the Assembly of First Nations (AFN), to ensure that work published is given the proper context and does not reinforce a deficit-based approach. Any analytical work they do they try to ensure these organizations review before publication to ensure the proper context is provided.

They also have an Indigenous statistical capacity development program. This program delivers training to Indigenous organizations on using statistics, both from Statistics Canada, and also using their own administrative data for statistical purposes. They are also working with FNIGC to support them in their implementation of the data governance strategy.

Despite these efforts, Statistics Canada is currently unable to be OCAP® compliant, due to the statutory mandate of the organization. This includes both the way that Statistics Canada shares data, and by the legal requirement for First Nations individuals to complete the census, with threat of fines if they refuse. There are anecdotal accounts of First Nations individuals being intimidated into completing the census, by threatening these penalties. This has been a matter of great concern to First Nations, with some communities refusing to allow access to the census in their communities.

As it stands, Statistics Canada data violates all of the provisions of OCAP®. The data is not possessed by First Nations, but by Statistics Canada. There is no control by First Nations over either what data is collected or how it is shared. First Nations have no more access to the data than anyone else does. As long as the legislative situation remains unchanged, Statistics Canada will continue to collect and distribute data without the permission of First Nations rights holders.

4.2.5 The Ministry of Education

The Ministry of Education has a number of systems to protect the data it collects. Applicant or licensee’s personal contact data, childcare program data, and childcare data for the Licensed Child Care Survey is collected and held on the Child Care Licensing System (CCLS), which is a secure database. Access is restricted to authorized internal users only. Some information is submitted with license application or revision to the childcare program’s service system manager after the applicant or licensee provides consent to share this information with them.

Data collected as part of the financial reporting process is accessible by Ministry financial analysts who perform the annual financial reviews and is held in the Ministry’s financial reporting system. The data is also accessible by Ministry staff that develop and support the financial reporting system. Access to the financial reporting system is restricted and reviewed on an annual basis.

The Ministry sends First Nations the Licensed Child Care Profiles, which are summaries of their childcare space data. Also available are the summarized results of the Ministry’s annual Licensed Child Care Survey, once they are prepared by the Ministry for use. First Nations are also able to contact the Ministry with any questions about the childcare data related to their First Nation.

While the Ministry of Education is aware of OCAP®, when asked about their compliance with it, they cited the legislative authority they have to collect data under section 71 of the Child Care and Early Years Act, 2014. This legislative authority fails to acknowledge the need for consultation with First Nations before collecting or using First Nations data, and thus fails to accord with OCAP® requirements. While they do make data available to First Nations, they fail to acknowledge First Nations ownership of the data, and do not currently ensure First Nation control or possession of the data.

4.2.6 First Nations Information Governance Centre (FNIGC)

The First Nations Information Governance Centre (FNIGC), as one would expect from the organization that stewards the OCAP® principles, has a strong information governance system around the First Nations health data it collects. The FNIGC has a national mandate from an Assembly of First Nations (AFN) resolution to gather and authorize the sharing of the data that they collect. The information is all de-identified, and there are permissions on the files so only analysts who need the data can access data. The entire process is designed to realize the values of OCAP®. Data is collected only with community consent as well as individual level consent.

The FNIGC publishes a national level report on the results, and some of the regional partners also prepare regional reports, and some communities may request community level data to prepare community reports, although this depends on sample size to ensure the results are meaningful. In addition, researchers can get access to the data through a data center. This requires the researcher to fill out an online application form, which is then assessed through an internal committee, with requests for especially sensitive information also going to a board committee for approval. FNIGC will only provide access to national level data; anyone looking for access to regional or community level data would need approval from the appropriate regional partner or community itself.

4.3 Social Assistance Services Data

4.3.1 Indigenous Services Canada (ISC)

The person I spoke with was not sure of the eligibility of the data held by Indigenous Services Canada (ISC) for Access to Information Privacy requests. If a First Nation contacted ISC asking to see report on their First Nation, there would be no reason to deny this request. The director would approve the release of data. However, they would not share data on one First Nation to a different First Nation without permission from Chief and council of the First Nation to which the data corresponds. The person I spoke with was not familiar with OCAP®.

4.3.2 Ministry of Children, Community, and Social Services (MCCSS)

As discussed in section 3.3.2, despite efforts to gather information on the data gathering and data governance procedures of the Ministry of Children, Community, and Social Services (MCCSS), at the time of completing this report they had not yet provided this information. As such, the data governance around social assistance data held by MCCSS is not known at this time.

4.3.3 The Ontario Native Welfare Administrator's Association (ONWAA)

As discussed above, the Ontario Native Welfare Administrator's Association (ONWAA) does some of its own research for advocacy and program planning purposes. Consent to use the data they use comes from individuals or from members of ONWAA, who are welfare administrators. This is a potential problem, since these are not rights holders for collective data. Some of the data, such as general administrative costs, may be general enough not to trigger data sovereignty worries, but other data is more sensitive.

In terms of data access, ONWAA provides aggregate information in the form of the published reports that they produce based on the data collected. They would also share data with COO if requested, although some data sharing requests might need to go to the board of directors. They would also provide aggregate datasets back to First Nations when requested.

4.3.4 Individual First Nations or Municipalities

Where First Nations manage their own social assistance programs, data sovereignty issues will generally not arise. The First Nation itself, as authorized by its rights holders, will possess and control the data collected, as required by OCAP®. The main issue would be with requirements to share data with outside agencies for funding or other legally mandated purposes, and those are discussed above.

One area where concern could arise is from the companies that provide the data systems used to collect the data. For example, many communities use A. D. Morrison for their data collection system. A.D. Morrison has no data sharing agreement with the communities it serves, so in theory they could legally use the data they hold for their own purposes. There is no evidence this has occurred, but the possibility is still a worry.

The other major system in use by communities to collect social assistance data is SAMS, and it too has some issues. Despite being asked not to, SAMS uses municipal codes as the organizing information for communities using this software. The problem is that municipal codes include both on and off reserve areas, so it is impossible to tell clearly who is on and who is off reserve. There is a work around that will identify people as on reserve, but it requires that caseworkers be trained to use it. This makes it hard to identify which ODSP (Ontario disability support program) recipients live on reserve. ACSD (assistance for children with severe disabilities) has the same problem.

In cases where municipalities administer social assistance services to First Nations, there are more serious data sovereignty worries. The municipality will possess sensitive data about all First Nations individuals receiving social assistance services, and there are no legal guarantees that they will appropriately consult with First Nations on the management and use of this data. This makes it concerning that some First Nations may be forced to move to municipal provision of social assistance services due to underfunding for the provision of these services by First Nations.

5. Barriers and Opportunities for OCAP®

The previous sections of this report have looked at what social data is gathered on First Nations in Ontario, where it is stored, and how it is managed. This has provided an overview of the data landscape, and shown both some of the successes and the gaps for realizing OCAP®. This section will now present a higher-level overview of some of the barriers to OCAP® and opportunities to enhance OCAP® compliance in the social sector.

5.1 Barriers to OCAP®

5.1.1 The design and implementation of CPIN

As discussed in section 4.1.1, the design and implementation of CPIN fail to adequately accord with the OCAP® principles. The data is held centrally and can be accessed by employees in any child protection agency. This means that even if the data is collected by an agency that has an agreement with the relevant First Nations to collect the data and manage it according to the First Nations expectations, this data can still be accessed by many other parties. This makes it all but impossible to exercise effective ownership and control over the data. In addition, MCCSS can also access this data, and even combine it with data from other ministries because of the BIPD's designation as an extra ministerial data integration unit. BIPD has so far attempted to screen out First Nations data from their data integration work, but this has two issues. On the one hand, due to data quality issues within CPIN, it is likely that some First Nation data will in fact be included in the analysis. Secondly, screening out First Nation data deprives First Nations of valuable information they might need for governance purposes.

Currently, three Indigenous child and family service agencies already use CPIN. For those agencies that were designated after CPIN was introduced, using CPIN was required as a prerequisite for the agency becoming designated. Thus, it appears that any new agencies will also be required to adopt CPIN, despite the considerable OCAP® issues raised by the system. Furthermore, the data systems used by the Indigenous child and family service agencies not on CPIN are all old and are either near or already at end-of-life with respect to ongoing support from vendors. Thus, they will need to transition to new systems sometime in the not too distant future.

5.1.2 Data collected without rights holders permission

Throughout the social data landscape, multiple levels of government collect First Nations data, either permitted or in some cases mandated to do so by legislation. In most cases this data collection began many years ago. There is a growing understanding in the government that First Nations consultation is necessary before using the data collected, although this is still far from universally recognized and the degree of consultation can vary significantly. The collection of the data itself continues without First Nation permission, however, even in cases where the uses of the data are recognized to be problematic. In particular, the rights holders over the data, who should be giving their permission before data is collected, are the First Nations communities themselves, through their representatives.

There are some heartening examples of data not being collected due to data sovereignty concerns. For example, Indigenous child and family service agencies have decided not to collect the identity-based data (IDbD) supplementary information from children and families they interact with, due to data sovereignty concerns. Similarly, Aboriginal Head Start in Urban and Northern Communities (AHSUNC) stopped collecting some forms of data that were not regularly used, out of recognition of the data sovereignty concerns with data collection. However, there remains a great deal of data collection that happens without any permission being sought. Often, when asked about this data collection, people would cite legislation that authorized the data collection. However, this legislation was not drafted with First Nation data sovereignty in mind. Legal authority is irrelevant to the question of whether such data collection violated OCAP®.

5.1.3 First Nations communities underfunded to provide their own services

The ideal case for OCAP® is when data is gathered, held, and used by First Nation communities themselves. This is the case when First Nations are able to administer and deliver their own social services, as is the case for most First Nations currently. OCAP® concerns can still arise for data that is required to be reported to the provincial or federal governments as part of receiving funding for these services, and with regards to the organizations that run the data gathering software used to hold this data. Still, the bulk of the data, and the most sensitive data, will be the administrative data gathered and held by the First Nation itself.

However, five First Nations currently do not administer their own social services, having nearby municipalities do so instead. Other First Nations have had to consider moving to a similar system. This is due to resource constraints. The provision of social services is underfunded in First Nations communities. This makes it difficult to recruit and retain staff, since they are unable to offer competitive wages.

It is discriminatory that First Nations are not provided with adequate funding to provide social services, in contrast to the municipalities that provide these services to other communities. It also raises data sovereignty concerns. When a First Nation moves to having a municipality provide social services, it loses control and possession of the data that is gathered as part of administering these programs. How exactly the First Nations data is treated will depend on the municipality, but there will naturally be concern over whether the First Nation will retain control and ownership over this data. Access can also be negatively impacted, since often when a municipality is providing the services the information of whether a client is on reserve or not is no longer captured. This makes it more difficult for First Nations to access the data they need for governance. Finally, no matter how sensitive a municipality may be to First Nation data sovereignty, having municipalities collect the data will clearly mean that the data is no longer in the possession of First Nations.

5.1.4 First Nations not included in data analysis

One response to worries about First Nations data sovereignty is to avoid using First Nations data when conducting research or doing analysis of data. This may seem like a way of avoiding the worries about using First Nation data without appropriate permission or in ways that fail to respect First Nation rights. However, this approach fails to respect First Nations right to have access to the data they need for effective governance and advocacy.

An example of this approach is the decision by the Business Intelligence and Practice Division (BIPD) of MCCSS to screen out First Nation data from their analysis of educational results for children in care. This means that the data from this project will exclude First Nations data. This is being done due to concerns that using First Nations data would potentially violate First Nations data sovereignty.

BIPD are offering to partner with individual communities who would like to be part of the analysis. However, this kind of opt-in system for individual communities will not create the kind of comprehensive First Nations data that would make up for the exclusion of First Nations from the main analysis.

The concern is that policy and funding decisions will be made on the basis of the results of this project. Since First Nations data has been excluded, that means that the needs of First Nations children will not be accounted for in these decisions. Furthermore, First Nations as a whole will lack the ability to make decisions and advocate for themselves on the basis of the data. The access component of OCAP® includes First Nations having access to the data they need, and excluding First Nations data from important projects exacerbates this problem.

5.2 Opportunities to Enhance OCAP®

5.2.1 Support Indigenous child and family service agencies to use alternatives to CPIN

As discussed above in 5.1.1, the agencies that do not use CPIN are using technology that is approaching the end of its usable life, and there will be the need for a transition. There are three options for what this new system could look like. The first option would be to adopt CPIN. The second option would be to create a single centralized Indigenous information system that could be adopted for all of the Indigenous child and family service agencies. The third option would be for each Indigenous child and family service agency to continue to operate their own independent information system, replacing their existing systems with whatever options are available commercially.

Given the data sovereignty concerns with CPIN, it would improve data sovereignty to support Indigenous child and family service agencies to adopt one of the other two approaches rather than joining CPIN. The Association of Native Child and Family Service Agencies of Ontario (ANCFSAO) has explored the possibility of creating a centralized Indigenous information system. They received funding from ISC to explore the technical requirements for such a system. Unfortunately, ISC terminated their funding for the project before the exploration of governance for the proposed system could be developed.

A centralized Indigenous information system would have some advantages over other alternatives. It would allow the system to be designed from the ground up for Indigenous data. For example, it would allow protection and prevention data to be stored in the same system, which is not currently possible with either CPIN or the alternatives currently in use. This would allow greater integration between protection and prevention services. This system could also be designed to capture the information that is important to First Nations. For example, it could be designed to clearly affiliate individuals with their respective First Nations and to allow participating First Nations to identify their own community's data.

A centralized system does raise some important governance issues. The rights holders under OCAP® are the First Nation citizens themselves. An Indigenous child and family service organization still needs to have proper permission from the First Nation to collect data, and will need to ensure that the First Nation can exercise control and access their own data. A shared system creates some difficulties for this ownership and control, since multiple agencies would potentially be able to access the data collected by one agency. This would require governance controls to ensure that First Nations retain control over who accesses their data and how it is used. Such a unified system would also be expensive to develop. Significant resources would need to be found to support this development and it is not clear where these funds could be found.

Having each agency remain with their existing technology, or transition to new providers individually, would also be preferable from the point of view of data sovereignty. This would potentially allow for less customization, and perhaps the need to go with a more "off the shelf" version of existing software. On the other hand, this avoids the significant costs of developing a new centralized system, and potentially raises fewer data governance concerns, since all uses of the data would be controlled by a single agency.

Both of these options have their advantages and disadvantages, but what is clear is that moving to CPIN would be worse from a data sovereignty perspective than either option. Thus, Indigenous child and family service organizations should be supported in their continuing resistance to adopting CPIN, and efforts should be made to identify a solution going forwards.

At the same time, the need will remain to improve the OCAP® compliance of CPIN. This is because approximately 40% of First Nations individuals are served by a non-Indigenous child and family services agency, and these agencies are and will remain on CPIN. There are some steps that could be taken to improve the OCAP® compliance of CPIN. For example, an Indigenous flag could be added to files, and access to files with this flag could be restricted. This could prevent, or at least mitigate, the loss of control over data that was noted earlier. However, this change, along with others that could make CPIN more suitable for First Nations, has not been implemented despite being pushed for by ANCFSAO for several years already.

5.2.2 Push for recognition of existing commitments on First Nation consultation

There are a number of legal and policy commitments to consultation with First Nations that can potentially be leveraged to address the collection and use of First Nations data without rights holders consent. At the federal level, UNDRIP has been recognized in the UNDRIP act, and contains several provisions that when properly interpreted point to a requirement to consult with First Nations over data collection and use. The same is true of the Truth and Reconciliation Commission of Canada's calls to action. See section 2.2 for a further discussion of the specific sections that are relevant.

Similarly, at the level of policy, the 2023-2026 Data Strategy for the Federal Public Service contains numerous commitments to First Nations data sovereignty. The strategy states that "support for Indigenous data sovereignty is a government-wide priority that contributes to Indigenous self-determination. Over the next three years, work co-developed with Indigenous partners will lay a strong foundation for a whole-of-government approach to support First Nations, Inuit, and Métis Nations as they realize their respective visions for data sovereignty." These federal commitments can potentially be leveraged to improve the OCAP® compliance of the data collected by the federal government.

Drawing on these commitments can allow First Nations to more effectively advocate for data sovereignty. By citing existing commitments, a clear case can be made that consultation with First Nations is a requirement before collecting or using First Nations data.

At the provincial level, there are fewer unambiguous commitments to First Nations data sovereignty. Still, there is often language used by assistant deputy ministers (ADMs) that express support for First Nation consultation and data sovereignty. The difficulty is that this commitment does not always filter down to the staff who are responsible for day-to-day operations of the Ministries, and thus fail to translate into true progress on data sovereignty. Finding ways to push for integrating existing commitments to data sovereignty into the ordinary practice of Ministries will be crucial to seeing these commitments translated into action.

5.2.3 Advocate for funding for First Nations service delivery

As discussed above, data sovereignty provides a further reason to support adequate funding for First Nations to deliver their own social assistance programs. Doing so will ensure that the data generated from administering these projects is in the possession of First Nations and can be used for governance and advocacy. When these services are underfunded, and First Nations communities must rely on local municipalities to provide these services, then they lose control over the administrative data generated.

Given the growing awareness of the importance of First Nations data sovereignty and the existing commitments to furthering this data sovereignty, this may be a way to advocate for increased funding for First Nations service delivery. This is currently an area where First Nations risk being forced to move backwards, relying on others to provide services and gather data on their behalf, so advocating effectively for sufficient funding is crucial.

5.2.4 Educate data holders on data sovereignty costs of excluding First Nations data

One of the reasons for the kind of exclusion of First Nations data discussed above in 5.1.4 is the mistaken belief that this will satisfy data sovereignty concerns. It is crucial to educate data holders that this is a misunderstanding of OCAP®. Making decisions that will affect First Nations without including them in the data is not a way of respecting OCAP®, and deprives First Nations of the ability to use data effectively for governance.

Data holders need to understand that excluding First Nation data is not a viable alternative. Instead, the only way to satisfy OCAP® and respect First Nation data sovereignty is to do the work of developing governance frameworks for First Nation data that will satisfy OCAP®, and building the relationships needed for rights holders to have appropriate control over the data. There is no work around to the need for this requirement, and First Nations need to make this clear to data holders.

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Appendix A: List of Organizations Contacted

Association of Native Child Family Service Agencies of Ontario (ANCFSAO)

Dnaagdawenmag Binnoojiiyag Child & Family Services

Employment and Social Development Canada (ESDC)

Indigenous Services Canada (ISC)

Ministry of Children, Community, and Social Services (MCCSS)

Ministry of Education

Native Child and Family Services of Toronto

Ontario Association of Children's Aid Societies (OACAS)

Ontario Native Welfare Administrator's Association (ONWAA)

Payukotayno James and Hudson Bay Family Services

Public Health Agency of Canada (PHAC)

Sarnia-Lambton Children's Aid Society

Statistics Canada