

Using Data to Enable Better Outcomes for Young People Leaving Care

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About this report

Youth in Care Canada is a core partner of Powered by Data, and member of an emerging data policy coalition facilitated by Powered by Data. This report explores potential use and misuse of administrative data in the child protection sector to advance a rights-based approach that empowers young people and addresses systemic inequities.

About Youth in Care Canada

Youth in Care Canada is a national, charitable organization driven by youth and alumni from child welfare authorities across Canada. Since 1985 YICC has engaged young people in and from care, and those who work with them, in: research, policy development, and training of caregivers and child welfare professionals. YICC has assisted development of provincial and community-level youth in care networks across Canada and helped to further the national and international youth in care networking movement.

About Powered by Data

With the goal of enabling the social sector to benefit from the rapidly changing ways society handles information, Powered by Data works with leaders in nonprofits, governments, and foundations to help them better use, share, and learn from data. Powered by Data also works with key stakeholders to open up their data for social impact. Powered by Data operates on Tides Canada's shared platform, which supports on-the-ground efforts to create uncommon solutions for the common good.

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EXECUTIVE SUMMARY

Canadian child welfare institutions lack a consistent and cohesive approach for the collection, protection, and use of data about youth in and leaving care. This data deficit means there is insufficient capacity within provincial and territorial child welfare systems to monitor trends and no way to aggregate and compare results across the provinces and territories. Within child protection agencies, case files are routinely used to record the relevant details about a young person's personal and familial history, legal decisions about their guardianship, their health and social care records, and personal information. Yet it is not a standard practice for young people to have access to these files nor the information contained within them while they are receiving child welfare service and after they have left care. In fact, case files are most often used in child welfare institutions to demonstrate compliance with ministry directives with respect to provincially mandated standards of care. Still unrealized is the potential for case files to serve as tools to enable shared decision-making, self-advocacy on the part of the youth, adherence to a plan of care, and thus better outcomes for young people.

Furthermore, because there are no shared standards for collecting and aggregating child welfare system data – administrative case file data and other forms of data (e.g., race-based statistics) – there remains insufficient external oversight of system functionality and outcomes. Independent research conducted about care-leavers suggests young people with histories of child welfare involvement experience disproportionately negative outcomes across a range of domains – work, health, housing, education, criminal justice involvement and victimization – when compared with the general population. Canadian child welfare institutions require data strategies that will enable better monitoring of systemic trends and the outcomes of individual youth in care. Young people receiving child welfare services also need a way to monitor and annotate their experiences as service users. As young people transition towards independence their personal information must be accessible to support a smooth and safe transition into adulthood.

This brief proposes tangible mechanisms for shared decision-making with respect to the case files and plans of care for young people growing up in Canada's child welfare systems. Grounded in a review of best and promising practices, with respect to rights-based data collection and oversight in child protection settings as well as shared decision-making with respect to electronic health records, we propose a rights-based

and custodial approach to administrative data collection and use as an immediate first step towards implementing a national rights-based data strategy for youth receiving child welfare services. Individual rights to access and privacy must be balanced by concerns for collective wellbeing and the assurance of human rights protection for all young people. Data must be made available in order to monitor systems-level youth outcomes; identify systemic inequities and structural drivers of inequality; and enable continuous quality improvement efforts within the system.

We offer a series of evidence-based use cases, which illuminate how a rights-based approach to administrative data access will serve as an effective mechanism for enabling better outcomes for young people leaving state care. While Canada's data crisis has implications for all Canadians, its effects are particularly pronounced for young people – who by virtue of their participation in public systems (e.g., education, child welfare), presence in public spaces (e.g., parks and streets), and dependence on civil sector organisations – are vulnerable to data gaps and data management issues that may reduce their access to life-sustaining services. Nowhere is this more apparent than in the case of young people who are dependent on the child welfare system.

This brief was written to be useful to policy analysts and decision-makers in provincial, territorial, and federal governments as well as advocates striving for better outcomes for youth in and leaving Canada's child welfare systems. The brief offers a comprehensive, practical, and policy-oriented view of problems and potential solutions to administrative data management and access in Canada's child welfare systems. We highlight key opportunities for enabling a rights-based and custodial data approach to be embedded in a national strategy. Specifically, we recommend:

Provincial and territorial governments responsible for delivery and oversight of child welfare services should:

- Protect and enshrine via legislation children and youth's rights to access their personal information at the level of corresponding personal health information
- Enable and convey transparent, timely, and accessible pathways for children and youth and former youth in care to access their personal information
- Enable and protect individual rights to annotate and/or correct personal information and administrative case file data (e.g., the OpenNote system for shared e-health record-keeping that has been successfully piloted in the US)
- Standardise and communicate recordkeeping practices vis-a-vis retention time; if and when a record is destroyed or sealed, the individual must be notified and pathways to access conveyed

- Establish a third-party intervener in dispute cases regarding accuracy of information
- Ensure standards and mechanisms for upholding data security and privacy when implementing electronic data management infrastructure
- Establish a governance and operational framework and privacy standards for sharing and integration of data sets across organisations contributing to a circle of care for youth in and leaving state care
- Ensure consistent oversight, including capacity-building and organisational supports among individual CAS organisations to ensure compliance with legislation

The Government of Canada should:

- Ratify Bill C-441 *An Act respecting the Office of the Commissioner for Young Persons in Canada*, in line with Canada's obligations under the United Nation Convention on the Rights of the Child
 - » Task the new federal Commissioner for Children and Youth to convene and oversee national strategy to harmonize a rights-based approach to child protection services and data management across provinces and territories
 - » Structure standing reporting and liaison between Office of the Commissioner and the Canadian Council of Child and Youth Rights Advocates to strengthen oversight and advocacy across provinces and territories
 - » Mandate and resource the Canadian Council of Provincial Child and Youth Advocates, working with the Canadian Coalition for the Rights of Children and Youth in Care Canada, to write summary national annual report based on provincial and territorial report cards to monitor the rights and wellbeing of young people in and exiting care across Canada
- Develop and maintain useable and secure infrastructure for data integration across respective service areas (e.g., child welfare, education, youth justice and health) that cut across provincial and federal jurisdiction
- Establish and empower prescribed provincial and territorial entities (e.g., Child and Youth Data Commissions that sit outside any provincial or territorial Ministry), which will serve as cross-sectoral child and youth data custodians (e.g., education, youth justice, child welfare, and child and youth health - including mental health)
- Ensure custodial rights and pathways to access child and youth data for research purposes (e.g., research to identify and monitor systemic inequalities; cross provincial comparisons of child welfare outcomes) and systems improvements



INTRODUCTION

In January, 2019, the Globe and Mail released “In the dark: The cost of Canada’s data deficit,” where they note, “Our ignorance is decades in the making ... provincial responsibility for health and education that keeps important information stuck in silos and provides little incentive for provinces to keep easily comparable numbers about themselves” (Andrew-Gee & Grant, 2019). For young people growing up in Canada’s child welfare system, ordinary aspects of their daily lives are defined by the nation’s data deficit. Child welfare files contain important information about serious occurrences (e.g., serious injuries; calls to police), deaths, educational outcomes, and even placement numbers of young people in care. However, these files are not accessible to the young people whose lives they represent nor is the information aggregated and tracked by oversight bodies. Concerns to protect the privacy of agencies and individual young people have trumped the rights of individuals to access their own health and social care information. Privacy has also taken precedence over collective oversight and accountability. Indeed, in Ontario, it was only in 2016 that a private member’s bill, Bill 117 (Taylor, 2015), required the mandatory reporting of deaths of children in the care of child welfare agencies (Kitts, 2016; Monsebraaten, 2015) —this legislation was repealed in 2018 (Ontario Child Advocate, 2019).

These data deficits are not limited to the state’s capacity to monitor trends; they have significant implications for individual well-being. A young person’s child welfare file contains important medical information, including: diagnoses, vaccination records, and treatment plans. In the absence of having access to an electronic health (e-health) record, young people leaving state care require access to their child welfare file information to enable self-care, treatment adherence, and health advocacy. This builds from a broader challenge that few Canadians currently have access to an e-health record. For example only 6% of people in the province of Ontario have access to their e-health record (Health Quality Ontario, 2019). The use of electronic records by medical practitioners is steadily increasing. A national survey indicates 77% of physicians use electronic files to enter and receive clinical notes (Gheorghiu & Hagens, 2016); unfortunately a lack of coordination limits interoperability on a national scale (Persaud, 2019). While clinical access continues to improve, patient access to e-health records is rolling out much more slowly. While Canadians are entitled to see their health records (whether paper or electronic, for the most part health records remain owned, stored, and managed by health institutions (CBC News, 2018). This is

especially the case for young people, who are even less likely to have access to an electronic health record than adults (Ransom, 2015). The ability to participate in the construction and management of one's electronic health records (e.g., through Open Note patient portals) supports patient self-care and treatment compliance (Esch et al., 2016; Ransom, 2015; Sarabu, Pageler, & Bourgeois, 2018). There is robust research to suggest shared decision-making increases communication, collaboration, and clinical decisions. This in turn promotes patient agency and self determination leading to increased trust and adherence to treatment (Barry & Edgman-Levitan, 2012; Elwyn et al., 2012; Sahl & Knoepke, 2018).

This brief explores possibilities for shared decision-making with respect to the case-files and plans of care for young people who grow up in Canada's child welfare systems. Specifically, we argue that a rights-based approach to administrative data access will serve as an effective mechanism for enabling better outcomes for young people leaving state care. While Canada's data crisis has implications for all Canadians, its effects are particularly pronounced for young people – who by virtue of their participation in public systems (e.g., education, child welfare), presence in public spaces (e.g., parks and streets), and dependence on civil sector organisations – are vulnerable to data gaps and data-management issues that may reduce their access to life-sustaining services. Nowhere is this more apparent than in the case of young people who are dependent on the child welfare system.

In this brief, we adopt the World Health Organisation's definition of young people (10-24 years of age). We use this expansive definition (i.e., young people rather than youth) because we are interested in the period of time when young people are in and leaving care. Our position is that preparation for independence begins when young people are still under the care and guardianship of the state. Improving transitions from care will allow the state to redress historically-situated, state-influenced patterns of exclusion, neglect, and discrimination. Ensuring young people have information about their own lives needed to participate effectively in the public sphere supports young people to exercise their fundamental legal rights to live without poverty and discrimination, have access to safe and adequate housing, be healthy, and participate fully in school and/or the workforce. In other words, access to data has an important human rights dimension. A Human Rights approach acknowledges that young people have fundamental legal rights enshrined in international human rights treaties (e.g., the United Nations Convention on the Rights of the Child - UNCRC). This brief pivots on the strategic use of administrative data to address systemic patterns of exclusion and neglect – in this case, evidenced by the disproportionate number of former youth

in care who go on to experience homelessness, educational exclusion, poor health outcomes, criminal-legal system involvement and victimization in Canada (Gypen, Vanderfaeillie, De Maeyer, Belenger, & Van Holen, 2017; Maloney, Jiang, Emily, Dalton, & Vaithianathan, 2017; Nichols et al., 2017; Scherr, 2007).

To build our argument, this brief:

1. Conveys the results of a cross-jurisdictional legislative review of child welfare legislation with respect to privacy and data;
2. Synthesizes the literature on data, ethics, and social policy;
3. Defines administrative data and articulates its utility in shared decision-making; and
4. Offers a series of use-cases, which illuminate how administrative data could be used to generate better outcomes for youth leaving care.



CROSS-JURISDICTIONAL LEGISLATIVE REVIEW

In Canada, child welfare services are provincially legislated and provisioned. In order to produce this brief, we conducted a cross-jurisdictional review of current Canadian provincial child welfare legislation to understand the scope of privacy and data rights. This review looked at embedded rights and mechanisms to access and obtain one's own information as well as overall privacy, information sharing, and record retention protocols.

Broadly, there are two themes present in legislation discussing privacy and access to information rights. The first theme is privacy and confidentiality vis-a-vis sharing of information, and the second is the right to access one's own information. Balancing information sharing with privacy considerations, especially when considering platforms that benefit from data use is a challenge faced by most provinces and territories. Our scan found that record keeping, privacy, and data utilization requirements differed significantly by province or territory. These differences are often replicated within the provinces and territories, where – as is the case in Ontario – individual children's aid societies collect different information with respect to the children and youth in their care.

In a 2018 Blog post for *Powered by Data*, Khan references a report by the Ontario Human Rights Commission (OHRC, 2018), which reveals 20% of Ontario's 49 child welfare agencies collect no identity-based data. Khan goes on to note that where identity-based data are collected, the OHRC reported inconsistency in the classification systems used by individual agencies to collect identity-based data. Indeed, some agencies were using dated and even racist terms to classify young people in their care – a clear example of ongoing systemic discrimination. Furthermore, the lack of standardization within and across provinces and territories renders the data less useful. These differences in provincial and territorial legislation, with respect to the child welfare system, are striking given considerable consistency in privacy and information-sharing legislation in other sectors such as healthcare.

For example, the recent overhaul of Ontario's child welfare legislation recognized that Ontario's practices of privatizing child welfare records were lagging behind other

Canadian provinces while putting sensitive information in harm's way through storage in insecure databases (Conteta, 2018 re: ransomware attacks targeted at two Ontario Children's Aid Societies using CPIN in early 2018; Isai, 2017 re: unresolved privacy and concerns with the database). Meanwhile young people are simultaneously prevented from access to their own information. In response to these issues, the province introduced Part X (Personal Information, O Reg 191/18) to the Child, Youth, and Family Services Act (CYFSA). Part X was proclaimed along with the rest of the CYFSA, coming into force on April 30, 2018 (Child, Youth and Family Services Act, 2017, SO 2017, c 14, Sch 1). However, enforcement of Part X has been held back – with an effective date of January 2020 – in order for the government to remedy its current record management infrastructure. Part X is meant to fill a legislative gap in the province, with respect to the collection, use, disclosure of, and access to personal information held by ministry-funded and licensed service providers including children's aid societies. However, in its current iteration, it is unclear how the regulation will be implemented and enforced.

While there is increasing recognition of the the need for better data systems in Canada's public sector, tensions between the right to privacy and the right to information continue to structure government responses. Balancing the promotion of access to information and the protection of privacy remains an important preoccupation. Unfortunately, in child welfare, the default position has been to significantly limit access to information, citing privacy rights of biological and foster family members over the access rights of young people. Our stance is that this is a misconceived use of legislation, whereby conceptualizations of privacy serve as a blanket shield to block young people's rights of access. In line with other jurisdictions and the variances across provinces, we suggest a rights-centred proactive approach to enable access to records for children and youth that does not require young people to retroactively navigate legislative instruments (Australian Department of Social Services, 2015; Australian Society of Archivists, 2016).

We conclude this section with a list of recommended practices, which we constructed on the basis of promising legislative provisions across the Canadian provinces and territories:

- Integration of provincial freedom of information and/or health record management legislation into the child welfare legislation;
- Separation of the roles of confidentiality, information sharing protocols, and rights to access information;

- Establishment of clear protocols for young people to access information with defined timelines; and,
- Implementation of mechanisms for youth and their advocates to correct information held in the child protections files.

Additionally, we recommend child welfare legislation serve as a mechanism to reinforce the rights of the children and youth who fall under it. To this end, we stress the importance of legislation that has: a clear assertion of the rights of young people; protocols through which young people's capacities as rights-holders can be developed; and the use of plain language to facilitate informed consent and shared decision-making processes. Finally, we offer a note of caution. Although cross-sectoral information sharing can be beneficial in the realms of outcome evaluation and integrated service delivery, there can be negative consequences if person-centred rights and privacy protocols are not at the core of these mechanisms. Data can be used to surveil, to criminalize, to restrict access, and make decisions that may disproportionately impact one group over another. It is thus essential that data are collected, managed, and shared in ways that preserve people's rights to privacy and data security.



ISSUE CONTEXT

Data, ethics, and social policy

Overwhelmingly, research suggests data sharing among service providers and sectors leads to continuity of care and more favourable outcomes for children and youth (Bai, Wells, & Hillemeier, 2009; Fallon, Filippelli, Black, Trocmé, & Esposito, 2017; Langworthy & Robertson, 2014; Nguyen, 2014; Peckover, White, & Hall, 2018; Spath, Werrbach, & Pine, 2008; Webster, Usher, Needell, & Wildfire, 2008). “Data-driven” and “performance-based” social services are becoming the norm in the United States and slowly entering the Canadian sphere. For example, Canada’s Homelessness Strategy Reaching Home, advocates for the collection and use of real-time data and standardized assessment and decision-making pathways to enable coordinated access to housing services and supports (Employment and Social Development Canada, 2018). This move is meant to streamline service delivery processes across the country.

Similarly, child protection agencies throughout the United States are beginning to use predictive risk modelling to assess the risk of childhood maltreatment and neglect. These models repurpose pre-existing administrative data (e.g., calls for service, historical data, demographic and socio-economic data) and attempt to predict the risk of child maltreatment. As governments across Canada move towards continuous data collection and monitoring (e.g., the Smart Cities initiatives re-shaping urban life in Canada), data-led surveillance (Zuboff, 2015), and data-driven decision-making practices (Gillingham, 2016; Gillingham & Graham, 2017), the need for ethical and rigorous data collection, data sharing and data use strategies is pressing – particularly for those young people whose lives are deeply impacted by their participation in public institutions like the child welfare system.

Indeed, this brief is premised on the idea that, for young people, transitions from state care represent a key institutional and policy juncture where protective interventions will make a profound difference to their long-term experiences of housing, medical, and social stability. When a young person is transitioning out of the child welfare system, they are often required to interact with new institutional systems (e.g., post-

secondary education, social or disability assistance programs, the adult mental health system, social housing). For young people to effectively navigate these new systems, they require access to the information contained in the files from the institutional systems they participated in as children and youth. It is essential for young people to have access to – and be knowledgeable about – the administrative data contained in their personal records (e.g., child welfare, K-12 education, and youth mental health case files) so that they can knowledgeably self-advocate with respect to their personal and familial medical histories, psycho-educational and/or mental health diagnoses, immigration status, and cultural backgrounds. Without full and consistent access to this information, young people are unable to independently and safely navigate the transition into adulthood and ensure they experience the actualization of their rights to housing, education, work, movement, safety, and a life free from poverty.

What is administrative data and why is it important?

Governments collect various forms of person level data through the administration of programs and social services—otherwise known as administrative data (Organisation for Economic Co-operation and Development, 2018). Administrative data is not census data or “open-data” as it contains private and often sensitive information about service users (Powered by Data, 2018). With the emergence of “data-driven” policy and institutional decision-making (highlighted in the previous section), the management and dissemination of administrative data is pertinent. When aggregated and anonymized, administrative data can assist researchers and civil society organisations with identifying systemic trends present in our governmental systems. For example, addressing the overrepresentation of Indigenous and Black children in care, or cases where children taken into custody by child protective services are denied the ability to obtain citizenship.

Important to the recommendations put forward in this brief, access to one's own administrative records can also help alleviate the fragmentation between social service systems, which undermines young people's safe and sustained transitions from state care. Enabling access to a young person's own personal level records can ultimately support effective self-advocacy, systems navigation, labour market, and post-secondary participation leading to better outcomes as young people transition into adulthood.

What is a rights-based approach to administrative data access and why does it matter?

Access to one's own personal information is a means to self-sufficiency and agency. When this information is understood to be owned by government agencies such as child welfare, education, healthcare, and criminal justice institutions, the information is used to advance institutional aims and objectives. Similarly, regulations about information production and distribution are oriented to protecting institutional interests.

A rights-based approach to personal records ensures that a young person's personal information is continuously available and accessible (e.g., written in plain language) to them, and that their private information is protected from others. Ultimately, young people should be seen as the rightful owners of their personal records and information, rather than simply subjects about whom case files are written.

Individual rights to personal information and privacy

When moving to a rights-based approach to administrative data access, there are two important issues to tease out:

1. Individual rights to accessing one's own personal information; and
2. Custodial rights to access and protect the personal information of others.

From a rights-based perspective, each young person has individual rights when it comes to their personal information, including the right to access their personal information and any administrative data pertaining to their experiences in state care. They should have the right to expect accessible and transparent pathways to enable access to their own information, as well as the right to annotate and/or correct information pertaining to their experiences in state care. Young people should also expect that their rights to data privacy and security will be maintained by those possessing custodial rights to their data. Designated agencies (e.g., independent research bodies and/or Ministries responsible for the care of children and youth) should have custodial rights to access personal information and administrative data for the purposes of research, systems oversight, and continuous quality improvement. Custodial bodies should also inform the creation of ethical governance and policy frameworks, including operational mechanisms for cross-sector data sharing. Finally, custodial bodies should have a responsibility to ensure young people understand their rights to information and know how to exercise them.



USE CASES

Individual Use Cases: Demonstrating the need for a rights-based approach to administrative data

CASE 1: HEALTHCARE AND CHILD PROTECTION.

A former youth in care has scars on her body from surgeries when she was a young child. She faces continuing health complications, and her current physicians suggest that the complications could warrant a case of medical malpractice. Under the Personal Health Information Protection Act (PHIPA), she has the right to request information from the provider (Information and Privacy Commissioner of Ontario, 2019)—the issue is she does not know who that would be. She does not have any precise information about the nature, reason, or physical location for a surgery she had as a young child; she is therefore unable to initiate a malpractice investigation. At the time of her surgery, a child welfare agency was her legal guardian. They are the only ones who have access to her private health information. They refuse to grant her access, preventing her knowledge of personal health history and her ability to self-advocate with regard to subsequent health-related interventions. The agency's refusal is within its legal rights given that in Ontario, Children's Aid Societies are private not-for-profit organisations with special designated powers to apprehend and manage the care of children under the provincial child welfare legislation. Her file is considered a business file and the property of the agency. The only remedial action is to lodge a complaint in civil court.

CASE 2: ACCESS TO SUPPORTS.

Formerly protected under a voluntary care agreement and a custody order during early adolescence, a young person discovered at age 16 she was ineligible for continued financial supports from the Children's Aid Society formerly responsible for her care. This discovery was made through lengthy work with a child advocate, where she learned her ineligibility for support was due to a temporary return to the care of her father (at 15 years of age), the absence of a Crown Wardship order, and the specific nature of her custody order. This ineligibility goes on to shape years of housing precarity and undue stress throughout adolescence, as the young person must juggle school and full-time work.

At 18 years of age, the young person is taken to court by their child welfare agency in order to terminate the custody and care order, meaning the order remained open throughout her adolescence despite not receiving financial supports during this time. The termination of the order means she will be ineligible for financial supports for post-secondary participation. The young person requests to review their own file (in this case, for evidence that they may have been mis-serviced or poorly informed and/or to find information that would prove their eligibility for supports). The child welfare agency refuses access, and the youth is left with no information that can prove their status or history of involvement in the child welfare system.

CASE 3: LEGAL IDENTIFICATION.

A former youth in care was brought to Canada by his biological parents as a child refugee. Shortly thereafter, he is removed from the care of his parents and placed into a Children's Aid Society's care as a Crown Ward. Although he was serviced by his agency throughout his childhood, he does not become a permanent resident of Canada while in state care. At 16 years of age, the Society terminates his Wardship Order through the courts. When he seeks to access social assistance, he realizes he has no permanent status in Canada. He has no official documentation needed to access social services (e.g. shelters, welfare programs, health services), nor to begin the process of seeking Canadian Citizenship. He asks his agency for assistance and information from his file that would provide him with eligibility for these services and they tell him his file is "closed". He lives at a homeless shelter (which receives no per diem funding from the government for his service use) until he is able to begin the arduous process of securing the legal documentation required to establish permanent residency.

CASE 4: ACCESS TO A YOUNG PERSON'S PRE-SENTENCING REPORT (R V ZW)

The examples highlighted in the previous cases denote challenges young people face when attempting to access their own records. During our review of legislation, we attempted to find a legal precedent to complement the anecdotal cases of the challenges young people faced while trying to gain access to their information. We were not able to locate a single case of a young person successfully receiving access to their information through a court proceeding. This is unsurprising given the immense financial and structural resources needed to pursue a court challenge. However, we located a case (R v ZW, 2016) in which the barriers faced by young people, that prevent them from pursuing a court challenge, at the same time pave the way for institutions

or individuals with more resources to take advantage of these legal loopholes. This starkly highlights the implications of personal information management policies and practices that are not guided by a human rights-centric approach, and therefore in default protect the rights and interests of institutions over those who the institutions have a duty to protect.

Confoundingly, we did find a case where a social worker was granted access to a young person's file in order to advance a legal case against the society. In *R v ZW* a former social worker was attempting to seek damages from her former employer at a residential youth centre, citing violence on the part of one young person at the centre. The social worker wanted to gain access to the young person's child protection file which contained various sensitive documents (such as sentencing reports, psychological assessments) in order to build a case about the young person, as someone with a history of violent behavioral issues. When she was not granted access through formal processes, she entered into civil proceedings and was ultimately successful in gaining access to information about the young person that would assist with her lawsuit. In this case, the social worker was able to access a young person's personal file, even though these files are consistently denied to the young people whose lives and histories they are meant to represent.

CASE 5: RACE-BASED DATA.

The collection and analysis of race-based data brought to light the disproportional representation of Indigenous and Black children in care. However, the collection and disaggregation of race-based data has only recently been pursued by governments and child protection agencies – in response to concerted efforts of activists. In 2015, the Toronto Children's Aid Society released race-based data, revealing that 30 per cent of children and youth in their care were Black – even though Black children and youth only comprise 8.5 per cent of the city's population (Children's Aid Society of Toronto, 2015). In light of this information, communities were better equipped to advocate for child welfare reforms, including education on anti-black racism and equitable social work practices (Balkisoon, 2018).

In December 2017, the Ontario Ministry of Children and Youth Services mandated all Children's Aid Societies to collect this information (Ministry of Children and Youth Services, 2017). Despite this mandate, an April 2018 report by the Ontario Human Rights Commission (OHRC) revealed that race-based data collection processes and

practices are a patchwork across Ontario, with little reliable, provincially consistent data about the overrepresentation of Indigenous and Black youth. The OHRC has noted that gaps in data collection undermine the impetus among Children's Aid Societies to: proactively address human rights concerns; measure the progress of equity-based initiatives; and build trust with communities and stakeholders who are concerned about racial disparities in the child welfare system. Further, lack of data also reduces the child welfare agencies' exposure to possible legal action and human rights complaints stemming from discriminatory practices (Ontario Human Rights Commission, 2018). A custodial rights-based approach to data collection and analysis would streamline data collection and analysis practices across Canadian provinces and territories, enabling better monitoring of human rights violations and promising legislative and programmatic reforms to address systemic inequalities.

Individual use-case summary

The cases illuminate concrete instances where access to one's own information would have enabled timely access to medical, housing, legal, and other services. Sustained and safe transitions from state care should be housing-led, while recognizing that housing is only one aspect of a complex array of supports a young person leaving care may need (e.g., they may also require supports to navigate health, immigration, or post-secondary education systems). The last case suggests ways that actualizing custodial rights to administrative data would enable ongoing monitoring of systemic inequities shaped by state services. Furthermore, where individual young people or their advocates suspect that a violation of their rights has occurred, the administrative case file contains the information they and their legal advocates required to pursue a just outcome.

Although navigating institutional systems as an independent young person is always immensely challenging, these cases illustrate the added barriers young people face when they are denied access to personal information. Enabling a rights-based approach to administrative data use is uniquely important in child welfare. Unlike other sectors, youth are dependent on the child welfare agency designated by the state to function as the young person's official guardian. Where the same agencies responsible for the protection and care of children and youth deny them access to vital information they need to survive (Nova Scotia Freedom of Information & Protection of Privacy Review Officer, 2014), the state has failed to protect young people's human and other legal rights. Beyond the material implications, young people end up growing

up without crucial information about their lives – whether it be questions about why they were brought into care; the history of their biological family; or whether they were treated fairly while in state care. Records held by the various organisations may fill gaps in knowledge and verify memory, enable access to essential services, promote independence, and support identity and connection to family.

In addition to individual-uses of administrative data, it is important to consider structural mechanisms for collecting, managing, and using data to monitor and improve within- and post-care outcomes for youth. We include four structural cases below. The first two show examples of child protection infrastructure designed to centralize and use data for decision making. Next are two examples of promising approaches to targeted data use in the youth justice system and a rights-based shared decision-making platform for youth. The four cases illuminate possibilities and pitfalls in government data collection, management, and use practices, particularly pertaining to the importance of data security and privacy protocols (Cases 1 and 3) and person-centred approaches (Cases 2 and 4).

Structural use-cases: The possibilities and pitfalls of government data collection and use

CASE 1: THE ONTARIO CHILD PROTECTION INFORMATION NETWORK.

In 2010, Ontario rolled out a five-year plan to implement the Child Protection Information Network (CPIN)—a single provincewide information system to be used by all Children's Aid Societies and the Ministry for case management, financial management, document management, and reporting. However, the implementation of CPIN has raised important concerns about security, personal rights, and privacy.

In 2017, 15 of the 48 Ontario Children's Aid Society agencies were using CPIN, there were 22 reported security breaches among them in the same year (Isai, 2017). In the case of CPIN, security breaches are further exacerbated by the fact that data housed on CPIN—though owned by the Ministry—is hosted by the individual agencies. This leaves the ministry with no oversight and enables agencies to create and adhere to their own set of privacy standards, and report breaches in security where they see fit. This approach undermines cross-system alignment and risk-mitigation.

Furthermore, the lack of accountability mechanisms surrounding CPIN pave the way

for violations of individual privacy rights. CPIN contains detailed personal information about many of Canada's most vulnerable children and youth. As a result of lax security measures, pertaining to embedded access protocols across the system, any person with access to the CPIN database can view the records of any child or youth whose information is housed on CPIN (Office of the Auditor General of Ontario, 2015) without having to make a formal request for access and demonstrate a warrantable reason for the search. This general scope of access is strikingly different from similar systems in other sectors such as health and criminal justice, where accessing client information is heavily regulated and monitored. In sum, the CPIN database suggests promising opportunities in terms of documentation practices, information sharing, and interoperability of data between different agencies. Unfortunately, it presents a structure that has been implemented without adequate considerations for the personal information rights of children and youth as well as security measures in the current information technology landscape. The risks thus outweigh the opportunities at this point in time.

CASE 2: ALLEGHENY COUNTY OFFICE OF CHILDREN, YOUTH AND FAMILIES (CYF).

In order to improve service outcomes and reduce caseloads, the Allegheny County CYF in Pennsylvania utilizes administrative data, demographic data, and program statistics to predict child abuse and neglect. This data is contained in the Key Information and Demographics System (KIDS), as well as the Allegheny Family Screening Tool (AFST). The AFST is a risk-assessment tool, built from mining the data stored in the Department of Human Services (DHS) Data Warehouse. Like all risk-assessment tools, AFST assesses the degree to which particular patterns in a dataset are a function of chance or not. These tools are useful for making population-level predictions, but should be used with caution in making individual-level predictions as there is simply too much variability. (de Haan & Connolly, 2014; Gillingham, 2016; Gillingham & Graham, 2017; Keddell, 2014; van der Put, Assink, & van Solinge, 2017). As such, AFST is supposed to support service-provider decision-making alongside a range of other tools (e.g., all of the information in KIDS). In reality, however, service providers began to increasingly rely on the AFST scores to make decisions about whether to open a child protection case or not (Eubanks, 2018).

Unfortunately, while useful as part of a screening process, the AFST has been found to have limited reliability as a predictive tool. Because of insufficient available data, the

model actually predicts referrals to the local child abuse and neglect hotline and child removals rather than child abuse. The referral data are proxy variables meant to stand in for the actual outcome the agency is seeking to prevent (i.e., child abuse). Further, the DHS data warehouse only contains data about people who utilize state services ("DHS Data Warehouse – Allegheny County Analytics: Reports, Visualizations and Datasets," 2018), and these are people more likely to be living in poverty than those in the general population. In sum, the model has proven only moderately accurate, routinely failing to predict harm at the individual level, and disproportionately targeting people living in poverty. It is an example of a government-centred, rather than person-centred approach to data collection and use in human service organisations.

CASE 3: JUSTICE DATA LAB – TARGETED CIVIL SECTOR ACCESS TO GOVERNMENT DATA.

The Justice Data Lab (JDL) is a unit within the United Kingdom Ministry of Justice (MoJ) able to provide secure access to reoffending administrative data to social service and civil society organisations for impact evaluation. The data used in the JDL are housed by the MoJ. Due to the sensitivity of justice data, organisations are required to provide the MoJ with the personal information of at least 60 offenders they are working with as well as the intervention they are attempting to evaluate. The JDL then matches the personal information details to the reoffending datasets held within the MoJ and uses statistical modelling to generate a matched comparison group with comparable demographics and employment, criminal justice, and social service utilization information. The JDL further provides organisations with a comparative analysis of the reoffending groups to assist them with their impact evaluations. This analysis is then also published on the MoJ's website for transparency ("Accessing the Justice Data Lab service," 2018; Gyateng, 2017; Lyon et al., 2015).

The JDL is an example of a data-sharing model that incorporates consideration of benefits and implications for organisations, government, researchers, and service users. It makes data accessible to organisations who would not otherwise have access, provides statistical analysis services, and makes clear the limits of analysis. In sum, the JDL data lab example provides both infrastructural and technical expertise, combined with stringent legislative requirements, to ensure the safety and security of individual level data. The JDL model has been replicated among other sectors and is gaining traction in various jurisdictions.

CASE 4: THINK OF US - A PROMISING DATA DASHBOARD APPROACH.

Think of Us is a small non-profit started by a former foster youth that aims to provide technology to assist youth in their transition out of care. Stemming from a White House Hackathon on Foster Care and Technology, Think of Us partnered with Box.com (a Health Insurance Portability and Accountability Act [HIPPA] compliant cloud storage service) to create a “digital locker” to house important documents that young people need as well as case management features to log items such as doctor’s appointments. Agencies would release information to individuals and assist them with their own case management, thus, encouraging “ownership” of information to be with the young person. While not appropriate for large scale data-linking, this platform provides a simple solution to help improve access and ownership of personal information as well as continuity of care and documentation between placements and across sectors (Brindley, Heyes, & Booker, 2018; “Hacking Foster Care at Box,” 2018; “Our Work on the Ground,” 2018).



DISCUSSION

Moving towards data-led governance in Canada – the importance of individual and custodial rights

Individual rights to access and privacy must be balanced by concerns for collective wellbeing and the assurance of human rights protection for all young people. Data must be made available in order to monitor systems-level youth outcomes; identify systemic inequities and structural drivers of inequality; and enable continuous quality improvement efforts within the system.

Currently, independent academic research provides the main avenue for tracking systemic inequities. To do so, academic researchers design, fund, and implement large-scale survey research studies. This approach is unnecessarily expensive and time-consuming, especially since public sector institutions have themselves been developing and implementing systems for systematically generating and storing personal information about public service use and outcomes (e.g., frequency of serious occurrences filed for youth in care). This approach also makes it difficult to track outcomes longitudinally and assess whether and how particular interventions are having positive effects on youth wellbeing. Furthermore, beyond tracking statistical trends (e.g., service use/outcome disparities), other data are needed to enable a systematic investigation of the conditions surrounding the patterns of systemic exclusion and neglect revealed through statistical research.

As we outlined earlier in this brief, administrative data refers to records and client information held by government and social services for operational purposes. Administrative data cannot be released as open data, however these data can be aggregated and anonymized for research and monitoring purposes. Systematic reviews of administrative (or case file) data would allow for ongoing assessments of the policy, practice, and programmatic conditions that give shape to particular statistical trends. Administrative data can also enable cross-sector monitoring and integrated service delivery. Because young people in state care already experience more intensive institutional monitoring than young people in the general population, efforts to enable cross-sector monitoring must be approached cautiously.

Administrative data should only be shared when supported by a strong rights-based framework, which ensures that young people:

1. Have access to their case file data;
2. Can review the information and confirm that it accurately conveys their experiences in care; and
3. Consent to having their data shared.

When these conditions have been met, administrative data can be shared or linked between service providers or sectors in order to monitor the degree to which an intervention in one sector (e.g., education) has impacts on outcomes in another sector (e.g., youth criminal justice). Administrative data can be anonymized and aggregated in order to track general trends across systems (e.g., tracking the high school credit accrual rates for current and former youth in care). Mechanisms for tracking the outcomes of an intervention can also be tracked on a case by case basis using individual client data. In the latter scenario, individual organisations or government agencies may gain access to service data for their clients in another sector (e.g., child welfare organisations can use data from the youth criminal justice system in order to track the recidivism rates for the youth they serve).

Data interoperability in social services is indeed a new foray to ameliorate the fragmented systems that currently exist, especially in the case of child protection where intersectoral, intergovernmental, and interagency collaboration are vital. However, in order to ensure that these are structured and delivered in the best interests of young people, we must change current policies and mechanisms to reaffirm notions of personal agency, safety, and privacy to protect against data being used in a manner which may exacerbate social inequities. A cross-systems participatory governance approach to managing administrative data is recommended, and above all ensuring the rights of young people to advocate for themselves and navigate the complexity of their situations in and out of the child protection system.



CALL TO ACTION

In contrast to other sectors such as healthcare, existing child welfare legislation in Canada lacks a rights-based approach to privacy and the distribution of personal information. This makes the transition from care extremely difficult for youth as they might not be able to access vital information about their history and as well as personal documents needed to access services. Young people are left without answers to important questions about their identity and the decisions made about them while they were in the child welfare system. This brief has highlighted the importance of a rights-based approach to governing access to and use of administrative data. This brief lays out overarching recommendations to protect both individual rights and improve custodial access to information. We also lay out key mechanisms that enable these rights, namely, legislation and information technology infrastructure.

Recommendations for Provincial and Territorial Governments

- Protect and enshrine via legislation children and youth's rights to access their personal information at the level of corresponding personal health information
- Enable and convey transparent, timely, and accessible pathways for children and youth and former youth in care to access their personal information
- Enable and protect individual rights to annotate and/or correct personal information and administrative case file data (e.g., the OpenNote system for shared e-health record-keeping that has been successfully piloted in the US)
- Standardise and communicate recordkeeping practices vis-a-vis retention time; if and when a record is destroyed or sealed, the individual must be notified and pathways to access conveyed
- Establish a third-party intervener in dispute cases regarding accuracy of information
- Ensure standards and mechanisms for upholding data security and privacy when implementing electronic data management infrastructure
- Establish a governance and operational framework and privacy standards for sharing and integration of data sets across organisations contributing to a circle of care for youth in and leaving state care
- Ensure consistent oversight, including capacity-building and organisational supports among individual CAS organisations to ensure compliance with legislation

Recommendations for the Government of Canada

- Ratify Bill C-441 *An Act respecting the Office of the Commissioner for Young Persons in Canada*, in line with Canada's obligations under the United Nation Convention on the Rights of the Child
 - » Task the new federal Commissioner for Children and Youth to convene and oversee national strategy to harmonize a rights-based approach to child protection services and data management across provinces and territories
 - » Structure standing reporting and liaison between Office of the Commissioner and the Canadian Council of Child and Youth Rights Advocates to strengthen oversight and advocacy across provinces and territories
 - » Mandate and resource the Canadian Council of Provincial Child and Youth Advocates, working with the Canadian Coalition for the Rights of Children and Youth in Care Canada, to write summary national annual report based on provincial and territorial report cards to monitor the rights and wellbeing of young people in and exiting care across Canada
- Develop and maintain useable and secure infrastructure for data integration across respective service areas (e.g., child welfare, education, youth justice and health) that cut across provincial and federal jurisdiction
- Establish and empower prescribed provincial and territorial entities (e.g., Child and Youth Data Commissions that sit outside any provincial or territorial Ministry), which will serve as cross-sectoral child and youth data custodians (e.g., education, youth justice, child welfare, and child and youth health - including mental health)
- Ensure custodial rights and pathways to access child and youth data for research purposes (e.g., research to identify and monitor systemic inequalities; cross provincial comparisons of child welfare outcomes) and systems improvements



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