



**Calgary Thrives /SAGE Collaborative
Data Partnership**

Final Report

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Submitted from: PolicyWise for Children & Families

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It is with thanks we acknowledge the many individuals and organizations who have contributed their wisdom, experience and perspectives to this project.

Sharing Guidelines

It is the hope of all those who contributed to this project that these findings are shared and used to benefit others and inform policy and practice to improve child, family and community well-being. PolicyWise asks the intent and quality of the work is retained; therefore, PolicyWise for Children & Families must be acknowledged in the following ways:

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In 2012, Calgary Thrives, established by the Centre for Child Wellbeing (CCWB), outlined the feasibility and importance of sharing data across community serving agencies to better inform service delivery. The Calgary Thrives collaborative partnership subsequently piloted a process for sharing aggregate data across diverse organizations and a number of barriers were identified. In January 2018, the Calgary Foundation supported a new initiative aimed at addressing many of these barriers as well as moving the potential for data sharing further. The current project made significant inroads in engaging and building trust with participating organizations. This newest initiative also served to mitigate many of the legal/ethical/privacy issues that hindered the pilot. Strong collaborative ties and relationships were built, and agencies were able to trust that their data was being handled appropriately and confidentially and were therefore more comfortable sharing it. An initial attempt to link individual-level data at a basic level also proved successful. This project was funded for one year with an extension granted (using excess funds) until June 30, 2018. This final report expands on the accomplishments across this time period.

In collaboration with Calgary Thrives and select organizations/initiatives, we addressed the following as deliverables:

- Devise implementation strategies for addressing legal/ethical/privacy barriers for sharing data at various levels.
- Investigate the potential for data linkage and matching at the individual level.
- Discover common meaningful indicators/predictors of poverty in the existing data sets for each of the contributing organizations.
- Demonstrate the value of sharing data related to common indicators across agencies.
- Gain intelligence regarding service use patterns, service overlap between programs, and outcome trajectories of clients where supported by data.
- Use linked, individual-level data (if possible) across multiple agencies.

The first two deliverables were reported on in the Interim Report submitted on June 30, 2017. Further progress on these two as well as the last four deliverables were addressed from July 2017 to June 30, 2018, and are all reported here.

1) Outcomes and Impact:

- a) This initiative was designed as a collaborative effort between PolicyWise for Children & Families (PolicyWise) and the CCWB at Mt. Royal University. Six agencies from the Calgary Thrives initiative, that self-identified as “data-ready” and served populations experiencing poverty in diverse ways (Food Bank, Families Matter, South West Community Resource Centre, Calgary Counselling Centre, Sunrise Community Link Resource Centre and the Calgary Urban Project Society (CUPS)) were involved in the project.
- b) The project team was aware that many organizations and people were looking at data collection from many different perspectives. We connected with a number of these projects to ensure that there was no duplication of effort and also to work together to align processes and learnings. For example, we met regularly with Geoff Zakaib and Ivan Sierrelta from the Catalyst funded “Enabling Data Sharing for Enough for All Evaluation Framework” initiative and, also connected with Derek Cook and Rita Yembilah from the Canadian Poverty Institute at Ambrose University. We all kept one another apprised of our learnings as we moved through our various projects.

- c) The Canadian Poverty Institute published a definition of child poverty that looks beyond income and material capital to measure an individual's well-being (Appendix A). Other factors were identified, each correlated with well-being, including relationships with oneself, relationship with others, and structural capital. Our project adopted this definition of child poverty to put context around the data collection.
- d) A modified Delphi approach was used to categorize and connect the data from the organizations with the Ambrose definition. A meeting was held with 2 outside participants in November and another meeting in December with all the participating agencies looking at these factors and determining what might work with the current agencies' data. While the agency data itself had hundreds of items potentially able to speak to these facets, attention was focused on three factors. The identified factors were monthly income, substance abuse, and family violence. An attempt was made to find interactions amongst these factors across agencies. As expected, the data showed that poverty is not defined by a single dimension but has attendant factors that limit an individual's ability to move forward, such as family violence and/or substance abuse. These data also painted a picture of each agencies client base that could be shared across agencies, including income brackets and prevalence of other issues. Maps were created showing these measures' general distribution across the city of Calgary.
- e) The quality of the agencies' extracted data identified where capacity could be further developed within certain agencies. This information further catalyzed agencies' willingness to improve upon their data collection practices and look at ways to build future data capacity.
- f) Legal, ethical, and privacy-related barriers were identified in the first Calgary Thrives initiative as a primary barrier for sharing data across organizations. In response to this, as well as to other research-related concerns, PolicyWise through the SAGE initiative, collaborated in the preparation of a report (Kiran Manhas, 2017) specifically focused on this issue (*Law & Governance of Secondary Data Use: Obligations of Not-for-Profit Organizations in Alberta*). Preliminary findings were presented on April 26, 2017 to the Calgary Thrives/SAGE Collaborative Data Partnership and on June 29, 2017 to the broader Calgary Thrives organizations. The full report can be found on the PolicyWise website @ <https://policywise.com/wp-content/uploads/2017/08/LAW-GOVERNANCE-OF-SECONDARY-DATA-USE.pdf>. The executive summary (See Appendix B), contains a summary of the key findings from the Manhas (2017) report.
- g) The ethical considerations of consent were also addressed. Most agencies have an explicit signed consent process as part of intake. This consent process relates to the sharing of personal information for services or for research. Some agencies have no consent process but instead rely on implied consent. However, regardless of the process, all agencies can be regarded as stewards of their own data. Non-explicit (implied) consent can limit data sharing. Generally, signed consent may allow data sharing within certain parameters. A meeting (November 10th, 2017) was arranged with Don Flaming from A pRoject Ethics Community Consensus Initiative (ARECCI) and the participating agencies, to provide an expert perspective on ethics as it pertains to the analysis of data from community organizations for evaluation and research purposes. ARECCI provides review and advice to research and evaluation projects that do not fall under legislated requirements for ethical review. Agencies found this very helpful in understanding their legal and ethical considerations regarding sharing data.
- h) Data Stewardship agreements (between the agency and PolicyWise) were executed with CUPS, Calgary Counselling Centre and South West Community Resource Centre, to transfer detailed

data assets to support analysis of the poverty indicators, and analysis of client overlaps between organizations.

- i) The Calgary Thrives/SAGE project represented a proof of concept for LinkWise: a privacy preserving record linkage application developed by PolicyWise. LinkWise links individuals from different agencies' data sources without revealing their identity. Instead of using actual names and other identifying information, LinkWise creates scrambled identifiers from personal information. These identifiers are a series of random characters and are near impossible to reverse engineer. Using the scrambled identifiers from each dataset we can compare which identifiers appear in more than one dataset and infer that services were offered for that individual for each of those agencies.

The results of the linkage exercise showed that there were many clients of CUPS and Calgary Counselling Centre who had also accessed the Calgary Food Bank at some point. Of course, in and of itself, this is not a startling finding. However, the way this finding was derived was wholly unique. Not only was this done entirely anonymously, but these links were made between agencies which had independently collected these data. No attempt was made to harmonize the data prior to linkage and no contact between agencies was required to successfully link data.

This underscores the advantages of data sharing amongst agencies. Future collaborations, using this methodology, have the potential to better address the needs of client populations.

- j) Participating in the poverty indicator analysis was a catalyst to build capacity within at least one agency. From the early stages of the project, this agency was deemed to have technical challenges that would preclude them from sharing data. However, this belies the fact that, in the past, this agency had put a lot of effort into collecting data with very complex, enterprise-scale tools. Unfortunately these tools were difficult to use. Due to a loss of corporate memory around these complex systems their data collection efforts had stalled. The data sharing exercise was incentive for them to build capacity to extract maximum information from these systems. It also served as a further catalyst for them to revise their intake processes and adopt a new data collection system.

2) Impact:

- a) This project allowed agencies to learn from each other through sharing of information. Data bases were discussed as were consent forms and general learnings about data collection. Agencies are beginning to trust the process of data collection while simultaneously providing safety to their clients. This increased sense of security results in agencies being more willing to continue to find ways to share data in meaningful ways.

3) Sustainability:

- a) All agencies remain interested and committed to this project. They are beginning to embrace the advantages of sharing data at an individual level. Additionally, PolicyWise remains committed to be the repository for the data that is collected. Further funding will be sought to move this initiative to a place where organizations will have the capacity to provide their data to PolicyWise for linking and analysis. PolicyWise will continue to work on capacity with one or more of the smaller participating agencies to create an efficient, inexpensive way of handling intake data. The goal will be to create a more user-friendly interface which will streamline data collection.

- 4) Learning:
- a. Capacity continues to be a barrier for many organizations. Data collection takes time, money, and resources of which many organizations have too little. Many agencies also experience time restraints at different times of the year, when their service to clients must take priority (e.g. the Christmas holiday season) or to funders (year-end), limiting times when this type of data sharing/linking can be a priority for them. Getting back to the agency with substantial technical issues, there has already been further incentive to refine intake processes and work with simpler, less expensive software. There is the intent to extend their efforts to other small community-based agencies and collaboratively build a better intake system. Implicit in this will be the ability to seamlessly share data amongst them. Furthermore, data collection and curation need not be done with expensive proprietary software packages. By focusing on data quality, using clear protocols, and implementing good governance agencies can fully harness their data using relatively simple and inexpensive software.
 - b. This project was a catalyst not only for the participating agencies, but also for the agencies involved in the larger Calgary Thrives initiative. While this project's poverty indicator may not be complex it was enough to build curiosity and commitment within the greater Calgary Thrives group. There is currently a larger group of agencies that wish to further explore dimensions of poverty within their data and link to other agencies' databases. There is also a collective desire to look beyond immediate challenges within agencies' client bases and to focus on protective and resilience factors. For example, agencies want to know: what sort of service clusters are within the data? Or how do we work together to move beyond providing remedial services and build better futures for clients?
 - c. When agencies' data is siloed there are myriad missed opportunities. Not only can agencies share learnings about their clients' presenting issues but they can also learn better ways of collecting and handling data that would benefit their clients directly. However, building better collection tools should not be done in isolation; many agencies have expended countless resources, duplicating effort time and again.
- 5) Recognition: The International Population Data Linkage Network (IPDLN) will be having its bi-annual conference in Banff, Alberta in September 2018. The results of this project will be presented at this conference in a presentation entitled **Calgary Thrives: Data sharing and linkage in the not for profit sector**. This presentation will have a particular focus on the overall linkage of clients amongst the participating agencies. The Calgary Foundation will be the recognized funder of this presentation.

Calgary Thrives/SAGE Data Sharing



Calgary Thrives Project: January 2017 – June 2018

POLICYWISE FOR CHILDREN & FAMILIES

6) Appendices:

A: Rights, Capabilities and Obligations: New Perspective on Child Poverty in Calgary. Executive Summary

In 2016, the Canadian Poverty Institute began an investigation into child poverty in the city of Calgary. The project was mandated to develop a multidimensional definition of child poverty and to measure the alignment between the new definition of child poverty and current practice in the city as a conduit to informing practice. Phase I consisted of a scan of socio-economic policy to determine what implicit and explicit definition(s) of child poverty guide decision-making and programming. In Phase II, the objective was to work with diverse stakeholders to develop a multidimensional definition of child poverty. The objective in Phase III was to assess the alignment of the new definition of child poverty with current policies and practices, after which a pilot phase will be launched. Phase II, which ushered in the active field research phase, commenced with two workshops to harness the collective insight of service providers, parents and other stakeholders. Information from the workshops was treated as data and also used to produce interview guides for the field research. The research was framed through the child rights, intersectionality and capabilities lenses. The child rights framework drew on the Convention on the Rights of the Child, its associated indivisibility of rights, and the fact that, as per the convention, childhood is entitled to special care and protection to keep the focus on the societal obligation to children. The intersectional framework emphasized the convergence of situations that produce a child's living circumstances, whilst the capabilities framework was used to identify the individual and societal factors that enhance or inhibit a child's ability to live an enriched childhood. Interviews were held with 37 study respondents including children (12-17 years), families, service providers and adults with a lived experience of poverty. The interviews sought insights into participant's conceptualizations of child poverty and wellbeing, their choices, frustrations, communities, and, among others, their ability to meet survival needs. Transcribed data was analysed using narratives and thematically. Preliminarily, five themes emerged from the data: ideas of poverty, parenting and parental resourcefulness, identity and belonging, system connections to poverty and child resiliency. Out of the preliminary themes, 4 higher level, commonly occurring themes, were extracted as key areas for deriving a multidimensional definition of child poverty. These 4 higher level themes were then framed around the idea of "capital" to derive Standard of Living, Child Self-Perception, Structural and Child Relationship Capital. Each of these capitals was envisioned as a range between endowment and deprivation and mapped as matrices, mapping standard of living capital to the other three types of capital to derive various types and intensities of child poverty. Subsequently, five scenarios of child poverty have been delineated—Child Self-perception Poverty, Structural Capital Child Poverty, Relationship Capital Child Poverty, Standard of Living Child Poverty and Multidimensional Absolute Child Poverty. Mapped as a Venn diagram, Multidimensional Absolute Child Poverty is defined as the convergence of disadvantage in all four capitals. Conversely, where a child is attaining highly in all four capitals, they may be described as being multidimensional non-poor. This definition was then assessed for its alignment with socio-economic policy and key programs for children and families in

Calgary. It was found that such an expansion of the definition of child poverty has implications for both policy and practice, particularly regarding funding, assessment of service provision and as a tool for identifying the particular needs of families and children.

B: Law & Governance of Secondary Data Use: Obligations of Not-for-Profit Organizations in Alberta. Executive Summary

The data-driven nature of society today involves the collection of significant, if not copious, amounts of information with the aims to share and re-use that data beyond the original purposes at collection. Not-for-profit organizations and registered charities (collectively, “NFPs”) are beginning to recognize the value of, and opportunities within, data especially in the social services sector. This paper presents the legal and governance issues for, and obligations of, NFPs when trying to harness a particular data-focused opportunity: the sharing and re-use of information beyond the service delivery directing collection.

When personal information or personal health information is collected, handled, used or disclosed, privacy concerns arise and privacy legislation could be invoked. In Alberta, the three privacy-related statutes are PIPA, the Health Information Act (HIA), and the Freedom of Information and Protection of Privacy Act (FOIP). This paper details when each of these laws could apply for a NFP, as well as the best practices dictated by these laws. Those best practices centre around ensuring reasonableness in the purposes for identifying information collection, use and disclosure; exacting minimalist standards on information use and disclosure; and ensuring the connection, unless legally exempt, between purposes and consent from the individuals whom the information is about. The legal interpretations of reasonableness, use and disclosure are key to understanding privacy expectations of NFPs. This paper analyzes these interpretations from the Office of the Information and Privacy Commissioner of Alberta orders from 2012-2017.

With respect to secondary use of data, intellectual property laws especially copyright and governance expectations around research-related secondary use are considered as they apply to NFPs. Copyright licenses represent one potential, but not always applicable, forum. Copyright protects the expression of an idea, not the raw facts or data in that idea: so when sharing information at the variable-level copyright may not apply outside of the data layout. Nonetheless, in theory and in practice by one NFP, open or managed licensing agreements offer a mode of clarifying rights and obligations while making information available for secondary use. Research ethics board are a critical legal tool in the secondary use of health information in Alberta. They also act as an important safeguard for NFPs when attempting to manage access to data, as demonstrated by the *Medicins Sans Frontiere* data sharing policy.

NFPs currently fall into several legislative gaps with respect to secondary use of data including identifying information. For example, privacy laws do not apply to duly incorporated NFPs carrying out non-commercial activities, and research ethics boards are not obliged to review the planned secondary uses of data by NFPs if there is neither university affiliation nor health information involved. Nevertheless, best practices around data governance and privacy protection abound. Societal expectations, ethical practices, and conservative business approaches all demand that NFPs

approach the secondary use of data from a legal and governance perspective. Such a perspective demands the development of a data and privacy policy. Such a policy should be formatted to include a vision statement that clearly links to recognized legal requirements and international Fair Information principles, and which details the NFP's expectations around the goals of data sharing and the tensions to balance. The content of the policy should then describe the safeguards in place, the access processes required for secondary use, and the monitoring processes for compliance.

Prioritization of consent, "need to know" directives, and reasonableness would promote compliance with privacy laws. Roles and tasks could be enumerated to promote effective implementation.