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# Issue 1: “It’s Better Late Than Never”: A Community-Based HIV Research and Training Response to Supporting Mothers Living with HIV Who Have Child Welfare Involvement (Part I)

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# Issue 1: “It’s Better Late Than Never”: A Community-Based HIV Research and Training Response to Supporting Mothers Living with HIV Who Have Child Welfare Involvement (Part I)

## **Authors**

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## ***"It's Better Late Than Never": A Community-Based HIV Research and Training Response to Supporting Mothers Living with HIV Who Have Child Welfare Involvement***

SAARA GREENE, ALLYSON ION, GARY DUMBRILL, DOE O'BRIEN TEENGs, KERRIGAN BEAVER, MARY-ELIZABETH VACCARO\*

Le projet *Positive Parenting Pilot Project (P4)*, qui repose sur des principes de recherche communautaire et un cadre d'analyse anti-oppression, est destiné à créer, à mettre en œuvre et à évaluer un module d'éducation et de formation sur le VIH. Ce module vise à améliorer le soutien offert aux familles affectées par le VIH qui risquent l'intervention des services de protection de l'enfance ou font déjà l'objet de ce type d'intervention. Pour renforcer la capacité des sociétés d'aide à l'enfance (SAE) en Ontario d'offrir des services respectant une analyse anti-oppression aux familles affectées par le VIH de diverses communautés, nous avons entrepris d'augmenter la capacité des travailleuses et des travailleurs sociaux qui soutiennent ces familles. En appliquant les principes de la recherche communautaire, nous avons communiqué davantage avec les SAE et forgé de nouvelles relations de collaboration entre celles-ci, ainsi qu'entre les SAE et le secteur des services aux personnes vivant avec le VIH, les parents qui vivent avec le VIH et les universitaires, afin de mieux répondre aux besoins des familles sur les plans sociétal et structurel. L'objectif de ce projet était d'élaborer, d'offrir et d'évaluer un cadre d'analyse permettant d'élaborer un module d'éducation et de formation anti-oppression tenant compte des multiples couches d'oppression que subissent les familles vivant avec le VIH, notamment la discrimination et la stigmatisation liées au VIH, le racisme, le sexisme, la violence et la pauvreté. Cet article présente l'analyse qualitative des groupes de discussions avec les travailleuses et les travailleurs des SAE avant et après leur participation au projet *P4* et les effets des pratiques émergentes sur le travail auprès des familles qui vivent avec le VIH ou en sont affectées.

Grounded in community-based research (CBR) principles and an anti-oppression framework, the Positive Parenting Pilot Project (P4) aimed to develop, implement, and evaluate an HIV education and training module to enhance the provision of support for families affected by HIV and who are at risk of or already involved with child protection services. We set out to strengthen the ability of Children's Aid Societies (CAS) in Ontario to provide anti-oppressive services to families affected by HIV from diverse communities by increasing the capacity of social workers who support these families. Applying the principles of CBR, we increased communication and forged new

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collaborative relationships within and between CAS agencies, the HIV service sector, parents living with HIV, and researchers in order to better address family needs at societal and structural levels. The goal of this project was to develop, provide, and evaluate a framework for an anti-oppressive education and training module related to the multiple layers of oppression that are experienced by families living with HIV including HIV-related stigma and discrimination, racism, sexism, violence and poverty. This paper presents the qualitative analysis of pre- and post- focus groups with CAS workers who participated in P4 and the emerging practice implications for working with families living with and affected by HIV.

OVER THE PAST DECADE, WOMEN HAVE ACCOUNTED for approximately 25% of people living with HIV in Canada.<sup>1</sup> In 2014, 16,880 adult women were living with HIV in Canada,<sup>2</sup> with 5,100 to 8,000 residing in Ontario.<sup>3</sup> As of 2013, approximately 57% of women living with HIV in Ontario were from countries where HIV is endemic, the majority being African, Caribbean, and Black women.<sup>4</sup> Furthermore, Indigenous women are significantly over-represented in the Canadian epidemic, accounting for 34% and 82% of all new HIV infections among women in British Columbia and Saskatchewan respectively.<sup>5</sup> In 2011, the HIV infection rate was 3.5 times higher among Indigenous people in Canada, and is characterized by more diagnoses in younger Indigenous women.<sup>6</sup>

This paper outlines the process and findings from the Positive Parenting Pilot Project, which sought to develop and implement an HIV education and training module. The Positive Parenting Pilot Project was meant to enhance the knowledge and skills of child welfare staff and social work students when working with children and families living with and affected by HIV in Ontario. As highlighted in our community-based research approach, this project also sought to establish a dialogue between families affected by HIV and the child welfare sector in order to shape capacity building and strengthen social work practice at the intersection of HIV and child protection.

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<sup>1</sup> Centre for Communicable Diseases and Infection Control, “At a Glance – HIV and AIDS in Canada: Surveillance report to December 31<sup>st</sup>, 2012,” Public Health Agency of Canada (2012), online: <phac-aspc.gc.ca/aids-sida/publication/survreport/2012/dec/index-eng.php> [perma.cc/U52T-99MM] [Public Health Agency of Canada, “2012 Report”].

<sup>2</sup> Centre for Communicable Diseases and Infection Control, “HIV and AIDS in Canada: Surveillance report to December 31<sup>st</sup>, 2013,” Public Health Agency of Canada (2012), online: <phac-aspc.gc.ca/aids-sida/publication/survreport/2013/dec/index-eng.php> [perma.cc/CA8W-SRM6].

<sup>3</sup> “Women and HIV in Ontario: The Facts in Brief,” Ontario HIV Treatment Network (2015), online: <aidsnetwork.ca/sites/default/files/WHAI%20fact%20sheet%20-%20Women%20and%20HIV%202015%20(2).pdf> [perma.cc/7968-A94R].

<sup>4</sup> *Ibid.*

<sup>5</sup> “HIV Strategy for Saskatchewan, 2010-2014,” Saskatchewan Ministry of Health (November 2010), online: <docs.wixstatic.com/ugd/bd5940\_c6a91b826473446abf4ebaabbac4d7dc.pdf> [perma.cc/QFP3-GWSU]; “HIV Annual Report, 2014,” British Columbia Centre for Disease Control (30 November 2015), online: <bccdc.ca/resource-gallery/Documents/Statistics%20and%20Research/Statistics%20and%20Reports/STI/HIV\_Annual\_Report\_2014-FINAL.pdf> [perma.cc/6QYP-TNP4].

<sup>6</sup> “HIV/AIDS Epi Updates, Chapter 8: HIV/AIDS Among Aboriginal People in Canada, December 2014,” Public Health Agency of Canada (December 2014) at 3, 26, online: <canada.ca/en/public-health/services/hiv-aids/publications/epi-updates/chapter-8-hiv-aids-among-aboriginal-people-canada.html> [perma.cc/63TM-RZ6Z].

## I. INTERFACE BETWEEN CHILD WELFARE AND HIV

Our focus on women living with HIV is important to our research and training in the child welfare sector due to this population's high degree of child welfare involvement in Ontario. Previous research conducted in Ontario noted that 29% of women living with HIV involved in the HIV Mothering Study, an observational cohort study, were currently or had previous interactions with the child welfare system.<sup>7</sup> Of the 29% who had child welfare involvement, 55% identified as Caucasian, 32% as African, Caribbean, and Black, and 14% as Indigenous. All of the Indigenous women (n= 9) who were involved in the Families, HIV, and Housing Study had prior child welfare involvement.<sup>8</sup> In addition, 43% of the 134 children living with HIV who were followed at a regional children's hospital from 1997 to 2011 had child welfare involvement.<sup>9</sup>

Indigenous, African, Caribbean, and Black families are disproportionately involved in the Canadian child welfare system.<sup>10</sup> The overrepresentation of Indigenous mothers investigated by child welfare agencies is intimately connected to Canada's legacy of colonization, as well as the discriminatory and damaging policies that continue to inform the "protection" of Indigenous children in Canada.<sup>11</sup> Although less than 4% of the Canadian population identifies as Indigenous,<sup>12</sup> an estimated 20–80% of children and youth that live in out-of-home care including foster, group, and institutional care identify as Indigenous.<sup>13</sup> Mothers from African, Caribbean,

<sup>7</sup> Punam Khosla, Allyson Ion & Saara Greene, *Supporting Mothers in Ways that Work: A Resource Toolkit for Service Providers Working with Mothers Living with HIV* (Hamilton, ON: The HIV Mothering Study Team and the Ontario Women's HIV/AIDS Initiative, January 2016) at 24, online: <sexualhealthandrights.ca/wp-content/uploads/2016/03/SMWTW\_FINAL\_Jan2016.pdf > [perma.cc/P2WZ-4Y2T].

<sup>8</sup> Saara Greene et al, "How HIV-Positive Aboriginal Women (PAW) Talk About Their Mothering Experiences with Child and Family Services in Ontario" (2014) 8:5 J of Public Child Welfare 467 at 473 [Greene et al, "Mothering Experiences"].

<sup>9</sup> Corry Azzopardi et al, "Medical nonadherence in pediatric HIV: Psychosocial risks and intersection with the child protection system for medical neglect" (2014) 38:11 Child Abuse & Neglect 1766 at 1771.

<sup>10</sup> Marlyn Bennet & Andrea Auger, "The Rights of First Nations Children in Canada," National Collaborating Centre for Aboriginal Health (2013) at 3 <cnsa-nccah.ca/docs/health/FS-RightsFNChildren-Bennett-Auger-EN.pdf > [perma.cc/SF6L-8ZW4]; Saara Greene et al, "(M)othering with HIV: Resisting and Reconstructing Experiences of Health and Social Surveillance" in Bryan Hogeveen & Joanne Minaker, eds, *Criminalized Mothers, Criminalizing Motherhood* (Toronto, ON: Demeter Press, 2015) 231 at 241; Michael Downey, "Canada's 'Genocide,'" *Macleans*' (26 April 1999), online: archive.macleans.ca/issue/19990426; Kike Ojo & Tana Turner, "One vision One Voice: Changing the Ontario Child Welfare System to Better Serve African Canadians," *Ontario Association of Children's Aid Societies* (September 2016) at 19, online:

<oacas.org/wp-content/uploads/2016/09/One-Vision-One-Voice-Part-1\_digital\_english.pdf> [perma.cc/4PXZ-TL3A]; Katherine Schumaker, *An exploration of the relationship between poverty and child neglect in Canadian child welfare* (PhD Thesis, Factor Inwentash Faculty of Social Work University of Toronto, 2012) at 30 online: <tspace.library.utoronto.ca/bitstream/1807/34913/5/Schumaker\_Katherine\_201209\_PhD\_thesis.pdf> [perma.cc/4XQ5-2MJJ].

<sup>11</sup> Michael Downey, *supra* note 10; Marlyn Bennet & Cindy Blackstock, "A Literature Review and Annotated Bibliography Focusing on Aspects of Aboriginal Child Welfare in Canada," First Nations Child and Family Caring Society of Canada, online: <fncaringsociety.com/sites/default/files/17LitReviewEntire.pdf> [perma.cc/6FBQ-TZQP]; Greene et al, "Mothering Experiences," *supra* note 8 at 470; Saara Greene et al, "A Community-Based Research Approach to Developing an HIV Education And Training Module for Child and Family Service Workers in Ontario" in H Monty Montgomery et al, eds, *Transforming Child Welfare: Interdisciplinary Practices, Field Education and Research* (Regina, SK: University of Regina Press, 2016) 163 at 168 [Greene et al, "HIV Education and Training Module"].

<sup>12</sup> Public Health Agency of Canada, "2012 Report," *supra* note 1.

<sup>13</sup> "Promises of Hope: Commitment to Change: Child and Family Services in Manitoba, Canada," Executive Committee of the Aboriginal Justice Inquiry – Child Welfare Initiative (August 2001), online: <aji-

and Black communities in Ontario are also uniquely impacted by experiences of systemic racism and discrimination in their encounters with child welfare agencies. They are not only disproportionately investigated by child welfare agencies, but also two times more likely than white mothers to have their children removed from their home once an investigation begins.<sup>14</sup>

Any attempt to address the disproportionate impact of the child welfare system on African, Caribbean, Black, and Indigenous communities must include an analysis of how child protection workers engage with mothers living with and affected by HIV. This inclusion is necessary because the mothers who are most impacted by child welfare involvement are also among the women who are most impacted by the HIV epidemic in Canada: Indigenous, African, Caribbean, Black, and other mothers who experience poverty, domestic violence, and other forms of oppression. The experiences of child welfare involvement for mothers from Indigenous, African, Caribbean, Black and other historically marginalized communities become further complicated by HIV-related stigma. As already noted by Greene and colleagues,<sup>15</sup> experiences of HIV-related stigma in other health and social care contexts contribute to the fear and anxiety that a disclosure of their HIV status will have on their relationship with their social workers.<sup>16</sup> Indigenous mothers in particular have expressed their concern about the negative impact that knowledge of their HIV status would have on their interactions with child welfare workers.<sup>17</sup> Regrettably, many child welfare workers do not have access to current information on the intersection of HIV and child welfare; rather, most available practice-based research dates back to the mid-1990s with a primary focus on guardianship arrangements and separation of mother and child prior to HIV disease progression.<sup>18</sup> The lack of attention on the intersection of HIV and child welfare in contemporary research, social work practice-based initiatives, training, and educational opportunities leave frontline child welfare workers without the necessary skill set to appropriately deliver child welfare services to families living with and affected by HIV.

In the current Canadian context, the development and success of antiretroviral therapy, the evolution of HIV to a chronic health condition, and the reduction of vertical HIV transmission rates for infants to less than 1% mean that the focus of child welfare work with mothers living with HIV needs to shift. In particular, it must move from the guardianship issues

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[cwi.mb.ca/pdfs/promiseofhope.pdf](http://cwi.mb.ca/pdfs/promiseofhope.pdf) [perma.cc/WJL3-NVLG]; John Beaucage, “The Aboriginal advisory’s report on the status of Aboriginal child welfare in Ontario,” Ministry of Child and Youth Services (2011), online: <[children.gov.on.ca/htdocs/English/professionals/indigenous/child\\_welfare-2011.aspx](http://children.gov.on.ca/htdocs/English/professionals/indigenous/child_welfare-2011.aspx) > [perma.cc/6M9S-55XH]; Jennifer Clibbon, “First Nations child advocate wins 1<sup>st</sup> battle with Ottawa on services,” CBC News (19 April, 2012), online: [cbc.ca/news/canada/thunder-bay/story/2012/04/19/f-aboriginal-cindy-blackstock.html](http://cbc.ca/news/canada/thunder-bay/story/2012/04/19/f-aboriginal-cindy-blackstock.html) [perma.cc/8U5V-VY4C].

<sup>14</sup> Ojo & Turner, *supra* note 10 at 21ff.

<sup>15</sup> Greene et al, “HIV Education and Training Module,” *supra* note 11 at 167.

<sup>16</sup> Saara Greene et al, “‘Under my Umbrella’: The Housing Experiences of HIV Positive Parents Who Live With and Care for Their Children in Ontario” (2010) 13:3 Archives of Women’s Mental Health 223 at 229 [Greene et al, “Under my Umbrella”]; Margarete Sandelowski & Julie Barroso, “Motherhood in the Context of Maternal HIV Infection” (2003) 26:6 Research in Nursing and Health 470 at 475; Saara Greene et al, “Who is There to Support Our Women? Positive Aboriginal Women (PAW) Speak Out About Health and Social Experience and Needs During Pregnancy, Birth and Motherhood” (2015) 7:3 Can J of Aboriginal Community Based HIV-AIDS Research 3 at 18 [Greene et al, “Who is There to Support Our Women?”].

<sup>17</sup> Greene et al, “Mothering Experiences,” *supra* note 8 at 470; Greene et al, “Who is There to Support Our Women?,” *supra* note 16 at 18.

<sup>18</sup> Rex Forehand et al, “The Family Health Project: Psychosocial Adjustment of Children Whose Mothers are HIV Infected” (1998) 66:3 J of Consulting and Clinical Psychology 513 at 518; Mary Rotheram-Borus et al, “The Impact of Illness Disclosure and Custody Plans on Adolescents Whose Parents Lived with AIDS” (1997) 11:9 AIDS 1159 at 1162.

that predominated the 1980s and 1990s towards a focus on how HIV intersects with other social determinants of health. Consequently, we argue for the need to engage in an anti-oppressive approach to social work practice that supports mothers living with HIV in ways that ameliorate rather than exacerbate their experiences of HIV-related stigma. The broader systemic issues that bring mothers living with HIV to the attention of child welfare are not dissimilar from other mothers in Canada, such as poverty and domestic violence. It is important to recognize, however, that these challenges are exacerbated for mothers who must navigate a web of health and social care systems, while at the same time confront HIV-related stigma and the lack of HIV knowledge held by their service providers within these contexts.<sup>19</sup>

## A. CHILD WELFARE PRACTICE AND HIV

Our review of the literature on the presence of HIV education within social work curriculum demonstrates that the HIV educational content in both Bachelor (BSW) and Master of Social Work (MSW) programs is marginal, and that electives on HIV are disappearing altogether.<sup>20</sup> What, then, does this mean for social work practice in the context of HIV and child welfare?

Child welfare settings are particularly challenging practice contexts. Workers operate with tremendous power under a mandate to protect children, continually assessing and managing risk while making decisions about child apprehension.<sup>21</sup> Yet, despite what is known about the challenges inherent to this work, very few studies exist that focus on the experiences, capacities and meaning-making processes of frontline child welfare workers who are given the responsibility of supporting mothers experiencing marginalization.<sup>22</sup>

A growing body of literature is giving a voice to mothers living with HIV and their experience with frontline child welfare workers, highlighting instances of HIV-related stigma and a perceived lack of HIV-related practice knowledge among frontline child welfare workers.<sup>23</sup> In our research, we have heard from Indigenous, African, Caribbean, and Black mothers that a disclosure of their HIV status exacerbates the already tense relationship they have with their child welfare workers.<sup>24</sup> According to Skyes, in the limited research that has been done, it is apparent that the ways child welfare workers understand the experiences of mothers on the margins is starkly different than the ways in which mothers view the circumstances of their lives.<sup>25</sup> Looking more closely at the Ontario context, this gap in understanding is not surprising. In our previous publications, we note that in Ontario, child welfare social work is typically carried out by social workers practicing at children's aid societies (CAS) throughout the

<sup>19</sup> Greene et al, "Under my Umbrella," *supra* note 16 at 227; Greene et al, "Mothering Experiences," *supra* note 8 at 474.

<sup>20</sup> Greene et al, "HIV Education and Training Module," *supra* note 11 at 170.

<sup>21</sup> Mimi Chapman et al, "Parental Views of In-Home Services: What Predicts Satisfaction with Child Welfare Workers?" (2003) 82:5 *Child Welfare* 571 at 584.

<sup>22</sup> Simon Lapierre & Isabelle Côté, "I made her realize that I could be there for her, that I could support her: Child Protection Practices With Women In Domestic Violence Cases" (2011) 17:4 *Child Care in Practice* 311 at 316.

<sup>23</sup> Corry Azzopardi et al, *supra* note 9 at 1768; Greene et al, "Mothering Experiences," *supra* note 8 at 474; Greene et al, "Under my Umbrella," *supra* note 16 at 227; Mary-Elizabeth Vaccaro et al, "I guess she just needs to do her homework: HIV-Positive Mothers Interactions with Child Protection Services Across Ontario" (presentation delivered at the Ontario HIV Treatment Network Research Conference, 12 November 2012) [unpublished].

<sup>24</sup> Greene et al, "Under my Umbrella," *supra* note 16 at 228; Greene et al, "Mothering Experiences," *supra* note 8 at 481.

<sup>25</sup> Jennifer Skyes, "Negotiating Stigma: Understanding Mothers' Responses to Accusations of Child Neglect" (2011) 33:3 *Children & Youth Services Review* 448 at 448-449.

province. The CAS is a leading site for social work practice education (field education) and for hiring new social work graduates. Social workers in Ontario who are employed by the CAS are expected to take a number of training modules and in-service workshops offered and coordinated by the Ontario Association of Children's Aid Societies (OACAS). The learning needs are identified through regular assessments and consultation with the Ministry of Children and Youth Services and individual CAS agencies. To date, none of the training offered by the OACAS examines the impact of HIV on the families they serve.<sup>26</sup> Consequently, our collective goal was to develop a training module for child welfare workers and social work students that would support frontline workers to more effectively respond to the intersecting areas of oppression experienced by families affected by HIV.

## **II. OUR APPROACH**

### **A. OUR COMMUNITY BASED RESEARCH (CBR) APPROACH**

CBR is a collaborative partnership approach to research that equitably involves community members, organizational representatives, and researchers in all aspects of the research process.<sup>27</sup> CBR demands that researchers work in collaboration with the community to ensure that research questions address community needs and that research results reflect the community's vision of social change in both the social policy and practice arenas.<sup>28</sup> Our research team was developed through community engagement and collaborative partnerships with mothers living with HIV, AIDS service organizations who work with HIV-affected families, child welfare agencies, and academic researchers. To increase the accessibility and equitability of the project, we created a number of avenues for people representing these perspectives to get involved. A core group of individuals formed the investigator team, which led and directed project activities; mothers living with HIV were involved in a leadership capacity within this group. Based on community partner recommendations, our team also included two advisory boards, which guided development of the data collection tools and the training module content. The Positive Parenting Advisory Board (PPAB) included eight mothers living with HIV who had child welfare involvement and who identified as Canadian Born and Caucasian (n=3), Indigenous (n=2), Latin American (n=1), Caribbean (n=1), and African (n=1). At the beginning stages of the project, there was also one father who participated in our PPAB. The Service Provider Advisory Board (SPAB) included the active involvement of twenty-five individuals from child welfare agencies (n=7), social workers and services providers based at HIV organizations (n=6), and other health and social care practitioners (n=12; Public Health and people working in Indigenous health and family-centered organizations, et cetera).

Engaging two separate advisory boards ensured an environment of confidentiality and safety for mothers living with HIV, allowing them to speak openly about their child welfare experiences without fear or concern about how it may influence or shape their interactions with child welfare officials. Members of both the PPAB and the SPAB were represented in the core

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<sup>26</sup> Greene et al, "HIV Education and Training Module," *supra* note 11 at 171.

<sup>27</sup> Barbara Israel et al, "Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health" (1998) 19:1 *Annual Rev Public Health* 173 at 177.

<sup>28</sup> Syed Ahmed et al, "Overcoming Barriers to Effective Community Based Participatory Research in US Medical Schools" (2004) 17:2 *Education for Health* 141 at 142-143.



investigator team to ensure representation of these different voices and perspectives, and to ensure continuity between the various groups contributing to the project.

## **B. SERVICE USER LEADERSHIP AND INVOLVEMENT**

A critical feature of this project was the diverse representation of service user voices within the development, implementation, and evaluation of the HIV training module. This representation was achieved by having mothers living with HIV contributing to the research as co-investigators and as members of the PPAB. PPAB meetings only involved mothers living with HIV and two members of the investigator team who did not have HIV. The original idea for the PPAB was to have a separate group where mothers living with HIV could contribute to the research design, including data collection tools, and to the HIV training module content. The PPAB became a space where women could talk about their child welfare experiences with their peers who understood where they were coming from; women were able to vent their frustrations, support each other, and discuss their successes and challenges. Members of the investigator team and two mothers living with HIV who acted as PPAB co-chairs planned and facilitated the first meeting. We assumed that PPAB members would want to advance their knowledge and skills around the conduct of research, and we developed a meeting agenda reflecting this assumption. For example, we planned that the bulk of the meeting would be a discussion about research methodology, how data is collected and analyzed, and what it means to advise a research process. We also planned to develop a Terms of Reference for the PPAB.

We discovered, however, that the women involved in the PPAB were less interested in developing research skills than we had initially expected. In the spirit of CBR, the researchers asked the women how they would like to contribute to the project in ways that were meaningful to them, and that reflected their unique and shared experiences with child welfare. Rather than focus on building research knowledge and skills, the PPAB members instead wanted to have ample time to talk about their child welfare interactions and support each other. In addition, rather than support the development of data collection tools, PPAB members wanted to translate their lived experiences of child welfare interactions into "case scenarios" that could be integrated into the HIV training module. We therefore shifted the time allocated with the PPAB members in order to co-develop case scenarios that they felt would build the capacity of child welfare workers to work more effectively with mothers living with HIV. This change was an important learning moment for those of us who were involved as researchers, as we had to shift our own thinking of what it means to meaningfully involve service users and mothers living with HIV in research. In this way, the core research team and PPAB members engaged in a process of reciprocal capacity building, where experiential and research knowledge was equally valued and shared. This process resulted in strengthening the content and potential for the HIV training module.

On a practical level, shifting our way of thinking about community based research, capacity building, and reciprocity resulted in opportunities for the academic researchers to deepen their knowledge and understanding of the child welfare involvement of mothers living with HIV. This shift included garnering a deeper understanding of how racism and HIV-related stigma are experienced by mothers living with HIV who identify as Indigenous, African, Caribbean, and Black within the context of child welfare. This process also ensured that the training module reflected the needs and experiences of mothers living with HIV, which fulfilled a critical component of our CBR approach to developing an HIV-specific social work education

curriculum. Importantly, members of the core investigator team met with the PPAB and SPAB multiple times during the formative phase between April 2013 and November 2014 in order to enable sufficient time for dialogue, critical reflection, decision making, and finalization of the data collection tools and content of the training module. Our CBR methodological approach to developing the training module ensured that the core research team, PPAB, SPAB, and research participants all contributed to finalizing the training content, ensuring the module accurately responded to child welfare workers' gaps in knowledge.

## **C. METHODOLOGY**

Following the formulation of our research team and advisory boards, we proceeded to conduct the study, which included a pre-training data collection phase, development and implementation of the HIV training module, and a post-training data collection phase.

### **1. PRE-TRAINING PHASE**

The pre-training phase had two purposes. One was to engage in a data collection process that would ensure the training module not only reflected the interests of the researchers, PPAB, and SPAB, but also addressed the learning needs of the participants. The second was to provide us with a baseline of the participants' HIV knowledge, attitudes, and skills for working with families living with and affected by HIV. The team agreed to engage in a mixed-method data collection process that included qualitative focus groups and a quantitative, self-report survey measuring knowledge, attitudes, and beliefs of HIV. Our pre-training activities therefore included:

1. Survey and focus group development in consultation with the SPAB, PPAB, and overall research team in order to develop the survey and focus group questions;
2. Survey administration to frontline child welfare workers and students in Bachelor of Social Work and Social Service Worker diploma programs using the HIV-KQ-18 scale;<sup>29</sup>
3. Focus groups with frontline child welfare workers and social work students to contextualize the survey data, and to deepen our understanding of the training interests, needs, and areas for practice skill development; and
4. Analysis of focus group data, as well as a series of meetings between the SPAB, PPAB, and research team members to inform and finalize the training module content.

We recruited child welfare workers to participate in the pre-training phase through SPAB, as well as research team members who represented four child welfare agencies in the greater Toronto and Hamilton areas. Staff of child welfare agencies could either express their interest directly to the Research Coordinator supporting the project or contact their agency

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<sup>29</sup> Michael Carey & Kerstin Schroder, "Development and psychometric evaluation of the brief HIV knowledge questionnaire (HIV-KQ-18)" (2002) 14:2 *AIDS Education & Prevention* 174 at 176. The HIV-KQ-18 scale is a brief, easy-to-administer, self-report 18-item questionnaire generating a continuous score indicating level of HIV knowledge. The HIV-KQ-18 was developed to evaluate HIV knowledge in program evaluations. The scale has demonstrated internal consistency across clinical and community-based adult samples with variable sociodemographic characteristics ( $\alpha = 0.75-0.89$ ), as well as test-retest reliability across several time intervals up to 3 months post-intervention ( $r_s = 0.76-0.94$ ).

training coordinator who helped to organize the study at the local agency. Participation in the pre-training data collection was voluntary and was neither connected to the worker's employment responsibilities to nor their performance evaluation. Two members of the investigator team obtained informed consent, facilitated the pre-training focus group, and administered the surveys.

We engaged social work students by integrating the HIV training module into course curriculum, including offering the training as part of a course on child welfare and through social work practice seminars. Student participants volunteered for the research component (*i.e.* pre- and post-training data collection), and was not connected to their assessments. Members of the research team who were affiliated with social work programs at three post-secondary institutions worked with course instructors to integrate the HIV training module into the course outline. Data collection (*e.g.* pre-training focus groups and surveys) occurred outside of class time. Additionally, the course instructor was not involved in this process to ensure it was separate from the course content on which students would be adjudicated. Similar to the process for the child welfare workers, two members of the investigator team obtained informed consent, facilitated the pre-training focus group, and administered the surveys.

Through this process, we administered surveys to 53 students and 67 child welfare workers. A subset of this sample, which included 37 students and 19 child welfare workers, was also able to participate in the pre-training focus groups. These pre-training data collection activities informed the development of the HIV training module as outlined below.

We obtained demographic characteristics of 58 social work students and 62 child welfare workers as part of the pre-training survey. The median age of social work students was 24 (range of 19 to 45 years) compared to child welfare workers who were on average 36 years of age (range of 24 to 61 years). No differences were observed between the two groups related to their country of origin (64% of social work students versus 63% of child welfare workers born in Canada) or gender identity (91% of students versus 85% of child welfare workers identified as women). Both social work students (43%) and child welfare workers (60%) were predominantly white, however, participants also identified as Asian (21% students, 13% workers), Black (7% students, 11% workers), Indigenous (7% students, 3% workers), and more than one ethnicity (10% students, 3% workers). More child welfare workers (26%) compared to social work students (19%) had ever received any training about HIV, however, such training had often been received prior to 1996 when HIV treatment significantly improved and HIV was viewed as a chronic health condition.

## 2. DELIVERING THE TRAINING: THE HIV EDUCATION MODULE

The pre-training phase resulted in a three-hour training module that was piloted with members of the SPAB and via webinar with members of the OACAS. To date, the training module has been delivered to a total of twelve groups, which included the following: sixty child welfare staff and management at four different child welfare agencies; 152 BSW students and eleven MSW students from two different institutions; six social service worker diploma students from a local college; and twelve students and staff from a private health care training facility. We delivered the HIV training module to a significant number of students by integrating the module into the social work curriculum as well as the research activities (pre- and post-training data collection); this ensured that the research component of the training module was voluntary. Similarly, participation in the pre-training data collection meeting was not a requirement to attend the

training when it was offered at child welfare agencies. Most child welfare staff who contributed to the pre-training data collection attended the training, but we were not able to involve all child welfare workers who added the pre-training meeting because of conflicting schedules.

Trainings were co-facilitated by multiple team members including a researcher, HIV educator, social worker, and a mother living with HIV. The final training module consisted of the following didactic and interactive components:

1. Understanding HIV transmission, prevention and clinical management;
2. Unique issues during the perinatal period for mothers living with HIV, *e.g.* clinical procedures and infant feeding;
3. Social and legal issues, *e.g.* emotional health, legal issues, HIV disclosure;
4. A presentation by a mother living with HIV (who was one of the training co-facilitators), on her experiences with child welfare, which included sharing both positive and negative experiences and recommendations for practicing child welfare workers;
5. Case scenarios developed by the PPAB that reflected the range of challenges that PPAB members experienced with child welfare workers and included questions and points for discussion (similar to the presentation by mothers living with HIV, which brought forward both the challenging and supportive experiences with child welfare, the case scenarios were an opportunity to apply the training content to real-world practice); and
6. Participants were left with a handout that outlined additional resources and websites, including information available from CATIE.<sup>30</sup>

### 3. POST-TRAINING PHASE

The post-training phase was carried out from November 2014 to June 2015. We conducted five post-training focus groups with fifty participants and administered post-training surveys to sixty-five participants. The post-training data collection meetings were facilitated by two members of the investigator team who also attended the HIV training module offered at the agency or academic institution. The focus groups gave participants an opportunity to reflect on their experiences of the training and its impact on their HIV knowledge and future social work practices with families affected by HIV. Survey data was entered into a database and analyzed using standard statistical techniques and summarized in aggregate format. Focus group data was entered into NVIVO, coded, and analyzed thematically. In line with our CBR process, themes were developed by a core team of academic and community researchers, service providers, and mothers living with HIV. The themes were then presented to the larger research team, including the SPAB and PPAB, who were encouraged to ask questions and add their thoughts and feedback regarding the core team's analysis. The focus of this paper is the qualitative data presented below.

## III. FINDINGS

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<sup>30</sup> "CATIE: Canada's Source for HIV and hepatitis C information," CATIE (website), online: <catie.ca/en/home> [perma.cc/5DX9-AMSE]. CATIE is Canada's source for up-to-date, unbiased information about HIV and hepatitis C. CATIE connects people living with HIV or hepatitis C, at-risk communities, healthcare providers, and community organizations with the knowledge, resources, and expertise to reduce transmission and improve quality of life.

We now present the qualitative findings from focus groups conducted with child welfare workers before and after they received the HIV training module. Although focus groups were also conducted with social work students, we decided to highlight the themes that emerged when consulting with frontline workers because of the potential to shift social work practice within child welfare agencies. The focus group data was analyzed thematically to increase our understanding of child welfare workers' knowledge and attitudes about HIV, experiences of working with families affected by HIV, and their training and education needs. What follows are the areas of knowledge and practice that were most critical to building frontline child welfare workers' practice capacity in the context of HIV.

## A. HIV KNOWLEDGE AND ATTITUDES

The pre-training focus groups revealed that many frontline child welfare workers had little or out-dated knowledge about HIV transmission, prevention and treatment, and the current realities of how HIV impacts the lives of people living with HIV. As one participant shared, "If I were to find out that a client was positive, I would have to do a heck of a lot of education for myself because I can't even start having those conversations because of my lack of knowledge." For some child welfare workers, the lack of HIV knowledge was not itself problematic because, as one child welfare worker suggested, "I feel like my knowledge is relatively limited ... but the skills, the skills to support are the same skills, that I would be using for whatever issue I would be looking at." Consequently, while it was unsurprising and positive that social workers were able to acknowledge their lack of HIV knowledge, we found the lack of consideration given to the social positioning of people living with HIV to be concerning. In relation to this study, this approach to practice demonstrated a lack of knowledge regarding how mothers living with HIV who are involved with child welfare may have their own set of unique issues related to their social positioning, which require specific knowledge and skills.

Interestingly, when we reconnected with child welfare workers in the post-training focus groups, we noticed a marked shift in the way they talked about the need for HIV education and training: "across the board for the workers in the agency so everyone knows what to expect, everybody is on the same page ... I think it should be mandatory training." This statement demonstrated an acknowledgement that increasing knowledge about HIV would enable them to engage more appropriately and effectively with mothers living with HIV.

Given the paucity of HIV-related content in the BSW and MSW curriculum,<sup>31</sup> it was not surprising that the participants had little to no exposure to HIV education. Consequently, most participants had only media representations of HIV that focused on gay men, people who use drugs, or "people from Africa" as the face of HIV, exacerbating harmful and racializing stereotypes:

I learned about it [HIV] from popular culture actually. Being a Queen fan growing up, I wanted to find out why Freddie Mercury died. That's how I learned about it ... Well, basically at that time, I learned it was because of his lifestyle. So the stigma attached to it was being slept around with a lot of different people and drug use and sharing needles and whatnot.

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<sup>31</sup> Greene et al, "HIV Education and Training Module," *supra* note 11 at 170.

Moreover, participants were also unclear about how HIV was actually transmitted. Often, when the facilitator asked if the participants knew how HIV could be transmitted, they seemed misinformed. They asked a lot of questions, such as: “It has to be direct contact right? Direct contact of body fluids? ... So sexual intercourse; I think there needs to be like that blood, the fluid. Because, I mean if I kiss somebody with HIV, I don’t know ... I don’t think you can get it that way?”

The dialogue that ensued during pre-training focus groups highlighted a lack of knowledge about HIV transmission and the contexts in which people are at risk. This knowledge gap is highly problematic; the socio-structural determinants of health that can lead to child welfare involvement (poverty, housing instability, intimate partner and domestic violence, substance use, et cetera) are similar to the factors that can increase one’s susceptibility to acquiring HIV infection.<sup>32</sup>

Interestingly, it was during the post-training focus groups that child welfare workers became more candid about the breadth and depth of their “not knowing” about HIV transmission. As one participant shared:

It [the training] definitely made me think more about how we look at people with HIV. Like I think everyone just sees someone who’s HIV and ... Oh my God, if anything happens, I could potentially ... and I think we really think we are more able to contract that from someone with HIV than we really can.

Some child welfare workers shared that before the training, they believed that they might even contract HIV as a result of coming into contact with someone with HIV as a part of doing child welfare work. They believed that HIV could be spread by mosquitos, sneezing, and even hugging. As the following participants shared:

You know, it can’t be transmitted through mosquito bites. Because that was one of my things that I used to think about in the past because I realized, okay, it’s in the air, it dies. But a mosquito is a living organism. So how can that make sense to me? If it stung somebody and took blood away, how can it not transmit it? So learning things like that, it helps me kind of get rid of some of my fears and anxieties. So this training, it was useful for us to know, right. It’s better late than never that we know that it doesn't get transmitted through a hug or even sneezing.

Echoing the research highlighting the nuances of HIV-related stigma in a range of health care settings, the concerns that were shared following the training demonstrate the range of misinformation that professional social workers have about HIV.<sup>33</sup> This misinformation can lead

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<sup>32</sup> Richard Parker & Peter Aggleton, “HIV And AIDS-Related Stigma and Discrimination: A Conceptual Framework and Implications for Action” (2003) 57:1 *Social Science & Medicine* 13 at 16; “Population-specific HIV/AIDS status reports-fact sheet. People from countries where HIV is endemic – Black people of African and Caribbean decent living in Canada,” Public Health Agency of Canada (2009), online: <[librarypdf.catie.ca/PDF/ATI-20000s/26205.pdf](http://librarypdf.catie.ca/PDF/ATI-20000s/26205.pdf)> [perma.cc/Y4UN-BFFB]; Dennis Raphael, *Social Determinants of Health: Canadian Perspectives* (Toronto, ON: Canadian Scholars Press, 2004) at 29; Dennis Raphael, “Social Determinants of Health: Present Status, Unresolved Questions, and Future Directions” (2006) 36:4 *Intl J Health Services* 651 at 668.

<sup>33</sup> Saara Greene et al, “‘Why are you pregnant? What were you thinking?’: How Women Navigate Experiences of HIV-Related Stigma in Medical Settings During Pregnancy and Birth” (2016) 55:2 *Social Work in Health Care* 161

to needless fears about their clients, fueling already-harmful realities of HIV-related stigma and its impact on people living with HIV.

## **B. CHILD WELFARE PRACTICES**

During the formative, relationship-building phase of our study, we heard from some managers working in child welfare agencies that they rarely, if ever, worked with families affected by HIV. It was not surprising to have this assumption echoed in the pre-training focus groups. As more than one social worker stated: "I have never had a client tell me that they were HIV positive." For some of the social workers, HIV was a disease that happened "over there." As one social worker revealed: "I hate to say it but, you know, there's a piece of me that thinks within myself that it's not in my community, it's not in my neighbourhood. Right? However, that's my own stereotype, right, my own bias. So I'd hate to just focus on the people over there, you know." This line of thinking is particularly troubling given the intersection between HIV and the child welfare experiences of Indigenous, African, and Black women in Ontario, Saskatchewan, and British Columbia.<sup>34</sup>

## **C. SOCIAL CONSTRUCTIONS OF MOTHERS LIVING WITH HIV**

In addition to most child welfare workers not having a background in working with mothers living with HIV, there was an assumption that they did not work with families affected by HIV or did not know if they were working with these families. Still, a few of the participants shared the view that, in the event they did find out that a mother was living with HIV, they would have questions about that mother's ability to care for herself or her baby because of her HIV status: "They're not going to care and they're not going to follow through with services. They're not going to be proactive in, you know, healthcare or, you know, any of those types of things ... Should they follow through with having a child?"

Although this kind of revelation was not a common perception of focus group participants, the fact that it was shared at all suggests the possibility of other child welfare workers holding the same concerns and attitudes. These mothers are not legally obligated to disclose, and one possible reason for not doing so is due to their child welfare worker. Consequently, it is not surprising that social workers rarely consider the possibility that some of their clients may not disclose that they are living with HIV since HIV is a highly stigmatized disease. For the mothers we worked with, HIV is not normally the point of entry in their relationship history with the child welfare system.<sup>35</sup> However, when HIV intersects with other stressors mothers may have, it can result in exacerbating an already stressful and stigmatizing experience.<sup>36</sup> In this context, a disclosure of HIV can often make an already tense relationship with their child welfare worker that much more challenging for a mother, especially if the worker has little understanding of HIV and enacts HIV stigma in the casework relationship and case

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at 162; Laura Nyblade et al, "Combating HIV Stigma in Health Care Settings: What Works?" (2009) 12 J Intl AIDS Society 15 at 16; Allyson Ion & Dawn Elston, "Examining the Health Care Experiences of Women Living with Human Immunodeficiency Virus (HIV) and Perceived HIV-Related Stigma" (2015) 25:4 Women's Health Issues 410 at 413.

<sup>34</sup> Greene et al, "Mothering Experiences," *supra* note 8 at 470.

<sup>35</sup> *Ibid.*

<sup>36</sup> Greene et al, "Who is There to Support Our Women?," *supra* note 16 at 5.

plan. In revisiting these assumptions post-training, we found that social workers were much more mindful of the possibility that they had clients on their caseloads with HIV, who had perhaps chosen not to disclose. Workers also came to understand why a mother might not disclose, as one social worker stated: “They might feel uncomfortable sort of sharing like ... then realizing that we have concern around what they’re saying or things like that, right? So again, if people feel comfortable sharing that information then we can advocate for them if it could be helpful.”

The shift in dialogue was apparent in the post-training phase. Workers began to conceptualize their role as an advocate if mothers living with HIV disclosed their HIV status, demonstrating their awareness regarding the complex reasons mothers may not disclose.

## **D. PERMANENCY PLANNING**

Despite advancements in HIV treatment, life expectancy, and quality of life, some participants assumed that their primary role in supporting a family affected by HIV was to plan child placement in the event of parental health deterioration or death. In these cases, child welfare workers assumed that an HIV diagnosis was akin to living with a life-threatening illness instead of a chronic health condition with a virus that can be effectively controlled through treatment. In assuming that a mother would eventually “get too sick” to care for her children, some participants suggested a practice approach that would have child welfare workers plan for the possibility of illness and death: “You will be well for a long time but something bad might happen. So be realistic. At the same time, optimistic. And work towards it ... I think what they need is hope. You can fight this. You can fight this for as long as you can. But you need the care yourself in order to fight this.”

While this participant had good intentions, that being to plan for any eventuality, the underlying assumption is that the mother is to blame for the possibility that “something bad might happen” and therefore, she needs to take care of herself. With these concerns in mind, mothers living with HIV are put under surveillance by their social workers. Framing support in this way shows assumptions of blame and possibly misplaces concern on the part of the child welfare worker that the mother will not be able to take care of herself. This framework provides a rationale for why the child welfare worker has to engage in what she identifies as “concurrent planning.” Hence, the surveillance of mothers living with HIV must be understood as being deeply connected to gendered experiences of HIV-related stigma<sup>37</sup> in addition to the medical and social contexts where women living with HIV perceive and are confronted by acts of surveillance.<sup>38</sup>

## **E. RISK MANAGEMENT**

An underlying theme in the dialogue among frontline child welfare workers in the pre-training phase was a focus on risk management. Risk management in this context was linked to the child welfare worker’s concern for the child’s safety regarding HIV transmission from the mother to her child(ren) in ways that are not possible or highlight the lack of knowledge and assumptions about HIV on the part of child welfare workers. For example, in the pre-training focus groups,

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<sup>37</sup> Carmen Logie et al, “HIV, gender, race, sexual orientation, and sex work: a qualitative study of intersectional stigma experienced by HIV-positive women in Ontario, Canada” (2011) 8:11 PLoS Medicine e100124.

<sup>38</sup> David Lyon, *Surveillance Studies: An Overview* (Cambridge: Polity Press, 2007) at 49.



some participants struggled between their own personal judgements about a client not disclosing their HIV status to a sexual partner and whether this decision was a child protection issue:

How do you differentiate between judgement and what you're trying to justify as protection? Okay, if you're not sharing with your partner, are you being safe? And if you're not being safe with your partner, are you being safe with your child? Does that then pose a risk to your child? And you sort of start spiraling a little bit in your thought processes.

This thought process as it relates specifically to child welfare practice demonstrates the dangers of having a lack of education around HIV-related stigma and disclosure. It not only negates the social context in which women living with HIV engage in sexual relations, including risk of sexual violence, but also assumes that a service user's decision not to disclose her HIV status is a child protection issue. It was not surprising, then, to learn that some participants felt that knowing about a service user's HIV status was important to their inquiry into child protection concerns:

Like I can think of certain families where to me if one of the parents had it, I would want to know just based on their, it sounds awful, but their lifestyle ... They don't follow through with medical care for themselves or their children. They don't keep ... The conditions of the home are absolutely deplorable. And not just messy but risky, right. So there's something on the floor that can cut and cause ... You know what I mean? ... Yes, I think it would be important for them to know.

The paradigm that "messy" equals "risky" is particularly problematic as it highlights ongoing moral judgments about service users while simultaneously contributing to stigmatizing child welfare practices. As already demonstrated, this way of conceptualizing child welfare practice in the context of HIV was reflected in questions about whether or not women living with HIV should become pregnant and have children.

This way of perceiving mothers living with HIV echoes their lived experiences. These practices have emerged as particularly harmful to Indigenous, African, Caribbean, and Black mothers who have been on the receiving end of child welfare practices that call into question their right to become pregnant and to care for their children.<sup>39</sup> On a positive note, participants who attended the post-training focus groups were able to shift this dialogue from one centered on "risk" to one focused on "trust:" "I think it's important to be calm and trust that clients, they have knowledge. And don't treat them as if they are ignorant and don't know, and may be of harm to themselves and others. So in that case, my client, she was knowledgeable and she knows how to protect her son."

Similar to findings presented by Ion and colleagues,<sup>40</sup> participants in the post-training focus groups came to understand the unique challenges that mothers living with HIV face in regard to accessing healthcare. These challenges included the ways that mothers bump up against HIV-related stigma:

<sup>39</sup> Greene et al, "Mothering Experiences," *supra* note 8 at 226; Greene et al, "Who is There to Support Our Women?" *supra* note 16 at 20.

<sup>40</sup> Allyson Ion et al, "Perinatal Care Experiences of Mothers Living with HIV in Ontario, Canada" (2016) 15:2 J HIV/AIDS & Social Services 180 at 188.

You know, if we have somebody who's pregnant, and they're not getting prenatal care, like you could see how we would like totally sweep in. And there is concern, right, but you also have to be mindful maybe why those reasons are. She's not ready, and she could easily become demonized that she's going to give her child AIDS. We have lots of people that don't get prenatal care for lots of reasons. And so how we engage with that person is going to be really important.

Recognizing these challenges resulted in focusing the practice discussion on how to engage rather than manage mothers living with HIV.

## **F. DISCLOSURE: WHEN, WHY, AND HOW?**

As already noted, there are many reasons for why a mother living with HIV would not disclose her HIV status to her child welfare worker. However, participants were unclear or struggled with their thoughts about whether and under what circumstances an HIV disclosure would be necessary. One theme that consistently emerged was the participants' lack of knowledge regarding their role and obligations concerning a client's right not to disclose her HIV status. Often, this issue was framed as a question, with a need for clarity about moral versus professional obligations. For example, one social worker shared:

And it's just kind of thinking now is there a moral obligation, right? Like if the person is ... If the partner is unaware of it. The same way we'd have to let one partner know if there's substance misuse, do we need to let the other partner know if the other ... you know. So these are the kind of the things that I go back with. And I mean like I said, I haven't ever dealt with that situation. But you know is there other kind of legal stuff that I don't know about that needs to happen?

In this pre-training focus group, the social worker was questioning whether or not she had a professional obligation to disclose her client's HIV status to her sexual partner. This lack of knowledge can result in mothers living with HIV feeling threatened by their social workers rather than viewing them as potential sources of support. This important conversation highlighted the need to include a section on disclosure, the criminalization of HIV non-disclosure law, social work responsibilities in the context of disclosure, and the rights of mothers living with HIV in the training module.

Importantly, including this information in the training resulted in providing social workers with the necessary information and skills to work with clients in the area of disclosure. Social workers shared some of their thoughts after the training:

It blew me away. I really didn't know that ... even that a parent doesn't have to let their child know, and stuff like that. And I think that that kind of information is important for workers to know because as a worker, I wouldn't have known that. And I might have went out there saying to a parent, well, no, you need to tell your child, or something like that. Not even realizing that legally they're not obligated to do those things. I think one of the things people learned or at least I learned is how we've been insensitive to people in the past and even maybe more currently as well

to people with HIV. And how although it may not ... we may not have tried to come off as being insensitive, like certain questions that we may have asked maybe something that we've now learned isn't really appropriate. So you know, asking a mother in front of her children, not really thinking that the child might not know that they're diagnosed with HIV and asking them about that. And being more mindful of that kind of stuff.

Hence, prior to attending the HIV training module, this worker may have advised a mother to disclose her HIV status to her child. This change highlighted the critical nature of providing social workers with up-to-date information on the rights of mothers living with HIV and how they can support rather than undermine the mothers' self-determination in this area of their lives.

## **G. DOCUMENTATION, CONFIDENTIALITY AND HIV-RELATED STIGMA**

Participants did not widely discuss what they understood or thought about the relationship between HIV-related stigma, disclosure, and documentation in the pre-training focus groups. However, in the post-training focus groups, participants became much more cognizant of the ways that they may be contributing to HIV-related stigma by how HIV is disclosed and documented in a client file:

I think for me in terms of the AOP [anti-oppressive practice] piece, the privacy and confidentiality and respecting people for, you know, wanting to keep some things ... not wanting to share some of those pieces about themselves, that was for me very important and critical. And even our documentation, how we're sharing that information between colleagues ... A client that I had, like when we were doing a transfer, I didn't share any of that. And I let that client decide whether she wanted to self-disclose or not.

This sentiment was echoed by another participant who stated, "I think that we know too much about our clients as it is. And I think we document it with such ease that we're not aware of the repercussions for our client as the person we're speaking about. So I think, you know what, it [the training] only reaffirmed I don't need to know." Discussing the consequences of disclosing a service user's HIV status in their file or in conversations with colleagues created opportunities for participants to consider their future practices with mothers living with HIV. As one participant exclaimed: "I think it's just being mindful about what is really child protection and what isn't." Hence, we found that participants developed an increased sensitivity and understanding about the implications of HIV disclosure, not only about the relation to sexual partners and children but also about the implication of sharing someone's HIV status in their file when their HIV status is irrelevant to the child protection issue under investigation. This change is particularly critical for Indigenous women living with HIV who are over-represented within the child welfare system and at greatest risk for HIV.

## **IV. DISCUSSION**

## **A. IMPLICATIONS FOR CHILD WELFARE EDUCATION AND PRACTICE**

Building in an evaluative component to the HIV training module enabled us to assess gaps in knowledge and practice skills amongst the social workers who participated in the Positive Parenting Pilot Project training and post-training focus groups. An important part of this process was engaging the participants in a post-training reflection process that centered on their thoughts about integrating HIV education and training for child welfare agencies and for the OACAS more broadly. Importantly, all HIV training participants shared that they found the training enlightening and necessary. As one participant shared:

That's where that education piece here is so very important. Because then you realize that what sometimes is asked – 'Oh, we need to have consent for medical records,' why? How is that now impacting what we are doing? Or geez, the child has to be sent for testing. Well, why? If the parents are both HIV positive, they are definitely concerned about their children's health. They definitely have to have their child tested. You know, like it's things that we just make automatic assumptions on. And that's where educational pieces like this, and hearing from service users, are so extremely important in informing our work but also for us taking that education and passing it on to others – our coworkers or sharing it with supervisors. That is so critical and so important so that a lot of the myths and discrimination can be dispelled.

This participant's reflections raised a number of important implications in thinking about how to best support families affected by HIV who are involved in the child welfare system. These implications include: considering what is and is not relevant information in regard to a client's HIV status; needing to provide education about HIV in order to dispel myths and challenge assumptions; and addressing stigma and discrimination experienced by families affected by HIV. This participant also acknowledges the value of having service users involved in educating child welfare workers about their experiences of HIV, and the need for managers and frontline child welfare workers who have taken this training or who have sound knowledge of HIV to champion HIV education among colleagues and within their agencies.

Regarding the relationship between knowledge and practice, participants also recognized the links between the education they received through the HIV training module and how to engage in anti-oppressive practice more broadly:

What I know about AOP [anti-oppressive practice] in a nutshell is it's system barrier people have to face, and how it is ... if you are AO [anti-oppressive] practitioner, you're trying to help them overcome the barrier ... So in our case, a child protection worker, HIV positive mothers have all the same rights as a regular mother. So that shouldn't be something that is stigmatized or it becomes a child protection issue ... it shouldn't be.

As highlighted earlier in this paper, the shift in thinking about child welfare practice with mothers living with HIV must also attend to the particular experiences of Indigenous mothers living with HIV. Our earlier work on the child welfare experiences of Indigenous mothers living

with HIV in Canada draws attention to the urgent need for developing child welfare practices that are grounded in an "indigenous epistemological perspective ... that acknowledges cultural practices, traditions and knowledge."<sup>41</sup> In response to this recommendation, Greene and O'Brien are currently engaged in a collaborative approach to developing a toolkit for service providers and Indigenous mothers living with HIV that is grounded in Indigenous ways of knowing and experiencing motherhood.

Conceptualizing and carrying out child welfare practice with all mothers living with HIV as something to be normalized rather than stigmatized is critical to providing support to families affected by HIV, and this includes thinking deeply about the rights of mothers living with HIV. Consequently, a final implication of this research is the need to integrate child welfare practice guidelines informed by Indigenous, African, Caribbean, and Black communities into the mainstream professional development opportunities offered by the OACAS.<sup>42</sup> This integration would support directors, managers, and frontline workers who work for child welfare agencies to work toward structural changes for families living with and affected by HIV. However, in order for this work to reflect participatory and anti-oppressive practice approaches to child welfare practice and policy development, service users, that is mothers living with HIV who are or have been involved with the child welfare system, must be engaged in this process. As we have argued in earlier publications, service users have enormous capacity to contribute to the development of practices, policies, and training in ways that will change their lives.<sup>43</sup> This contribution has been demonstrated by the mothers who took on leadership positions throughout the entire process of developing, executing, and evaluating the Positive Parenting Pilot Project. It is our aim to ensure that mothers living with HIV continue to take on these roles as we continue to pursue our shared desire to bring HIV knowledge and training to frontline social workers in Ontario and beyond.

## V. CONCLUSION

This paper presents an important shift in thinking about practice with families living with and affected by HIV, which occurred among frontline child welfare workers who participated in the Positive Parenting Pilot Project. This shift included a change in practices focused on surveillance and risk-management towards a more supportive and anti-oppressive practice paradigm. Our findings substantiate the dire need to integrate HIV knowledge and skills-based training into professional development opportunities within child welfare agencies. Importantly, the focus groups highlighted the baseline knowledge, attitudes, and skills of child welfare workers, and showed how HIV-specific training can have a positive influence on their future practice with families affected by HIV.

During this project, it became clear to us that the Positive Parenting Pilot Project participants wanted to provide high quality social work service to the children and families they worked with. It also became clear that most of the participants did not know how to do this with families affected by HIV; most were misinformed about HIV, depended on literature that was outdated, or relied on stereotypes and myths about HIV. Participating in the project was voluntary, so likely those who took part already recognised that they had learning needs in this area. Even so, pre-training measures indicated that participants did not fully recognize the extent

<sup>41</sup> Greene et al, "Mothering Experiences," *supra* note 8 at 482.

<sup>42</sup> H Wong and J Y Yee, "An Anti-Oppression Framework for Child Welfare in Ontario. Toronto, Canada" (delivered at Ontario Child Welfare Anti-Oppression Roundtable, 2010) [unpublished].

<sup>43</sup> Greene et al, "HIV Education and Training Module," *supra* note 11 at 181.

to which this type of training was needed. After the training, many of the participants were alarmed by how inappropriate their pre-training ideas and practices were, which resulted in suggestions that the training ought to be compulsory. Significant topics included their assumptions that they were not working with families affected by HIV, the lack of HIV knowledge among child welfare workers, and their roles and responsibilities when working with families affected by HIV. These findings were critical in our study given the high numbers of Indigenous, African, Caribbean, and Black children who are in care or who are at risk of being in care coupled with the rates of HIV infection and risk of HIV infection amongst these populations. Aside from child welfare workers valuing the training because of its focus on HIV, the training was also valued because it drew attention to issues faced by mothers living with HIV, and the intersection of multiple sites of oppression. As such, the training provided an entry point to consider broader issues of anti-oppression in child welfare practice.

Our paper aims to give a voice to frontline child welfare workers as they consider their level of HIV knowledge and their capacities for supporting families affected by HIV. The Positive Parenting Pilot Project offered frontline child welfare workers the opportunity to participate in a training module that was delivered and implemented in the spirit of CBR and service user leadership in an effort to increase their capacities for effective service delivery when working with this population. Training participants found the involvement of mothers living with HIV who had child welfare system involvement to be a profound aspect of the training. The mothers helped to increase the participants' awareness of how social work practice can not only exacerbate or minimize HIV-related stigma, but also play a vital role towards connecting mothers living with HIV with appropriate resources. Our evaluation suggests that our training module has led to positive practice shifts. However, in order for these shifts to result in institutional change, targeted training that goes beyond our study and policy changes within the child welfare system are necessary.