

Mothers' Voices Thunder Bay Project

September 2017 to April 2019



**Summary Report:
Creating an Integrated Service Delivery Program
for Substance Involved Pregnant and Parenting Women in Thunder Bay:
Exploring the Perspectives of Service Users**

Research Team: L. Bishop, K. Jones-Bonofiglio, J. Cotnam, R. Turuba, in collaboration with the Thunder Bay Drug Strategy, Maternal Substance Use and Child Working Group

Funding support by: TBRHSC/RI Research Seed Funding Grant

Acknowledgements

The research team wishes to first and foremost acknowledge the mothers who participated in this project. We are grateful for their brave choice to participate, generosity in sharing their experiences and expertise, and commitment to helping others as an outcome of this project.

We also thankfully acknowledge members of the Thunder Bay Drug Strategy Maternal Substance Use and Child Working Group and Research Sub-Group, and all the collaborating local community organizations for their contributions to the Mothers' Voices project. We would also like to acknowledge the contributions of graduate students Ms. Roxanne Turuba and Mr. Nikzad Eskandarkhalaj for their extensive literature review activities. The research team acknowledges the kind assistance and expertise of Ms. Erica Sawula at the Thunder Bay District Health Unit for her contributions to the use of data contained in the BORN Data Repository.

This project was funded by a Thunder Bay Regional Health Sciences Centre/ Research Institute (TBRHSC/RI) Research Seed Funding Grant (\$10,000; 09/2017) for the proposal titled, "Creating an Integrated Service Delivery Program for Substance Involved Pregnant and Parenting Women in Thunder Bay: Exploring the Perspectives of Service Users." Ethical approval for this research was obtained with three amendments.

SUMMARY REPORT

Research Study

Purpose: to inform decisions for changes to local service provision and delivery for mothers* with the lived experience of substance involvement and their children.

**Hereafter in this report, the term mothers will refer to women who are pregnant/parenting with the lived experience of past or present substance involvement and includes women who have children in foster care or adoptive circumstances.*

Lay Summary of Research: In a successful collaborative effort with twenty-eight local community organizations, this project facilitated focus groups and expert consultant interviews with mothers to explore their experiences with services for health, social, and recovery needs in Thunder Bay, Ontario, Canada. The results of this project will inform the Thunder Bay Drug Strategy Maternal Substance Use and Child Working Group (TBDS-MSUCWG) in the collaborative development of an integrated service delivery strategy for this population in Thunder Bay.

Research Question: From the perspectives of mothers, what are the factors that help and what are the factors that act as barriers when accessing services for health, social, or recovery needs in Thunder Bay?

Research Methods:

Phase One utilized a focus group approach with mothers (18 total), facilitated by a mother with the past experience of substance use (in a stable phase of recovery). There were no audio or video recordings of the focus group sessions. Data were collected using a flip chart to document discussions and confirm details with participants at the end of the focus group session (member checking). Researchers took their own detailed field notes. Participants were asked about their personal experiences with medical, counselling, and social services providers and organizations.

Phase Two utilized one-to-one interviews with mothers (5 in total) to receive feedback on the findings from Phase One and to have mothers' input on preferred future knowledge translation activities. Due to the high level of stigma (and perhaps also fear/anxiety) related to being a woman and mother who is/was substance involved, this phase did not include video recording or transcription of any of the interview sessions.

Findings: Findings from an extensive academic literature review, three focus group sessions with 18, and five expert consultant interviews are presented collectively and descriptively, with attention to key themes about potential priority areas. A comprehensive final report has been provided to TBDS-MSUCWG.

This summary report of the research will be disseminated to all partnering local community organizations and local stakeholders (upon request) to contribute mothers'

perspectives to future decision making about local service provision and delivery models. Further, in an effort to make the finding more fully accessible the following documents have been created:

- Research Snapshot (see Appendix A)
- Community Poster (see Appendix B)
- Phase One Academic Poster (see Appendix C)
- Vignette & Video (see Appendix D)

Knowledge Translation Activities

Dissemination of the study findings is ongoing and occurring on multiple levels.

It has been presented locally at two events in February 2019 (St. Joseph's Research Showcase; Lakehead University Research & Innovation Week, Faculty Research Day).

Still to come are local community presentations with service providers and mothers, as requested by collaborating organizations.

Lakehead University Centre for Health Care Ethics will host presentations on this project on May 22 and 23, 2019. An article about these events will be submitted to the Chronicle Journal newspaper. The presentation will also be available via video-conference to the Northwestern Ontario Region and live webcast on May 23/19. For further information please contact the Centre for Health Care Ethics via email at chce@lakeheadu.ca.

Also, the study will be presented internationally at the Schwartz Center Compassion in Action Healthcare conference in Boston, MA, in September 2019.

An academic manuscript of the literature review for this study was submitted to the journal Women & Health in April 2019. It is currently pending review. Two separate academic manuscripts are in preparation for submission to peer-reviewed journals on the study findings and the study methodology, respectively.

Conclusion & Next Steps

The purpose of this study was to explore mothers' perceptions of local service experiences. These findings should be used to inform and support local decision making among health, counselling, social and addiction services and providers. The results of this study should have a direct impact on decisions made by, for, and with MWSI in Thunder Bay, ON.

The TBDS-MSUCWG has considered a spectrum of integrated care options such as a brick-and-mortar hub that all/most services could be delivered from, a virtual hub (a.k.a. care pathways) that service providers could navigate with/for clients, or a middle ground with champion organizations that would provide partnered services in a single or shared location.

Appendix A: Research Snapshot

Community Engaged Research: Mothers' Voices Thunder Bay



April 2019

Creating an Integrated Service Delivery Program for Substance Involved Pregnant and Parenting Women in Thunder Bay: Exploring the Perspectives of Service Users



Background: The criminalization of substance-use in pregnancy, meant to deter women from using, has been largely ineffective. In fact, mothers with substance-involvement (MWSI) and their children are placed at greater risk for adverse health outcomes, as this deters women from seeking health care and support due to the potential personal, social, and legal consequences. Harm reduction models have been recommended for addressing substance-use in this population, which aims to empower women and facilitate their engagement in supportive programs based on their individual needs. These types of strategies encourage safer practices and better outcomes.

Keywords: *substance use, women, pregnant, parenting, health care access and delivery, qualitative research*

What is the research about? The goal of this study is to inform decision-making about local practice and service delivery.

What did the researchers do? Funded by a Research Seed Funding Grant from Thunder Bay Regional Health Science Centre (TBRHSC)/Research Institute, three focus groups were held (18 women), followed by individual interviews (5) with MWSI as research consultants. Also, a systematic literature review was conducted to assess the existing qualitative studies on MWSI's experiences accessing services. This study involved over two dozen local collaborating organizations.



Thunder Bay Regional
Health Sciences
Centre

What did the research find? MWSI continue to experience stigma from society, services, social networks, care providers, and even from themselves, hindering their ability to access safe and effective care.

Theme #1- Self. Based on the literature review, women reported feelings of low self-esteem and abandonment related to past traumas, and often lacked assertiveness as they felt undeserving of support. Substance use also appeared to be associated with feelings of guilt, shame, and fear. Recognizing women's efforts, strengths, and other roles beyond their addiction allowed women to feel capable and helped them develop positive coping strategies to prevent relapses.

Theme #2- Provider Relationships. Care providers' relationships with MWSI appeared to be one of the most influential factors hindering or facilitating women's access to social and health services, as well as instigating or reducing fears of child apprehension. Applying a trauma-informed approach when caring for MWSI was found to be important, as many reported histories of traumatic events. The following care provider attributes were associated with positive and empowering experiences:

- Respectful
- Trusting (includes confidentiality)
- Non-judgmental
- Comprehensive knowledge of addiction
- Providing support (versus punishment)
- Client-focused, individualized approach
- Promoting self-efficacy and self-confidence
- Recognizing the value of children in their lives

Theme #3- Social Networks. Sober and non-judgmental friends and family were also important for providing ongoing support, alleviating extrinsic barriers, and increasing service utilization. The following social interventions assisted recovery:

- Helping women disengage with substance-using networks.
- Educating friends and family members about addiction.
- Encouraging women to re-evaluate unhealthy relationships with family members and/or romantic partners.
- Accessing support groups with other recovering substance-users to decrease feelings of isolation and normalize their struggles.

About the researchers:

Dr. Kristen Jones-Bonofiglio is Director, Centre for Health Care Ethics and Assistant Professor, School of Nursing, Lakehead University, Thunder Bay, ON.



Theme #4- Structural Barriers. These factors exacerbate women's situations and include financial barriers, lack of transportation and childcare, unstable housing, and problems navigating health and social care systems. Women felt that providers and organizations were unaware of the challenges they face as MWSI. Women wanted access to reliable information and education to understand and address problems in their lives.

Further, women want coordination between and among services and service providers. This includes social welfare, legal services, mental health services, housing, financial services, and addiction treatment services, which would ideally be located in the same location. Based on the literature, integrated care models appear to provide women with better support overall, as they help women solve barriers to accessing care and provide services based on their individual needs. Integrated service models also appeared to reduce care provider misconceptions/stigma about substance use due to the continuity of care among multidisciplinary teams. However, this was not always the case, demonstrating that the coordination of care may not be as important as having appropriate staff attributes.

How can you use this research? Findings from this study are intended to guide local decision making about services (what is offered) and service provision (how it is provided) for both MWSI and their children. This research is for care providers and organizations who care for and about MWSI and their families. This research may also inform policy makers to enhance service access and delivery and provide further insight into educational and professional development needs for health and social services professional students and providers.

Ms. Lisa Bishop (Principle Investigator) is Associate Staff at TBRHSC and an Anishinabe Registered Midwife at Dilico Anishinabek Family Care, providing specialized care to highly marginalized and/or substance involved women and families.

Ms. Jasmine Cotnam has an educational background in addiction and mental health and holds a social service worker diploma. She is a research coordinator at Women's College Hospital and an APHA liaison at the Canadian Aboriginal Aids Network.

Ms. Roxanne Turuba holds an MPH (Lakehead University) and is a Research Assistant for Dr. Jones-Bonofiglio and the Centre for Rural and Northern Health Research (CRaNHR), coordinating research projects on women's reproductive health.

Appendix B: Community Poster

Mothers' Voices Research Project

Kristen Jones-Bonofiglio, Lisa Bishop, Jasmine Cotnam, & Roxanne Turuba

What we did: We asked mothers with substance involvement about their experiences with local health, counselling, social, and addiction services. We teamed up with the Thunder Bay Drug Strategy- Maternal Substance Use & Child Working Group and 28 local community organizations.

- **3 focus groups** (total of 18 mothers), led by a researcher who is a mother with past experience of substance involvement.
- **5 expert consultant interviews** with mothers with substance involvement to review the findings and give us ideas about how to share this work with others.

Findings: Positive relationships are very important, with self and with others.

Providers need to listen and understand more about a woman's story. Providers need to learn about who I am, how I got here, how I feel, and what I need right now.

Ask me about...

- How being a mother matters, but is really hard.
- How trauma is linked to addictions.
- Past experiences with service providers.
- Connections to partner, family, and/or community.
- Needs for services and resources, such as financial assistance, food, housing, bus tickets, baby items, child care, mental health services, and addiction treatment options.

Research over the last twenty years confirms these findings. Many women feel judged by service providers when accessing health, social, or addictions services. They report feeling afraid to lose their children to child welfare and being punished for their efforts. They want to be understood, respected, supported, and cared for in their roles as mothers. Harm reduction approaches, trauma informed perspectives, a strengths-based focus, and integrative care models can contribute to better outcomes.



THUNDER BAY
Drug Strategy



Each petal on the flower suggests a way to support the health and well-being of mothers with substance involvement and their children.

Questions?

Please contact:
Kristen Jones-Bonofiglio
Email: Kristen.Jones@lakeheadu.ca, or
Lisa Bishop Email: bishopl@bh.net

Acknowledgements: Thank you to the mothers who were part of this study!

Funding: TBRHSC/RI Research Seed Funding Competition Grant

Appendix C: Phase One Academic Poster

Listening to Mothers' Voices: Substance Involvement & Local Service Needs

K. Jones-Bonofiglio, L. Bishop, J. Cotnam, & R. Turuba



Background/objectives: Women who are pregnant and/or parenting and substance involved are typically viewed as a hard to serve population. Poor outcomes not only impact these mothers, but also their children. The purpose of this qualitative (descriptive) research is to inform practice and service delivery in Thunder Bay, Ontario for individuals and organizations working with and caring about substance involved mothers.

Methods: Following the manifesto of "nothing about us without us," we reached out to mothers to hear their voices and concerns about issues of substance involvement and their experiences with local medical, counselling, social, and addictions services. We collaborated with the Thunder Bay Drug Strategy- Maternal Substance Use & Child Working Group and 28 community organizations. The research team held three focus groups with a total of 18 mothers, led by a research facilitator who is a mother with past experience of substance involvement. We provided a \$25 cash honorarium, bus tickets, on-site child minding, and a meal for all participants.

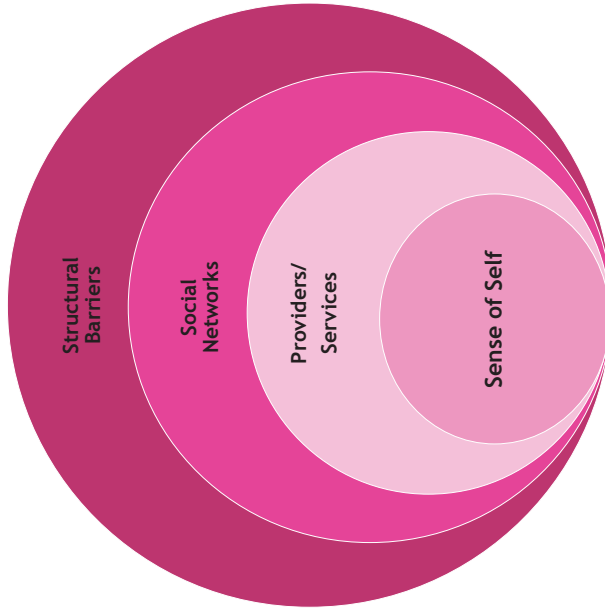
Results: According to the participants in this study, mothers who are substance-involved continue to experience stigma and discrimination from society, care providers, and social structures, hindering their ability to access safe and effective care.

Key themes include:

- 1) structural barriers;
- 2) social networks;
- 3) providers/services; and,
- 4) sense of self.

These inter-related themes are described with a socio-ecological model (see left) and further explored within the context of a recent comprehensive literature review using a multi-petal flower diagram (see right) designed by R. Turuba.

Conclusion: This study is now moving into phase two. Mothers' will be interviewed one-to-one as expert consultants on the findings of this study. They will inform next steps in future knowledge translation activities and may choose to be included as co-authors and co-presenters. All community partners will receive a summary report of the completed study that should inform decision making about current practices and service delivery models.



Thunder Bay Regional Health Sciences Centre



Questions?

Please contact:
 Dr. Kristen Jones-Bonofiglio
 Email: Kristen.Jones@lakeheadu.ca or
 Ms. Lisa Bishop Email: lishop@trbh.net

Acknowledgements:
 Funding: BRHSC/RI Research Seed Funding Competition Grant
 Other contributions: Primary literature review for this project completed by MPH student Nizad Eskandarkhalaj. Updated literature review completed by MPH student Roxanne Turuba. Thank you!

Appendix D: Vignette & Video

MWSI Vignette

This case study was created by focus group participants during one of the sessions. It is offered here as a resource for service providers and organizations to stimulate discussions about mothers' experiences and strategies to create positive change. This vignette does not depict a real person or single experience.

Martha is 28-years old and from Kakabeka, Ontario. Her family doesn't like her boyfriend. They don't know it but he does coke and crack. Martha gets pregnant. When she goes to the doctor she is told that she is losing weight. After this continues for a few appointments the doctor mentions CAS. Martha has anxiety. She desperately wants to keep the baby. The doctor orders a drug test. Martha used one time on payday, otherwise she has been sober. Her doctor tells her that she needs to be a good parent. What is that supposed to mean?

MWSI Video

This video was created by the research coordinator from real details noted during this research project. There is nothing here that was not specifically mentioned by MWSI. This video is offered as a resource (as an alternative to written information) for service providers and organizations to stimulate discussions about mothers' experiences and strategies to create positive change. This video does not depict a real person or single experience. It is 2 minutes 36 seconds long.

Access at: <https://videos.mysimpleshow.com/iyx94t3Qo0>