Prenatal Opioid Exposure and Neonatal Abstinence Syndrome: A Research Project with 13 First Nations Communities in Ontario

Summary Report

CHILD-BRIGHT Network

IC/ES

Publication information

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Language used in this report

This report was written for and with the First Nations communities involved in this project. We have tried to use language that is accessible to a broad audience. In addition, although the terms "women" and "mothers" are used throughout, we note that these terms may not describe all pregnant people, such as those who identify as transgender or nonbinary. In discussions with the Core Research Team and participating communities, these terms were thought to be the most accessible for the report. In addition, for the sections on the data that were collected, it should be noted that the administrative health data that are available do not have variables on self-identified gender, and the language of the qualitative data collection focused on women and mothers.

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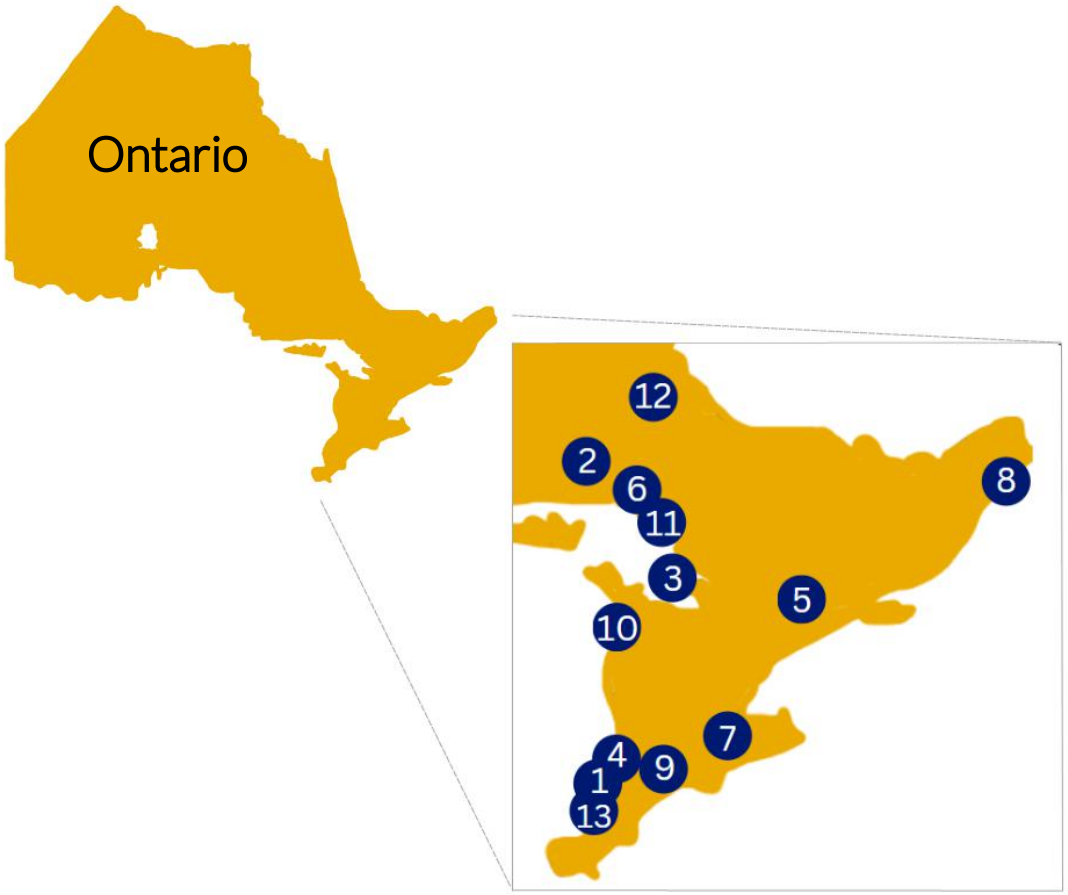
The 13 First Nations communities who participated in this project are:

1. Aamjiwnaang First Nation
2. Atikameksheng Anishnawbek
3. Beausoleil First Nation
4. Chippewas of Kettle and Stony Point First Nation *(participated in the quantitative research only)*
5. Curve Lake First Nation
6. Henvey Inlet First Nation *(participated in the quantitative research only)*
7. Mississaugas of the Credit First Nation
8. Mohawk Council of Akwesasne
9. Oneida Nation of the Thames
10. Saugeen First Nation #29
11. Shawanaga First Nation
12. Temagami First Nation
13. Walpole Island First Nation

Community partners span the lower half of Ontario, Canada, and include those that are close to urban centres to those in more rural and remote areas, on islands, and along the Canada–United States and Ontario–Quebec borders.



The authors wish to thank the participating First Nations for their partnership on this project. These communities prioritized research on prenatal opioid exposure, provided extensive guidance, and undertook community outreach. The result is a project that is founded on community strengths, knowledges, and needs of the participating communities.

We want to acknowledge the individual participants from all communities who shared their experiences and perspectives on prenatal opioid exposure.

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Background

Canada has been significantly impacted by the global opioid crisis. High rates of opioid use and addiction are the result of a complex set of factors, with contribution from the overprescription of opioids for the management of long-lasting pain, increasing opioid use for purposes other than those intended or prescribed, and the availability of powerful illegally obtained opioids such as fentanyl. Indigenous communities have raised significant concerns regarding opioid-related harm and deaths, including those affecting pregnant women and youth. For First Nations communities, opioid addiction is often the result of individual, collective, and intergenerational trauma, and those same communities hold the knowledge and solutions to support intergenerational healing.

This research project was initiated in response to concerns raised by several First Nations communities in the lower half of Ontario about the health of school-age children exposed to opioids prenatally. A research team was formed, which included First Nations and non-Indigenous team members with expertise in working with First Nations communities, child and maternal health, mental health and addictions, and community-engaged health research. Thirteen First Nations communities participated in this project. By working with the project team, participating First Nations communities aimed to learn more about the impact of prenatal opioid exposure on children, mothers, families and caregivers, service providers and educators, and the community at large – within each First Nation and across all participating First Nations.

Prenatal opioid exposure and neonatal abstinence syndrome: definitions

Prenatal opioid exposure is when babies are exposed to opioids before being born. This happens when a mother takes opioids during pregnancy. Opioids include:

- Those prescribed to help control pain
- Opioid agonist therapy such as methadone or Suboxone to treat opioid use disorder
- Those that were made or obtained illegally such as fentanyl or heroin

Babies exposed to opioids prenatally can be born prematurely and may go on to experience behavioural, physical, social, and mental health issues. Environmental risk factors also shape a child's health and development, such as exposure to other substances like alcohol during pregnancy, poverty, instability in the home environment, caregiver quality, and maternal mental health issues. Interventions and supports for children, mothers, and families impacted by prenatal opioid exposure can improve long-term outcomes.

Neonatal abstinence syndrome (also known as neonatal opioid withdrawal syndrome or NOWS) is when babies go through withdrawal after prenatal opioid exposure. Common symptoms include inconsolable crying, poor feeding, shaking, tremors, fever, vomiting, and diarrhea. Some babies require a short course of medication and often a longer hospitalization, but many will respond to skin-to-skin contact and other soothing interventions.

Not all babies with prenatal opioid exposure will go on to experience signs of withdrawal. It is most common in infants of mothers treated with opioid agonist therapy, especially methadone. However, there is strong medical consensus that opioid agonist therapy should not be discontinued during pregnancy as it treats the symptoms of opioid use disorder and reduces the use of illegally obtained opioids which improves the pregnancy outcomes for both the mother and baby.

Research approach

Information on prenatal opioid exposure, neonatal abstinence syndrome, and the health of mothers and babies was compiled using existing health records information from 2003 to 2019. The health records are housed at ICES and governed by First Nations. Qualitative information was gathered from focus groups and interviews with people who have personal lived experience, families and caregivers, health and social service providers, educators, Elders, and community leaders and members. The qualitative research explored the impacts of prenatal opioid exposure, the strengths in communities to address the issue, and strategies that could be implemented to further prevent prenatal opioid exposure. This project was grounded in First Nations' understandings of well-being and a strengths-based approach with the goal of using the research to shift from patterns of intergenerational trauma to intergenerational healing.

Recognize
the issues

The numbers

The following is a short summary of the main findings.

The health records data showed that:

- 10.2% of babies born in the 13 participating First Nations between 2013 and 2019 had prenatal opioid exposure, compared to 1.7% of all babies born in Ontario.
- Patterns of prenatal opioid use have changed over time for the 13 First Nations, with an increase in the percentage of babies with prenatal opioid exposure from 9.8% in 2013 to a peak of 12.8% in 2015, and then decreasing to 7.2% in 2019.
- 4.2% of babies born in participating First Nations between 2003 and 2019 were diagnosed with neonatal abstinence syndrome, compared to 0.5% of babies born in Ontario overall.
- On average, babies with prenatal opioid exposure from the 13 First Nations were more likely than babies without prenatal opioid exposure to be:
    - Born early (before 37 weeks gestation)
    - Need a higher level of care (neonatal intensive care unit)
    - Stay longer in the hospital after birth (six days versus three days after birth)
    - Removed from the mother's care at birth
- On average, mothers from the 13 First Nations who used opioids or were treated for opioid use disorder during pregnancy had two previous children and were more likely than mothers who did not use opioids during pregnancy to receive care at a hospital in the two years before delivery for substance use or mental health issues.

- When comparing the mothers from participating First Nations to all Ontario mothers who used opioids during pregnancy:
    - A much higher overall proportion were being treated for opioid use disorder (66% versus 39% for Ontario), fewer were on long-term prescription opioids for pain control (17% versus 45% for Ontario), whereas rates of use of opioids that were likely obtained illegally were similar.
    - Amongst those mothers on opioid agonist therapy, prescribing of buprenorphine versus methadone for First Nations pregnant women was lower overall and did not increase as much between 2013 and 2019 compared to the rest of Ontario (19% to 34.9% for Ontario, versus 9.9% to 20% for the 13 First Nations). Professional guidelines now recommend buprenorphine alone, or with naloxone (Suboxone), as safe for use during pregnancy, and having fewer side effects than methadone for the infant. While the decision around which medication to use may reflect the healthcare provider's recommendation and the mother's preference, it also relates to which treatments are accessible.

The impact of opioid use on communities

Prenatal opioid exposure and neonatal abstinence syndrome have far-reaching impacts. Participants spoke about the increase in opioid use in First Nations communities over the last 15 years, including in pregnancy. They shared that the impacts of the drug trade and substance use in the community were very visible. Within communities, participants spoke about higher rates of crime, violence, suicide, and death due to overdose or toxicity. In many communities, people expressed concern that youth were experimenting with substances, including prescription medication, at a young age. Most thought these issues were getting worse and were troubled that opioid use was becoming increasingly normalized. Geographic location was seen as an issue for some First Nations communities with increased access to drugs due to being close to the United States border, or geographic isolation, resulting in higher rates of unemployment, poverty, and substance use.

> *"A big part of it is our community as a whole is kind of ignoring the problem. It's almost becoming normal to see this stuff happening. It's crazy, but it's becoming the norm. I keep saying if our whole community would get on board and admit that we have a huge problem here that we could actually work toward fixing it. Young people are dropping dead. Even community leaders' families are being impacted. I personally thought that would be the wakeup call for the community, but nope. We're waiting for the next funeral."*

In almost all communities, participants explained that opioids were cheaper and more accessible than other substances. They discussed the highly addictive nature of opioids and how it is one of the hardest drugs to stop because of the severe withdrawal symptoms. Across communities, participants pointed to the role of some health professionals in the opioid crisis and the overprescription of opioids and opioid agonist therapy by doctors to First Nations people with non-Insured Health Benefits coverage. They characterized this as a targeted practice of "preying on the weak" to make money.

The link between poverty and opioids was discussed by many. For example, they described some seniors selling their medication for added income due to the high cost of living, and were concerned that their communities are turning a blind eye to the issue. Many shared stories of opioid use being an issue for all people, including those with good reputations or high social status in the community.

Participants in every community spoke to the relationship between addiction and trauma, including intergenerational trauma related to the residential school experience. They explained that individuals who use opioids and other substances often experience domestic violence. Some community members commented on sex work by women to support their addiction, and some become pregnant. People shared concerns about high rates of sexual abuse, and participants from some communities raised the issue of human trafficking.

Most participants remarked on the intergenerational cycle of substance use and how people living with trauma might turn to opioids and other substances as a coping mechanism to numb their pain. People expressed that the opioid epidemic had in some ways eroded the relationships that held their community together — rather than community members working to help each other, many described feeling fractured and tired due to the overwhelming loss and resulting grief.

The impact of opioid use on babies and children

Concerns were raised about the impacts of high rates of child apprehension, foster care, and adoption of First Nations children outside of their communities. Participants identified the shortage of foster care parents in communities as a challenge. A lack of secure attachment and bonding resulting from the separation of mother and baby due to a higher level of medical care required in hospital, apprehension, or neglect resulting from substance use at home were seen by participants as leading to poor outcomes for children. Many discussed the intergenerational impact of trauma on early attachment — parents may struggle to establish secure attachments with their baby if they did not experience this with their own primary caregiver.

Participants shared that prenatal opioid exposure can impact children's physical, social, mental, emotional, and spiritual well-being — and they thought these impacts can be lifelong. Those who care for and work with children with prenatal opioid exposure pointed to issues with speech and language, motor development, attention, self-regulation, and hyperactivity. Importantly, many reported that some children exposed to opioids prenatally had no developmental challenges, and that for others, the impacts may not be seen until they're older. Some participants remarked on the lack of research on the long-term effects.

> *"Over the years, I get a lot of different difficult situations in my work, and something I've always done is I've gone to see kids at the daycare. Just for the energy. I like going because I like seeing those happy eyes. Those beautiful, brown, happy eyes. But I notice some of them happy eyes now aren't happy. They're not focused. You can see developmentally, the delays or difficulties they're having. I'm not a professional, but the children's energy is starting to become different. That's just something I've noticed over the past bit of time."*

Participants from all communities acknowledged the difficulty in determining if these health and developmental challenges were solely related to prenatal opioid exposure or other factors such as family and social issues. They raised the breakdown of the family unit and children living in unhealthy environments as large concerns. Participants remarked that children are keenly aware of the reality in their homes and communities. They spoke about children being exposed to situations such as family violence, parental drug use and drug paraphernalia in the home, sex work, police intervention, the death of a parent from an overdose, and poor parenting practices. They described that these experiences result in trauma for children that have lasting impacts, and with which they need help to understand and process.

“Sometimes you are not too sure whether all of the effects are specifically because of substance use or if some of the effects are linked to the whole bio-psycho-social.”

The impact of prenatal opioid exposure on mothers

Participants reported that many community members who use opioids during pregnancy experience stigma, judgement, gossip, lack of confidentiality, and rejection by family, healthcare providers, and their community. Participants described affected mothers as carrying an enormous fear of having their baby apprehended at birth, which often keeps them from disclosing their opioid use. These experiences can impact women and their babies negatively in multiple ways, including hiding their pregnancy, avoiding or delaying prenatal care, not seeking out support from their family and the community, social isolation, termination of pregnancy, and poor mental and spiritual health and well-being. Many participants spoke about the strong grip of addiction that makes it difficult for mothers to appreciate the consequences of their opioid use on them and their babies. However, some provided examples of pregnancy motivating mothers to seek treatment. Participants indicated the importance for healthcare providers and community members to understand why mothers use opioids. Participants agreed that past and current trauma underpin opioid use and addiction.

Although participants had different opinions on the role of opioid agonist therapy in treatment, all agreed that most mothers on opioid agonist therapy did not receive the counselling or other treatment approaches necessary to return to good health. While those who took methadone during pregnancy thought that it was a healthy choice, some reported not having been adequately advised about the side effects, including the potential for neonatal abstinence syndrome. Participants also commented on opioid agonist therapy being overprescribed to First Nations people, women being kept on higher doses for long periods of time, and a lack of plans for weaning.

Many participants agreed that during childbirth First Nations mothers were often treated poorly in hospitals, experiencing both anti-Indigenous racism and discrimination for their opioid use. Many shared stories of traumatic and clinically complex births, inadequate pain management during labor and delivery, healthcare providers who did not understand addiction, and the presence of child protective services immediately after delivery. The lack of ability to bond with their baby due to apprehension or the baby going to the neonatal intensive care unit often amplified their trauma. Many mothers spoke about being alone in the hospital, without support or an advocate. Participants reported that mothers were often discharged without the appropriate supports in place and had limited access to treatment facilities, as most do not allow mothers to be accompanied by children. Participants explained the difficulty for mothers who may not have a caregiver for their children while seeking treatment, and do not want to depend on foster care for fear that they won't get their child back.

Participants shared that the fear and threat of apprehension persists after discharge from hospital. The continuous scrutiny of the Children's Aid Society, even with family support, is very stressful for parents. Some mothers expressed feeling guilt and shame because of feedback about the higher needs of their children at school or in the community. Even if the child thrives, they described staying on high alert watching for signs of difficulty. Most mothers shared that one of their biggest fears is that their children would grow up and face addiction.

> *"I could never have pictured myself to ever choose anything over my child, but I did, and that is still heavy. A real big guilt – to know all that pain. I mean it finally clicked. It finally triggered for me to heal; to heal those traumas and to work endlessly to fix that. Because I couldn't bear to ever put my baby through that again, or me for that matter."*

The impact of prenatal opioid exposure on families and caregivers

Participants shared the challenges of caring either for a pregnant family member on opioids, or subsequently for their children with prenatal opioid exposure. They spoke about the strain from sleepless nights, constant worry, and the frustration of not being able to help, or not knowing if their daughter, sister, or partner was alive. Many explained how challenging it can be to understand addiction and why people who use drugs can't stop, especially pregnant women knowing it can affect the baby. As a result, many family members and caregivers described feeling anger, fear, shame, resentment, and a sense of powerlessness. They spoke to the struggle between wanting to help their adult children and enabling their continued addiction. On top of these issues, many participants spoke about the stigma they experienced because of their family member's substance use.

> *"The sleepless nights. You never know from one day to the next whether your child is going to be alive."*

Participants described the incredible role that families and caregivers, including aunties, uncles, siblings, grandparents, and great-grandparents play in raising children impacted by prenatal opioid exposure. In all communities, participants reported that grandparents and great-grandparents are often the caregivers when parents are not able due to their substance use. Grandparents are often pressured into raising their grandchildren so that they can stay in the community and out of foster homes. Participants described the challenges that grandparents face in assuming this role, in particular those who are older or in poor health. Participants spoke to financial hardships associated with raising grandchildren, along with the physical and emotional demands, especially without the necessary training and resources to support children with developmental issues. Despite all the challenges, there were many stories of resilient families and grandparents raising healthy children, even in the face of adversity.

The impact of prenatal opioid exposure on service providers and educators

Service providers shared how much they love and care about their community and their commitment to improving members' health and well-being. However, they reported being overwhelmed due to prenatal opioid exposure with high rates of turnover due to burnout. Service providers spoke about the stress of trying to create workable solutions within tense family situations, such as finding foster families. In many communities, participants expressed that there are too few service providers in the face of increasing demands for support, counselling, and help to access treatment due to the opioid crisis. Staff reflected on doing their best, but workloads were unsustainable and jeopardized their health, well-being, and home life. In addition, educators in daycares and schools described numerous challenges related to the higher needs and behavioural issues of some affected children.

Participants highlighted communication challenges between hospitals, doctors, and community-based health and social service providers, particularly after an infant leaves the hospital. Health and social services departments often work in silos, preventing optimal care for mothers and babies. They also raised the issue of staff needing to be more knowledgeable about programs and services available within and outside their communities.

See the
Resilience

The strengths

Love, family, community, and people

There were many strengths and strategies addressing prenatal opioid exposure that existed in the participating First Nations communities. Across communities, participants spoke about the strength of love, family, and community. People also shared stories that illustrated the transformative role that compassionate responses play in reducing blame, shame, guilt, and judgement. Participants held the perspective that all children are gifts and recognized the strength and resilience of those with prenatal opioid exposure.

People shared examples of passionate and strong people working to make positive changes in their communities. These included reaching out personally to people, providing transportation and links to services, and being a trusted person. Participants named specific programs in communities, and in some cases "wraparound" services where diverse healthcare professionals and service providers worked in a coordinated way to provide high-quality care to mothers, children, and families. Daycares and schools were recognized as providing consistent and structured environments for children, serving as a venue to address some of the challenges children exposed to opioids prenatally may face.

Although participants identified challenges living in small communities, such as issues with gossip, most were quick to identify that their community was tight-knit, and people cared immensely for one another. Similarly, while many people stated that leadership needed to develop a better understanding of opioid use and prenatal opioid exposure, many thought that their community leaders were becoming increasingly aware of the issues and impacts related to substance use and addiction.

Finally, participants noted Jordan's Principle as a critical potential funding source for products, services, and supports for families.

“My family would remind me of how I used to be and how it was. And how I was different. They reminded me all the time; it wasn't just one day. It does make you think when somebody tells you, ‘Oh my God, I don't know what I would do without you’ or ‘You're such a good person.’ It does do something to you as a person; that you're important, that you matter. If you don't have somebody there telling you that, then you just think that if I die tomorrow nobody would notice.”

Plan to

Respond

The response

All participating communities are working to address opioid use in their communities and some of the suggested strategies specific to pregnant mothers, their children, and families have been implemented in some communities. The following summarize the range of community-led strategies participants shared that could further address the impacts of prenatal opioid exposure, many of which they wanted their community leaders, including Chief and Council, to support.

Support for mothers

Wraparound care in pregnancy and through childrearing

- Skilled first point of contact to establish rapport and trust
- Compassionate and nonjudgemental healthcare providers knowledgeable about addiction and pregnancy
- Meeting mothers "where they are at" and letting them determine their care pathway
- Counselling or therapy to identify and address trauma
- Expanded, cross-disciplinary circles of care to meet diverse needs of families

Improved support for in-hospital birth

- Explicit discussions with health or social service providers prior to delivery on:
  - Pain management during childbirth
  - Neonatal abstinence syndrome and the potential for the infant to require intensive medical care, medication, and longer stay in hospital
  - Potential involvement of the Children's Aid Society and Indigenous Child and Family Well-Being Agencies
- Hospital visits and advocacy from community-based staff to ensure mothers:
  - Receive high quality care and emotional support
  - Have what they need while in hospital and to take the baby home (e.g., car seat and transportation)
- Options to facilitate early bonding, skin-to-skin contact, and breastfeeding such as rooming in or extending maternal hospital stays
- Coordinated discharge planning between the hospital and community-based health and social service providers to promote continuum of care

Improved support once mother and baby are home

- Formal (professional) and informal (e.g., community grandmothers and aunties) home visits, respite care, and help with childcare and other household responsibilities
- Programs that promote bonding and attachment
- Personalized outreach and warm handoff for services
- Peer support and mentorship programs to expand mothers' network of support, promote mental health, and reduce insolation
- Caring and encouraging words and gestures, and celebrating small successes such as a mother adhering to her opioid agonist treatment program

Education in healthcare settings on the:

- Impacts of prenatal opioid exposure
- Side effects of opioid agonist therapy, including neonatal opioid withdrawal syndrome
- Healthy childhood development and parenting

Addressing the needs of families and caregivers

- Practical training on caring for children with complex needs and parents with substance use disorders
- Long-term plans for children that take into consideration the age, disability, and potential death of the grandparent caregiver
- Specialized mental wellness services, respite care, and a dedicated support group
- Focused programming for men/fathers

Appropriate services for children

- Greater access to qualified professionals like nurses, speech pathologists, counsellors, and occupational therapists in communities
- Increasing and maintaining strong relationships between community health and social service providers with specialists and children's development centres outside the community
- Enhanced developmental screening and assessments for babies and children
- Infant, toddler, and child mental health supports and counselling for children with prenatal opioid exposure to process their trauma
- Programs to build social skills and improve emotion regulation

Support for daycares and schools

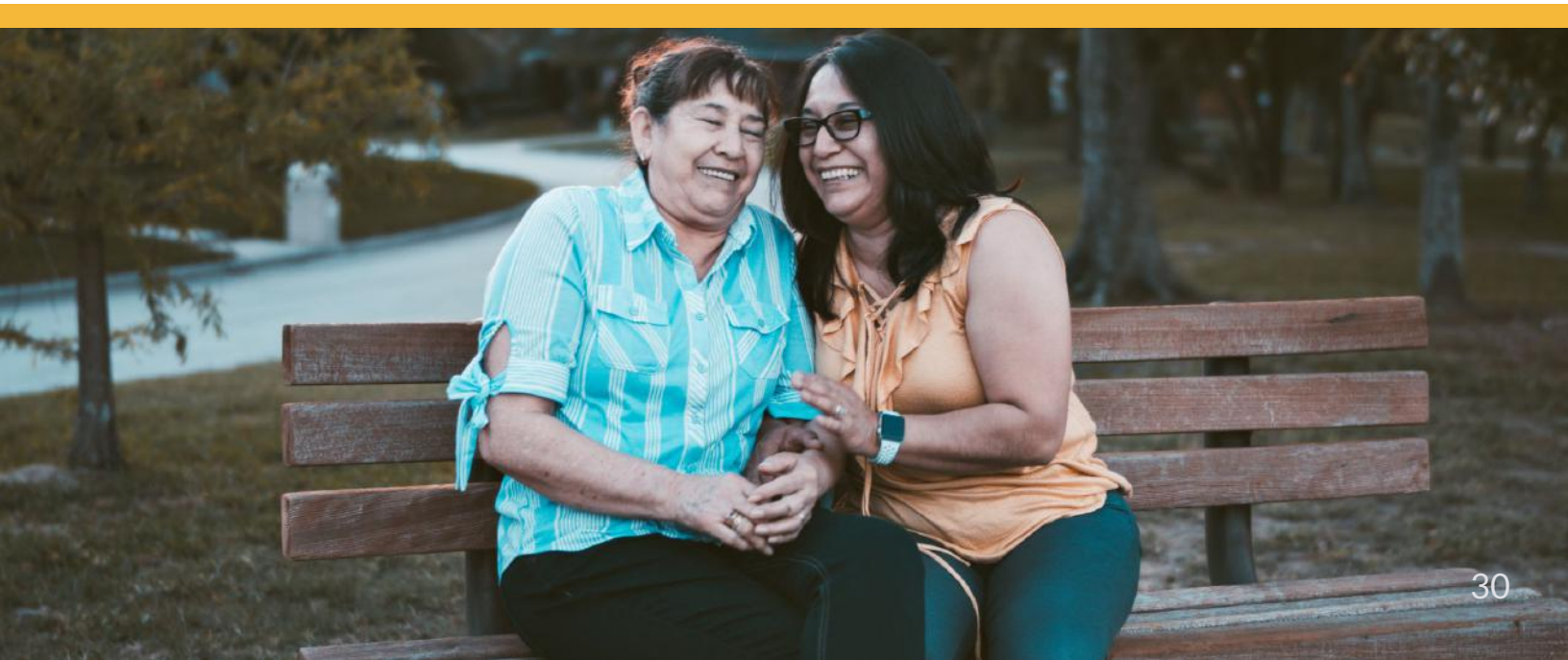
- Training on how to better support children with complex needs
- Greater access to qualified professionals such as educational assistants, teachers, counsellors, and mentors
- Dedicated therapist in the school to support children's emotional health
- Universal developmental screening and assessments for early identification and interventions
- Age-appropriate education on substance use and sexual health
- Programs to help build social skills and improve self-regulation such as art, music, play, and recreational therapy

Support for service providers and educators

- Adequate staffing to address the growing mental health and addictions crises in communities
- Trauma-informed approaches
  - Professional training on trauma-informed care
  - Education and healing initiatives related to intergenerational trauma and its impacts
  - Strategies to address stigma and promote understanding, compassion, and support for people impacted by addiction
- Ongoing training on addictions, mental health, prenatal opioid exposure
- Accessible and up-to-date information on programs and supports within and outside the community
- Regular cross-departmental meetings
- Support with job stress and burnout, including regular debriefing meetings, and self-care as part of the culture of service provision
- Increased outreach and consultation with community members to inform programming

Improvements for the foster care system

- Better training and support for foster families to take in children from the community or provide respite care
- Changes to foster family eligibility criteria so that more children can stay in the community
- Improved communication with foster families and more background information about the children so they can provide better care

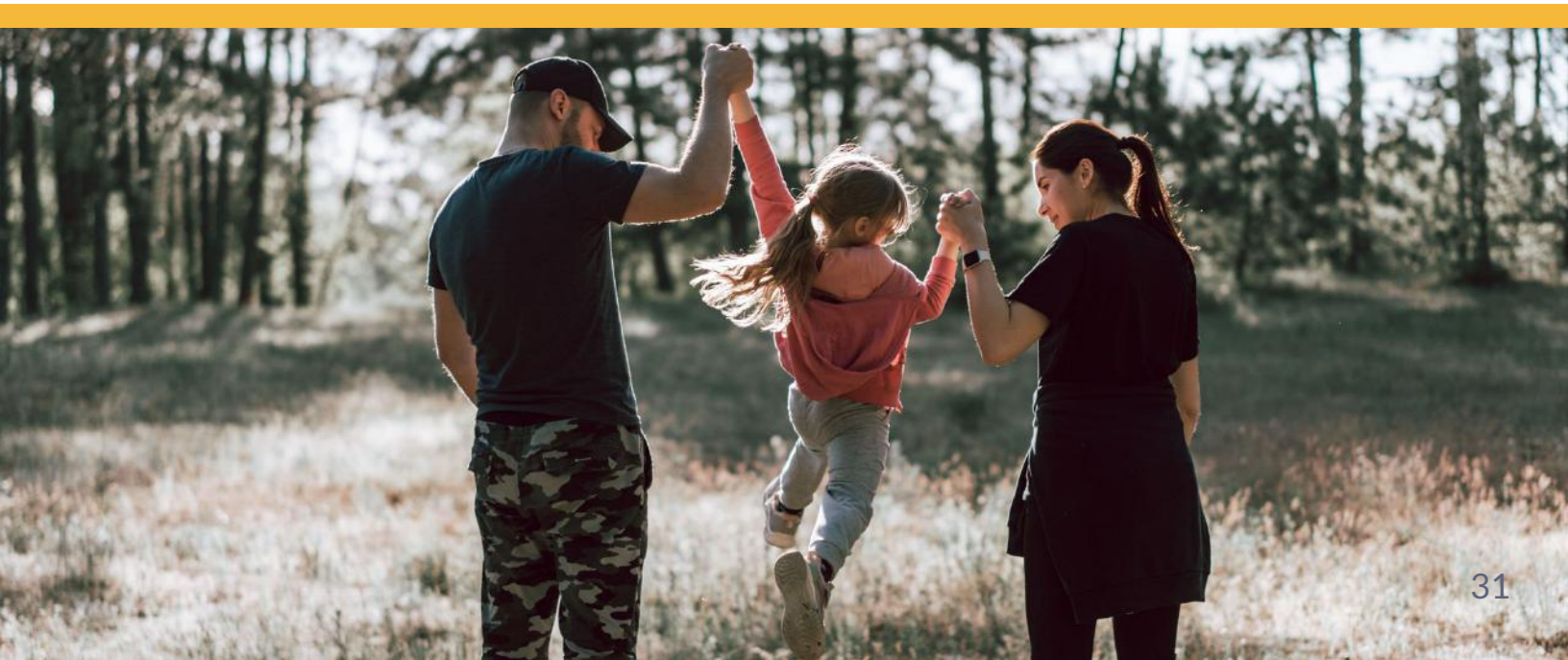


Other community-wide strategies

- Education and awareness campaigns to reduce stigma and increase knowledge on trauma informed ways to recognize and support those with substance use disorders
- Safe and dependable housing
- Transitional housing such as supportive living apartments where women and children can access help 24/7, and learn skills such as cooking, budgeting, and developing healthy relationships
- Transportation services to access support and healthcare within and outside the community
- In-community treatment options including:
  - Opioid agonist therapy programs where women are partners in their treatment plan
  - Healing centres where mothers can bring their children
  - Men's shelters and treatment programs
  - Healthcare and addictions services in the evenings and weekends; 24/7 support is ideal
- Family-friendly community events to promote bonding
- Programs to reconnect to culture, language, traditional teachings, land, and ceremony
  - Women's circles to share important teachings on mothering
  - Engage Indigenous midwives, Elders, spiritual advisors, Medicine People, and Clan Mothers to provide spiritually and culturally based care and guidance to mothers

Participant suggestions for community leadership

- Continue to acknowledge prenatal opioid exposure as an issue
- Model compassion for people living with addiction
- Codevelop strategies with people who have lived and living experience to reduce opioid use in their communities
- Allocate more funding to the prevention and treatment of substance use and addiction
- Design and implement policies to prohibit or reduce the use of opioids in the community



Prevention: moving forward

Prevention was identified as a critical priority. To prevent prenatal opioid exposure, participants emphasized that addressing intergenerational trauma was pivotal, as well as changing social norms about drug use, and the continuing integration of culture into community life. They emphasized that when community members in each stage of life maintain or regain balance in their physical, social, mental, emotional, and spiritual health, cycles of trauma can be broken, leading to intergenerational healing and the reduction of prenatal opioid exposure.

“Our community works hard at keeping our children within the community. If the parent isn’t able to take care of the child because of an addiction, our community is usually pretty good in finding or having a home ready for them. And I think that keeping children exposed to opioids prenatally in the community, and around their culture, and around their other family members is a huge strength.”

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