

**Parental Mental Health in Neonatal Follow-up Programs: Parent and Service Provider
Perspectives**

by

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Abstract

Neonatal Follow-up Programs (NFUPs) lack integrated parental mental health services, despite a higher prevalence of anxiety, depression, and posttraumatic stress (PTSD) among attending parents. A convergent parallel mixed-methods design was used to answer (1) to what extent do NFUP parents have unmet mental health needs, and (2) what are parent and service provider perspectives on barriers and opportunities to increase access to mental health services? In Study 1, parents attending a Manitoba NFUP ($N = 49$) completed a mixed-method online survey through REDCap. Quantitative (analyzed descriptively) and qualitative data (analyzed through conventional content analysis) were integrated to elucidate parents' mental health, related service use, barriers to service use, and service preferences. In Study 2, NFUP service providers ($N = 5$) participated in one of two focus groups via Zoom to discuss service improvements to address parents' mental health service needs (analyzed using reflexive thematic analysis). The perspectives of both samples were integrated and reported using a narrative approach. Parents endorsed 2 – 4 times higher prevalence of clinically significant depression (59.2%), anxiety (28.6%), and PTSD (26.5%) than the general postpartum population. However, most parents were not using mental health services (55.1%) predominantly due to resource insecurity (e.g., time, cost, childcare, staffing, referrals). Identified service improvements include bridging the gap between services by screening for anxiety, depression, and PTSD, and developing online platforms to provide psychoeducation and peer support groups for support during stressful transitions. Future research employing the findings is warranted to improve generalizability and inform a national approach to addressing unmet parental mental health needs in NFUPs.

Keywords: parental mental health service use; barriers to mental health service use; parents of high-risk infants; Neonatal Follow-up Program; service provider perspectives

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Parental Mental Health in Neonatal Follow-up Programs: Parent and Service Provider
Perspectives

The World Health Organization reports that 15 million high-risk infants are born yearly (WHO, 2018), with The Canadian Institute for Health Information reporting that as high as 14.4% of Canadian infants are deemed high-risk at birth and admitted to the Neonatal Intensive Care Unit (NICU) for further care and assessment (Fallah et al., 2011). High-risk infants are defined as infants born premature or with a health concern that has short and potential long-term implications for the infant's life (Paolo, 2012). The experience of having a high-risk infant in the NICU is incredibly stressful for parents and is perceived by most parents as a traumatic life event (Sabnis et al., 2019). Parent mental health problems are a significant concern for 18 – 63% of NICU parents, who describe the NICU experience as “an emotional roller coaster” with uncertainty and fear around whether their infant would survive following abrupt hospitalization (Provenzi et al., 2016, pp. 533) and variations in the length of stay within the NICU (Baía et al., 2016; Woodward et al., 2014).

Despite the emotional impact of the NICU on parents, parents prioritize their infants' needs far above their own and do not access mental health support (Mousavi et al., 2016). Many NICUs have incorporated parental mental health services into their programming. Once discharged, infants deemed high-risk of developmental concerns (high-risk infants) are seen for continued care within Neonatal Follow-up Programs (NFUP) while parents are left without continued integrated mental health services despite findings that parents of high-risk infants desire supports, such as mobile technologies that connect them to social support and service providers (Liu et al., 2011). More information is needed on parents' unmet mental health support needs in the Manitoban NFUP, including parents' mental health, their perceived motivators and

barriers to mental health service use, current use of mental health services, and mental health service preferences to promote service engagement while in the NFUP. Additionally, NFUP service providers recommendations for addressing parents' unmet mental health service needs is warranted to inform feasible mental health service implementation. Taken together, such information will inform how the unmet mental health support needs of parents in Manitoba's NFUP can be addressed to mitigate the adverse impact of unaddressed mental health concerns on the parent and family.

Mental Health of Parents of High-Risk Infants

Studies have shown that the prevalence of anxiety, depression, and posttraumatic stress symptomology is higher among mothers of high-risk infants in the NICU than mothers of infants who did not need NICU admission (Bonacquisti et al., 2020; Segre et al., 2014). Compared to mothers of infants not deemed high-risk, mothers of high-risk infants in the NICU are two times more likely to experience anxiety in the postpartum period: 11 – 21% and 18 – 43% respectively (Dennis et al., 2017; Fairbrother et al., 2015; Fairbrother et al., 2016; Voegtline et al., 2010). A qualitative study found that mothers still felt anxiety and fear concerning their infant's health and development one year postpartum (Garel et al., 2007) and fathers in NICU have described feeling anxious and inadequate as a parent (Johansson et al., 2020).

Across 26 studies included in a systematic review, an estimated 20 - 40% of mothers of high-risk infants receiving NICU care experience postpartum depression (Vigod et al., 2010), which is nearly double the rate of general postpartum population norms (10 – 24%; Kendall-Tackett, 2017; Mayberry, Horowitz, & Declercq, 2007). Some studies have found prevalence of depression in mothers of high-risk infants to be as high as 63% (Ballantyne et al., 2013; Miles et al., 2007). Mothers describe feeling withdrawn, isolated, and guilty for having a high-risk baby,

with no improvement in such feelings from two months to one year postpartum (Garel et al., 2007). Further, postpartum mothers metaphorically described their depression as a thief robbing them of the happiness that they dreamt of feeling when they had their baby (Beck, 2020). It has also been found that depression and PTSD symptomology co-occur among mothers of high-risk infants (Anderson & Cacola, 2017).

An estimated 23% of mothers in the NICU experience PTSD symptoms with rates increasing up to 40% by 14 months postpartum, which is over double to four times as high as postpartum population norms respectively (0 – 8%; Alcorn et al., 2010). One month after their high-risk infant's NICU admission, 8% of fathers show clinically significant levels of PTSD (Lefkowitz et al., 2010), with prevalence only decreasing to 5.0% between 4 – 8 months postpartum (Parfitt & Ayers, 2012). Moreover, a mother's belief that her infant's health condition will worsen or last a long time is associated with higher maternal stress levels (Hames et al., 2021) raising concern for parents whose infant needs continued care and assessments from NFUP. Mothers suffering from PTSD are three times more likely to develop disordered alcohol use (Sartor et al., 2010). Research that looks at PTSD beyond 14 months postpartum among parents of high-risk infants is lacking (Garthus-Niegel et al., 2017). The mental health of this parent population is crucial to understand, as parental mental health concerns can negatively impact infant growth and development, parental ability to follow their infant's complex medical regimens, the parent-infant bond, and adjustment to parenting.

The Importance of Parental Mental Health

Maternal anxiety, depression, and PTSD are linked to behavioural, cognitive, and social-emotional problems in infants as they develop (Anderson & Cacola, 2017; Garthus-Niegel et al., 2017; Kendig et al., 2017). There is a bidirectional relationship between maternal PTSD

symptomology and feeding and sleeping challenges, which adversely impacts the infant's growth and maintains stress among mothers (Pierrehumbert et al., 2003). Studies have shown that postpartum depression symptoms in mothers of non-high-risk infants hinders their ability to adhere to their infant's medical regimen (Minkovitz et al., 2005). Mothers experiencing depression or distress are often less responsive, warm toward, and securely attached to their infants (Field, 2010). Such parenting styles hinder the development of the parent-infant bond and adversely impact the infant's health and development well into preschool (Holditch-Davis et al., 2014; Huhtala et al., 2012). While in the NICU, distressed parents of infants in the NICU report feeling a loss of their parenting role from an inability to provide the care that their infant needs (McGrath, 2008; Obeidat et al., 2009), leaving them to feel helpless and dependent on medical staff to care for their infant (Alkozei et al., 2014; Baía et al., 2016; Woodward et al., 2014). Given the adverse impact of parental mental health concerns on infant growth and development, parental ability to follow their infant's complex medical regimens, the parent-infant bond, and adjustment to parenting, understanding these parents' use of mental health services to address mental health concerns is crucial.

Parental Mental Health Service Use

The intensity and frequency of service use vary among formal (e.g., individual therapy or group-based therapy) and informal mental health services (e.g., seeking mental health information online, and using well-being phone apps). Use of patient-oriented mental health services that are timely, integrated, and consider patient's needs and barriers to accessing care have been found to be protective against worsening mental health in NICU parents (Lean et al., 2018). As such, it is conceptualized that mental health services among parents in NFUPs would be protective against worsening mental health, though such research is limited. A national survey

administered to NFUP parents by the Canadian Premature Babies Foundation found that NFUP parents (64%) desire mental health screening, referrals, and support groups though felt such care was lacking across Canada, with only 25% accessing psychological support (counsellor, psychologist, psychiatrist; Provincial Council for Maternal and Child Health, 2017). One parent wrote, “*My child was exceptionally well cared for. It was me (mother) who was suffering from PTSD and panic disorders stemming from [my] NICU stay. Help was hard to find once I recognized I was not right* (Provincial Council for Maternal and Child Health, 2017).” Fathers have been found to be less likely to use mental health services than mothers, with fathers being more likely to attend when services are tailored to their needs and experiences, such as having a male service provider and father-only online forums or in-person groups (Berlyn et al., 2008; O'Brien et al., 2017).

Parental mental health services are lacking in Canadian NFUPs (Cano Gimenez et al., 2015; Mendelson et al., 2017). Research suggests that parental mental health services employing a cognitive behavioural approach for depression (Mendelson et al., 2017), individualized approach for anxiety (Cano Gimenez et al., 2015), and trauma-informed approach for PTSD symptomology (Gamble et al., 2009; Shaw et al., 2013) are examples of evidence-based practices found to improve the mental health of parents in the NICU. Combinations of CBT and trauma-focused care are particularly beneficial for NICU parents compared to a non-combined approach, given that many experience both depression and PTSD and that a combined approach has shown decreased symptoms for up to six months following the intervention (McGowan et al., 2017; Shaw et al., 2013) which is the earliest an infant would enter a NFUPs. However, few post-service assessments have looked at parental mental health at six-eight months postpartum when infants enter the NFUP, with even fewer post-assessments looking at the 18 – 24

postpartum (Lean et al., 2018). Within Canada, studies have assessed the benefits of employing a Family Integrated Care model in NICUs, where parents are integrated into their infant's care from admission onward to develop skills and confidence in caring for their high-risk infant (Dien et al., 2022). Such approach has shown a reduction in anxiety and depression symptoms and increase in parents' confidence in caring for their infant up to seven months postpartum when parents would enter the NFUP, though their impact beyond seven months postpartum is unknown. Additionally, NICU discharge planning could be improved by incorporating parental mental health and considering parents' barriers and motivators to using mental health services, though such information is lacking in the literature (Purdy et al., 2015). Current discharge planning leaves parents without mental health services in NFUPs despite a continued need (Hall et al., 2015; McGowan et al., 2017), illustrating the importance of enriching our understanding of parental mental health service use, facilitators, and barriers while their infant attends a NFUP.

Barriers to Parental Mental Health Service Use

Increasing the use of mental health services can be achieved by maximizing parents' expressed motivators and minimizing their perceived barriers to using such services. The Network Episode Model-II Theory (NEM-II; Pescosolido & Boyer, 2010; Pescosolido et al., 2013) helps describe pathways and barriers specific to mental health service use. Within this theory, key factors that impact mental health service use are understood as their *episode base*. The *episode base* includes the severity and chronicity of a person's mental health, their social and geographical location (e.g., age, gender, income) and resulting organizational constraints (e.g., inability to afford services).

Research on social and geographical factors while parents are in NFUPs is limited, though gender, marital status, the number of children within the household have been identified

as key social factors impacting parental mental health service use while in NICU (Lean et al., 2018). Additionally, limitations in enabling factors such as education, employment status, income, time, and energy, childcare, and spousal support adversely impact parents' use of mental health services (Alkozei et al., 2014; Cameron et al., 2020; Lean et al., 2018). Studies have shown that higher levels of trauma experienced by the parents regarding medical concerns and procedures their infant endures while in the NICU results in lower parental mental health service use (Gamble et al., 2009; Samra et al., 2015). After NICU discharge, parents spend a considerable amount of time adjusting to the home environment and a complex medical regimen, often referring to service providers a substantial amount (Dellenmark-Blom & Wigert, 2014) impacting the severity and chronicity of adverse parental mental health. Organizational barriers to parental mental health service use in NFUP include limitations in space and staff with adult mental health expertise (Dykes et al., 2016) and the time and duration of the service (Glazebrook et al., 2007; Kantrowitz-Gordon, 2013), cost, and uncertainty around how access mental health services (Cameron et al., 2020). Together, these barriers underscore the importance of integrating parental mental health services into NFUPs, similar to programs in NICUs. Yet, such services are absent and no model for such services in NFUPs exists. While understanding parents' perceived barriers to using mental health services is crucial in fostering engagement, there has been a long-established understanding that service implementation and accessibility relies on service providers (Turnage & Carrier, 2000).

Service Provider Perspective on Parental Mental Health and Related Services

Service providers' perspectives of parental mental health services in NFUPs are understudied though needed to inform organizational barriers and feasible service implementation. NICU providers agree that fostering positive parental mental health and a strong

parent-infant bond are key to successful infant health and development outcomes from the NICU (Flacking et al., 2012). One study including 57 NICU service providers of varying specialities (e.g., nurses, doctors), found that most of their sample felt competent (87.8%) and confident (93%) when discussing mental health with parents (Twohig et al., 2016). However, competence was correlated with years of experience ($r = 0.304, p < .022$), as lack of training was recognized as a barrier to providing parental mental health support. Further, this sample recognized a lack of psychological support for parents in the NICU, with 53.6% of service providers reporting that psychological support was rarely offered to parents. Of concern for parents with infants continuing to NFUPs, 45.6% of NICU service providers reported a perception that psychological support was not offered to parents after discharge from the NICU (Twohig et al., 2016).

Service providers have also identified key barriers to implementing parental mental health services within the NICU. A lack of training in parental mental health, time to address parental mental health, staffing resources, and mental health professionals integrated into NICU programming to simplify the referral process are key barriers (Mosqueda et al., 2013; Twohig et al., 2016). Parents' perception of the importance of attending the program, sense of vulnerability or fear, limited family resources (e.g., time, finances, childcare), hours of operation, scheduling, budgetary cuts, and changes in healthcare organizations as barriers (Ballantyne et al., 2014). Healthcare provider and parent perspectives were not always congruent (e.g., the former viewing fear of bad news regarding their infant as a barrier to parent attendance, while the latter viewing this as a motivator; Ballantyne et al., 2014). A mismatch between parents' and service providers' perspectives on the organization of care has been identified in the literature as a barrier, suggesting that incorporating both perspectives is helpful when considering the development of parental mental health services (Lantz & Ottosson, 2014; Latour et al., 2010).

Summary of Gaps in the Literature

Key limitations in the relevant literature include that the mental health and related support needs during six months to two years postpartum when high-risk infants attend NFUPs is understudied (Lean et al., 2018). Understanding and addressing parents' mental health support needs while in NFUP is critical to mitigating the adverse impact of parental mental health concerns on the parent, their engagement in their infant's care, and the family at large. More information is needed on areas of unmet need regarding mental health services for parents of high-risk infants in NFUPs, parents' current approaches to mental health service utilization, and their perceived motivators and barriers to mental health service use, as well as service providers' perspectives on how to meet parents' needs. Finally, quantitative and qualitative information regarding parents' experiences in NFUP care is lacking in conjunction with service providers' understanding of their organization. Consolidating NFUP parent and service provider perspectives is necessary to optimize parent engagement and ensure recommendations for mental health service development can be feasibly implemented.

The Present Study

This two-part study aims to elucidate how parental mental health service gaps in NFUP can be improved by consolidating the perspectives of NFUP parents and service providers in Manitoba. A convergent parallel mixed-methods design was used to answer (1) to what extent do NFUP parents have unmet mental health needs, and (2) what are parent and service provider perspectives on barriers and opportunities to increase access to mental health services? Research questions were answered by integrating the results of two studies. Study 1 aimed to examine how parents of high-risk infants experience mental health services across barriers, access, and service preference considerations through an online mixed-methods survey. Study 2 aimed to understand

NFUP service providers' perception of barriers and opportunities for service improvements to address parental mental health needs using focus group methods. The mixed-method approach aimed to integrate the views of patients and service providers to 1) highlight where views on needs differ between parents and service providers, and 2) inform the development of future NFUP parental mental health services. The results informed opportunities to meet this parent population's mental health needs that consider parents' needs and preferences as well as what service providers can feasibly implement.

Study One Method

Data was collected as part of a broader study which aimed to assess parent and service provider perspectives on the mental health, parenting support, and stress management needs of parents of children ages 0 to 5 who are currently involved with one of the following agencies in Winnipeg Manitoba, Canada: KidTHINK, Manitoba Adolescent Treatment Centre's Attention Deficit Hyperactivity Disorder program, St. Amant, and SSCY Centre.

SSCY Centre's Neonatal Follow-up Program in Manitoba, Canada

SSCY Centre's NFUP involves a multidisciplinary team of health care providers who see high-risk infants in need of follow-up or further assessment after discharge from the NICU. In one appointment, infants are seen by a developmental pediatrician or neonatologist, physiotherapist and occupational therapist. Although this organization's NFUP encounters parents at-risk for mental health problems, they have not previously assessed the scope of their mental health needs nor offered parental mental health services.

Participants

A target sample size of $N = 50$ parents of high-risk infants attending the NFUP at SSCY Centre in Winnipeg, Manitoba, Canada, were recruited. The target sample was informed by

prevalence rates of anxiety, depression, and PTSD in parents of high-risk infants being between 20 – 40% (Alcorn et al., 2010; Bonacquisti et al., 2020; Dennis et al., 2017, Vigod et al., 2010), suggesting that 10 – 20 out of 50 parents would meet criteria for at least one diagnosis.

Considering the clinical overlap in symptoms and comorbidity of diagnoses (anxiety and depression comorbid among 40 – 60% of parents of high-risk infants; Bonacquisti et al., 2020), it was estimated that 20 – 30 out of the 50 recruited parents would endorse either anxiety or depression. With comorbidity of anxiety and depression with PTSD anticipated to add 5 – 10%, it was estimated that 23 – 33 out of 50 recruited parents would endorse at least one mental health concern, offering a sufficient sample size considering the predominant qualitative focus of the study, with quantitative data being used descriptively rather than inferentially. The target sample was congruent with mixed-methods studies on exploratory models of patient-oriented research to inform next steps regarding program development (Onwuegbuzie et al., 2015). Further, an exploratory model was used given the lack of literature to inform the next steps in parental mental health service development, for which confirming adequate statistical power at 80% was not critical. Participants were obtained through convenience and snowball sampling. Parents were eligible if they had an infant in the NFUP within the past five years. Exclusion criteria included parents' inability to read English and lack of access to a device with Internet access given that the survey was administered online in English.

Study Procedure

Parents were recruited through multiple methods outlined in Table 1. Interested parents were emailed a REDCap link to the consent form and a 20 minute survey. Parents who completed the survey were entered into a draw to win a \$100 electronic gift certificate to a location of their choice. This study was approved by the University of Manitoba's Fort Garry

Research Ethics Board and SSCY Centre's Research Review Board.

Measures

Sociodemographic Variables

Sociodemographic variables included household size (*number of adults and children*), relation to the child (*mother, father, other*), marital status (*married/common-law, divorced, separated, widowed, single/never married*), employment status (*full-time, part-time, on leave, not employed*), household income (*intervals of \$10,000 starting at \$1 – 10,000 and ending at \$140,000 or higher*) and education level (*ranging from some high school to Ph.D.*; Lean et al., 2018). Parents were also asked information regarding their high-risk infant attending the program such as whether their infant was born premature (less than 37 weeks as per prior research; World Health Organization, 2015), how far along they were (week in pregnancy) when their infant was born, whether their infant has any developmental or behavioural diagnoses, and which (if any) services they may have accessed for their infant.

Parental Mental Health

Assessment of parental mental health included screening for anxiety, depression, and posttraumatic stress disorder (PTSD) symptomology based on prior research (Bonacquisti et al., 2020; Segre et al., 2014). Measures used in research involving the general population rather than perinatal-specific measures were used for each disorder given recruitment of parents who attended the NFUP in the past five years. Using general population measures rather than both perinatal and general population measures allowed for direct comparison of all parents with high-risk infants in the program. Perinatal nuances in parental mental health experiences were captured through added open-ended questions. Mental health measures were included to identify parents in need of accessing a mental health service. Need was operationalized as parents who

met cut-off scores indicative of mild – severe anxiety, depression, or PTSD. Mild severity cut-off scores were used based on score interpretation guidelines for the PHQ-9 and GAD-7. Such score interpretations specify that treatment needs for those meeting criteria for mild depression or anxiety should be determined based on a clinician’s judgment regarding chronicity and impact on functioning, indicating that the parent needs to see a mental health professional (Kroenke & Spitzer, 2002).

The *Generalized Anxiety Disorder (GAD-7)* 7-item scale was used to assess parental anxiety on a 4-point Likert scale ($0 = \text{not at all sure to } 3 = \text{nearly every day}$). An empirically established cut-off score of ≥ 5 out of a possible 21 signified parents in need of mental health services with 89% sensitivity and 82% specificity among the general (Spitzer et al., 2006) and perinatal (Simpson et al., 2014) population. The GAD-7 has excellent internal consistency ($\alpha = 0.88 - 0.93$) and construct validity (Cameron et al., 2020; Löwe et al., 2008).

The *Patient Health Questionnaire 9-item Version (PHQ-9)* was used to assess parental depression symptoms experienced in the past two-weeks on a 4-points Likert scale ($0 = \text{not at all to } 3 = \text{Nearly every day}$). An empirically established cut-off score of ≥ 5 signified parents in need of mental health services with 88% sensitivity and 88% specificity among the general (Kroenke, Spitzer, & Williams, 2001) and perinatal (Wang et al., 2021) population. Total scores between 5 – 9 were considered indicative of subsyndromal depression (Kroenke et al., 2001). Previous studies have shown excellent internal consistency ($\alpha = 0.89$) and validity (Kroenke et al., 2001).

The 20-item *Posttraumatic Stress Disorder Checklist for DSM-5 (PCL-5)* was used to assess parental PTSD symptomology on a 5-point Likert scale ($0 = \text{not at all to } 4 = \text{extremely}$). An empirically established cut-off score of ≥ 33 signified parents needing mental health services

with 74.5% sensitivity and 70.6% specificity among the general (Bovin et al., 2016; Weathers et al., 2013) and perinatal (Heumen et al., 2018) population. The PCL-5 has excellent internal consistency ($\alpha = .90 - .95$) and validity (Blevins et al., 2015; Bovin et al., 2016).

Parental Mental Health Service Use

Parental mental health service use was assessed using the 10-item *Parent Mental Health Service Utilization* measure developed within the Hearts and Minds Laboratory for use in the current study (see Appendix A). Responses within this measure were based on past year parental use of various professional, community, and self-guided mental health services., either in-person or virtually. This measure also assessed whether various factors are perceived as barriers and motivators to mental health service use by those who did and did not access services within the past year (e.g., cost, interest in a service, belief in whether they needed help, etc.). An item on honest responding was also included to assess for social desirability.

Open-Ended Questions

Respondents were asked open-ended questions throughout the survey (see Appendix A sections A – D). Within Sections A and B, parents were given the option to select ‘other’ and type a response to elaborate on particular demographics. Within Section C, open-ended questions were included to allow parents to elaborate on conception difficulties. At the beginning of Section D, parents who reported worsening mental health in pregnancy or postpartum were asked to elaborate on the changes they noticed when they improved. Parents were also asked a question regarding thought content when worrying. Following the PCL-5, an open-ended item was provided to allow parents to provide more detail about the stressful problem they considered when answering items in the PCL-5. Finally, within the Mental Health Service Use measure, parents answered open-ended items regarding their biggest barriers and motivators to mental

health service use. An ‘other’ option was also provided in items listing possible motivators and barriers to capture additional impacts to mental health service use.

Data Analysis

Quantitative Data Analysis

Data Processing. All analyses were conducted using IBM Statistical Package for the Social Sciences (SPSS) Version 28. Before running descriptive analyses, data were cleaned through several steps based on Meade and Craig (2012). Cases completed by a scammer ($n = 31$), where all measures were not complete ($n = 22$), and where one or more measures were not completed honestly (e.g., selected “prefer not to say” on over 90% of items; $n = 1$) were removed. Scammers were identified by REDCap IT staff as those who filled in information that did not make sense (e.g., that their infant was born at 60 weeks) and those who wrote codes commonly used by scammers in open-ended responses (e.g., edna). No duplicate entries occurred, and no participants who scored at or above the 99th percentile on time-to-completion were removed ($M = 55.37$, $SD = 41.54$, range = 17 – 218). A final sample of $N = 49$ remained, with 0 to 4.1% missing data per measure. Little’s MCAR test was employed, showing that data were missing randomly, $p = .118$ to $p = .634$. Thus, missing data values were estimated using expectation maximization. Dichotomous variables were created for parents’ need for mental health services ($1 = endorsed one – three mental health concerns indicating need$ and $0 = no need$) and use of mental health services ($yes = used any type$, $no = no use$).

Descriptive Statistics. Descriptive statistics were run to describe parents’ demographics, mental health severity, service use, and motivators and barriers to mental health service use. Two crosstab analyses were conducted to compare similarities and differences in key factors influencing mental health service use across parents grouped by (1) infant health concern

and (2) type of mental health service use. Infant health concerns were based off of standard eligibility for Canadian NFUP and included: (1) prematurity (29 – 33 weeks, 26 – 28 weeks, <25 weeks), (2) low birth weight (2,000g – 1,500g, 1,499g – 1,250g, 1,249g – 800g, <800g), (3) neurologic concerns (e.g., brain injury, hypoxic ischemic encephalopathy, seizures, stroke), (4) cardio-respiratory concerns (e.g., congenital diaphragmatic hernia, bronchopulmonary dysplasia, extracorporeal membrane oxygenation), and (5) other (e.g., syphilis, small for gestational age based on Fenton Growth Charts (2003; Albaghli et al., 2019)). Standard eligibility criteria were used to allow findings to be generalized across the 26 tertiary NFUPs in Canada and inform a national approach to addressing parental mental health in these programs. Key factors included aspects of parents' episode base informed by Pescosolido's NEMI-II model (e.g., age, gender, mental health severity; Pescosolido et al., 2013), infant health complexity (number of diagnoses and number of services being accessed for the infant), mental health service use, and service preferences. Expected cell sizes were too small to compare key factors among parents grouped by infant health concern. Where possible (e.g, income from increments of \$10,000 to \$40,000), categories were collapsed to increase expected cell sizes, though were still less than five. As such, rather than comparing responses on key factor variables across parents grouped by infant health concerns, responses on key factor variables were described by group. Expected cell sizes were large enough to compare the association between endorsed mental health concerns (anxiety, depression, PTSD) and parents' use of mental health services. Such findings inform whether parents endorsing a certain mental health concern are more or less likely to use mental health services. Means and standard deviations for binary data or frequencies for continuous data were obtained from all descriptive analyses. Chi-square values were obtained from crosstab analyses.

Qualitative Data Analysis

To enrich the understanding of parents' mental health, related service use and barriers to use, and service modality preferences, qualitative open-ended responses outlined in the measures section were analyzed following a conventional content analytic approach (Hsieh & Shannon, 2005). Use of conventional content analysis allows the researcher to stay close to the data by basing code categories solely off the data collected rather than preconceived understandings of the phenomena based on previous theory or data. This approach was most appropriate given the lack of prior research on parental mental health and related service use in NFUPs and need for new insights, as well as its organized and systematic approach to coding and tracking the number of times specific content was mentioned (Hsieh & Shannon, 2005). Conventional content analysis begins by considering an observation (i.e., mental health services for parents of high-risk infants in SSCY Centre's NFUP are absent, leaving parents with continued need for mental health support without care) that informs the research question (i.e., are parents of high-risk infants attending a local NFUP using mental health services or experiencing barriers to accessing such services, and do they have preferences toward certain service modalities?). To explore this research question qualitative survey responses were pulled from REDCap into a password-protected excel file. Each response was initially given a code that summarizes the text while staying as close to the words used by the parent as possible. Initial codes were then grouped across parents to form categories that capture larger chunks of data across participants. Within each code category, similarities and differences in parental experiences and preferences were determined and the number of codes within each category was considered (Hsieh & Shannon, 2005). The coding process was led by myself, with two trained research undergraduate students to help with coding and my advisors for consultation on coding decisions.

Rigor. Several steps were taken to ensure rigorous and trustworthy results within the

present study as informed by Tracy's "Big-Tent" Criteria for Excellent Qualitative Research (Tracy, 2010). Rigorous qualitative results require sincerity, which involves each member of the research team to recognize and be transparent regarding how their life experiences and biases may impact their interpretation of the data (Tracy, 2010). To achieve sincere results, each coder independently coded open-ended responses and kept a coding journal as an audit trail of coding decisions, uncertainties, and challenges, enhancing transparency around the data analytic process and credibility of the results (Creswell, 2014; Tracy, 2010). Weekly team meetings were held to discuss coding decisions and uncertainties and settle discrepancies collaboratively until a unanimous decision was reached. This collaborative approach also helped to ensure self-reflexivity and sincerity in the results by giving opportunity for the inevitable impact of each coders' backgrounds, beliefs, and biases on the data analysis process to be identified and addressed. Additionally, main and subthemes were reviewed and refined by the full coding team (PI, co-advisors, and trained undergraduate research assistants) at two time-points, first after roughly a third of the participants data was analyzed and again after two-thirds had been coded, to ensure that the breadth and depth of parent responses were being captured.

Study Two Method

Two semi-structured focus groups with service providers from SSCY Centre's NFUP were conducted to assess providers' understanding of parents' mental health needs and recommendations for service improvements to address needs and barriers and support families.

Procedure and Sample

Service providers who work within the NFUP at SSCY Centre (developmental pediatricians, neonatologists, physiotherapists and occupational therapists) were recruited through purposive sampling. The sample size was driven by the number of service providers that

work within the NFUP ($N = 5$). Service providers participated in one of two 60-minute focus groups via Zoom Healthcare led by myself, with a research assistant present for notetaking. Before each focus group, informed consent was collected and service providers completed a 5-minute demographic survey via REDCap. Discussion covered service provider's perception of parental mental health, barriers and motivators to parents' mental health service use, the current approach to addressing parental mental health, and recommendations for service improvements (see Appendix B for the semi-structured interview guide). A gift card for a team lunch was provided to the NFUP as honorarium. Focus groups were audio-recorded through Zoom Healthcare, transcribed using TRINT software, and reviewed for accuracy and de-identification in a word document for analysis.

Data Analysis

Focus group transcripts were analyzed through reflexive thematic analysis, a flexible and collaborative approach that considers researcher subjectivity in the coding process (Braun & Clarke, 2019). Reflexive thematic analysis was most appropriate given the lack of pre-existing literature to guide an a priori framework. It aligns with an exploratory and inductive approach to data analysis while still providing a flexible but systematic way of moving through the coding process. The coding process was achieved collaboratively and iteratively through six steps (Braun & Clarke, 2006). First, transcripts were read by myself and two trained undergraduate students to gain familiarity with the data. Second, each coder independently generated initial codes describing the content of each sentence. Third, initial codes were grouped into main and subthemes of shared meaning. Fourth, coders returned to the data to ensure that developed themes captured the full scope of the data. Fifth, content coded under each theme was reviewed to determine theme names and definitions. Finally, generated themes were written up to explain

the data captured within the theme and its relation to the original research question. Rigorous and credible results were achieved following the same methods outlined in the qualitative rigor section for Study 1. However, in line with reflexive thematic analysis, quality results were achieved by allowing nuances in data interpretation to develop reflexively rather than reaching a consensus between coders (Braun & Clarke, 2019).

Patient Engagement

The co-director of the NFUP was consulted during the research design phase of this study to refine research priorities, processes, recruitment materials, and survey and focus group questions. Further, parent survey questions were informed by the parent advisory board within the Hearts and Minds Laboratory. Parent consultation regarding the research design, data collection, and data analysis phase was not possible, given challenges in recruiting families and site-induced limitations on engaging patients to ensure that families are not overburdened by research within the centre. NFUP Service providers also provided insight on adjustments to recruitment strategies throughout the data collection phase to ensure the desired parent sample was obtained.

Integration of Findings

Quantitative and qualitative findings from Study 1 and Study 2 were integrated through three levels (Fetters et al., 2013). At the design level, a convergent parallel mixed-methods approach was employed, allowing for the integration of quantitative and qualitative data during collection and analysis within each study and in consolidating the perspectives from both studies. At the methods level, quantitative and qualitative data were integrated through embedding, where data collection and analysis connected at multiple points (e.g., collecting and analyzing parent mixed-methods data regarding barriers to mental health service use while collecting and

analyzing qualitative data from service providers and integrating findings from both studies). Finally, at the reporting level, joint tables were used to illustrate connections between quantitative and qualitative findings from parents and providers. Additionally, a weaving narrative approach to writing the results was used, where parental mental health, related service use and barriers, and opportunities for service development was described by weaving related quantitative and qualitative data from both samples together (Fetters et al., 2013).

Results

Participant Characteristics

Parent Demographics

Of the total sample of parents ($N = 49$), the majority identified as female (89.8%) and had an average age of 32.46 ($SD = 6.79$). Most parents identified as having European origins (57.1%), with some identifying as having Indigenous Origins (14.3%) or Asian origins (10.2%). Most parents identified as being married (87.8%) and having an average of 2 children ($SD = 1.14$) in their household. The average age of the child accessing the NFUP was $M = 2.31$ years, $SD = 1.40$, with 12.2% of parents having an infant within 12 months postpartum and 87.8% being beyond 12 months postpartum. Parents' education level ranged from some high school to a professional degree, with the majority having a diploma from college/technical school (34.7%) or a bachelor's degree (28.6%). Most parents specified that they were working full-time (36.7%) or part-time (22.4%) and had an annual household income between \$20,000 - \$100,000 (48.9%; Median = \$80,000 - \$90,000). Parent demographics are presented in Table 2.

Service Provider Demographics

All service providers ($N = 5$) were female and ranged from 38 to 70 years old. Most participants identified as having European origins (60%), with some identifying with South

American origins (40%). Their education level varied based on their role within the program, with most having a professional degree (60%). Providers included two developmental pediatricians, a neonatologist, a physiotherapist, and an occupational therapist. The number of years of service providers worked within the NFUP at SSCY ranged from 2 to 15 years ($M = 8.2$, $SD = 5.93$), with all service providers currently working full-time. Service provider demographics are presented in Table 3.

Integrated Perspectives of Parents and Service Providers

To uncover areas of unmet need regarding mental health services for parents of high-risk infants in NFUPs, I consolidated parents' and service providers' perspectives on parents' mental health in the NFUP, their barriers to mental health service use, current mental health service utilization, and how such unmet needs can be addressed to improve family wellbeing. This aim was explored through two studies, one gathering parents' perspectives ($N = 49$) through an online survey and one gathering service providers' perspectives ($N = 5$) through two focus groups. Qualitative analysis of transcripts from the two service provider focus groups informed the development of a thematic framework with four main themes, each with related subthemes: (1) Service provider perspectives on parents' mental health (*mental health concerns, risk factors to worsening parental mental health, protective factors against worsening mental health, and parent coping styles*), (2) Barriers to parental mental health service use (*parent barriers, organizational barriers*), (3) Current approach to addressing parental mental health (*there is no process or person in place, where do we refer parents?*), and (4) Changes to address parental mental health service gaps (*bridge the gap between NICU and NFUP, mental health screening and follow-up, parent-led support groups, and psychoeducation for patients and providers*). The resulting thematic framework is representative of all service providers from both focus groups

conducted in Study 2. Figure 1 illustrates the thematic framework, including the relationship between the main and subthemes, and where parent and provider perspectives were similar or different. Each main theme and subtheme from the service provider focus groups is described below using a narrative approach, with quantitative and qualitative data from the online parent survey weaved in to consolidate the perspectives of both samples (Fetters, 2013). Table 4 provides integrated perspectives from service providers' qualitative data and parents' quantitative and qualitative data concerning each theme, and highlights where perspectives differed and themes only discussed by service providers. An overview of integrated findings is provided in Figure 2.

Parental Mental Health in the Neonatal Follow-up Program

Four subthemes concerning parental mental health were developed from provider focus groups: (1) Parental mental health concerns, (2) risk factors for worsening mental health, (3) protective factors against worsening parental mental health, (4) and parents' coping styles.

Parental Mental Health Concerns. Data from both service providers and parents highlighted that NFUP parents experience PTSD, anxiety, and depression. Service providers mentioned that they felt NFUP parents experience multiple mental health concerns, which was supported by quantitative findings in the parent survey. Of the full sample of parents, 13 (26.5%) endorsed no mental health concerns, 15 (30.6%) endorsed one mental health concern, 11 (22.4%) endorsed two mental health concerns, and 10 (20.4%) endorsed three mental health concerns. The comorbidity of depression and anxiety was found to be higher (40.8%) than depression and PTSD (22.4%), or anxiety and PTSD (20.4%) among parents.

PTSD. Service providers explained that most NFUP parents experience posttraumatic stress from their time in the NICU, with one developmental pediatrician stating, "*their baby can*

die at any time (DP2).” Service providers’ perception was supported by scores on the PCL-5 within the online parent survey which found that 13 (26.5%) endorsed posttraumatic stress levels that warrant needing to use a mental health service. The NICU was the most identified trauma context identified by parents, with one parent writing, *“our twins were born at 23 weeks, and one was in the NICU for six months. Our firstborn only lived three weeks. A lot of hard things happened in that time, to our son and the relationship between my husband and I (ID 36).”*

Anxiety. Service providers noted that by the time families are discharged from the NICU, death is no longer a concern though parents attending the NFUP present as anxious. Service providers’ perception of parents being anxious was supported by total scores on the GAD-7, which found that 25 (51%) endorsed anxiety levels that warrant mental health service use, with 11 (22.4%) parents endorsing mild anxiety, 7 (14.3%) endorsing moderate anxiety, and 7 (14.3%) endorsing severe anxiety. The most discussed content of worry among parents was their infant’s prognosis. One parent wrote,

“Are her lungs going to be alright? Will BPD [bronchopulmonary dysplasia] limit her lifespan? How to keep her safe from illness? Will she ‘catch up’ developmentally? Will she always be so tiny? Will she develop speech well? (Yes) Will she resent that we picked Audio-Verbal therapy rather than sign language as a speech acquisition modality? Is she eating enough? Is isolating against RSV and then COVID-19 going to have put her behind socially? Are other children going to tease her for her small stature? Will she have friends? Will she be ready to start kindergarten at 5 (ID 79)?”

One provider explained that beyond worrying about their infant’s prognosis, parents are worried they *“won’t be able to cope, won’t be able to meet baby’s needs and that their child’s outcomes are a reflection of them as a parent (DP1).”* Further, analysis of qualitative responses

within the online survey determined that parents worried about their interpersonal relationships (e.g., partner and other family members), resources (e.g., finances, childcare for other children), their ability to manage role demands (e.g., homeownership, work, large to-do lists, caring for other children), doing enough for their children, and something bad happening to them or their children.

Depression. Service providers explained that they had limited experience identifying depression among adults, but characterized parents they perceived as withdrawn and presenting with low mood during appointments as having depression. Their perception of the parents' being depressed was supported by the results of the PHQ-9 in the online parent survey, which found that 29 (59.2%) of parents endorsing levels of depression that warrant mental health service use, with 17 (34.7) endorsing mild depression, 4 (8.2%) endorsing moderate depression, 4 (8.2%) endorsing moderately severe depression, and 4 (8.2%) endorsing severe depression. One parent wrote, "*I fell into a deep depression during my pregnancy with my twins. Not able to get out of bed, couldn't stop crying, wasn't able to care for my then 3-year-old (ID 102).*"

Risk Factors to Worsening Parental Mental Health. Beyond describing the mental health concerns they perceived parents attending their program to have, all service providers discussed their perception of factors that put parents at risk of worsening mental health. Service providers discussion of risk factors for worsening parental mental health highlighted four subthemes: (a) *transitions*, (b) *managing multiple role demands*, (c) *interpersonal relationships*, and (d) *social disparities*.

Transitions. All service providers discussed three key transition timepoints where parents are at risk of worsening mental health: leaving the NICU, entering the NFUP, and the end of maternity leave. These transitions were characterized as periods with gaps in mental health

support and increased parental stress due to less reassurance from medical professionals, and uncertainty around their infant's prognosis and their ability to care for their infant. One service provider explained, "*parents go from having constant healthcare support and data to support that their infant is okay [in NICU] to being on their own (OT).*" Parents identified a fourth transition as a risk factor for worsening mental health: the transition into being pregnant again following traumatic birth experiences where their baby was admitted to NICU. One parent captured this, writing, "*After my first child was born prematurely and had an extended NICU stay, I was concerned for my 2nd child's health (ID 47).*"

Managing Multiple Role Demands. Another risk factor that service providers discussed was having to manage multiple demands. Service providers explained that parents attending the NFUP have intensive caregiving demands for their high-risk infant, including attending multiple healthcare appointments and learning and performing treatment regimens for their infant, along with the typical demands of caring for a newborn. Parents were attending an average of two services for their high-risk infant ($M = 2.04$, $SD = 2.189$), with the highest proportion accessing five services for their infant in the past (20.4%). Service providers also discussed additional demands that parents manage, including caring for their home and other children or family members, leading to exhaustion and worsening mental health. One parent echoed this, saying, "*I'm concerned I am not doing enough for my children. They both need a great deal of therapy. There is never enough time in the day to do it all. I feel like I am failing them both (ID 47).*" This is particularly concerning for single parents (12.2%) who manage multiple responsibilities without the support of a partner.

Interpersonal Relationships. Service providers identified that conflicts or lack of support from their partner/spouse were key risk factors for worsening parental mental health, evident

when both parents would attend appointments in the NFUP. Lacking support from other family members, most notably grandparents, was also discussed as a risk factor for worsening parental mental health. A few service providers also discussed relationships with other children in the household as a possible risk factor for worsening parental mental health. Service providers perceived some parents as struggling or feeling guilty around more focus and attention being directed toward caring for their high-risk infant than their other, typically older, children. One service provider also noted that explaining their high-risk infant's condition to other children was a source of stress. This is notable, as 67.3% of parents identified as having multiple children.

Social Disparities. Beyond interpersonal relationships, social disparities were also perceived by service providers as a risk factor for worsening parental mental health. Service providers mentioned that parents who have lower socioeconomic statuses tend to have limited resources, putting them at greater risk of mental health concerns. One service provider stated, *“Generally, families with more resources may still have as much anxiety, but they’re better able to cope with that. It can be more resilient than families who have other stressors in addition to what they have (DP1).”* This is concerning as 20.3% of families identified as low income (\$0 - \$40,000).

Protective Factors Against Worsening Parental Mental Health. In addition to discussing their perception of what puts parents at risk of worsening mental health, service providers noted protective factors. All service providers discussed their perception of what protects parents against worsening mental health, based on how parents presented (e.g., more hopeful, optimistic, and engaged) and engaged in appointments (e.g., willingness to engage versus being withdrawn, exhausted, or frustrated). Service providers discussed four subthemes depicting their perception of factors that were protecting parents from worsening mental health,

including (1) social support, (2) support within the healthcare system, (3) and religion and faith.

Social Support. All service providers noted social support (partner, family, friends, grandparents, and community) as “the most important” protective factor against worsening parental mental health. Service providers perceived parents who had social support as coping with the stress of caring for their high-risk infant better than those with less or no social support. One service provider stated,

“I feel family support plays a big role, like I always, always in-clinic asked if they have family in Winnipeg. Like if they have no siblings and parents and grandparents, I think family support may play a significant role if they feel they are completely on their own, they’re even more stressed and anxious and depressed (DP2).”

Another service provider said, *“For sure, the extra family support or friend support is huge, even for just attending appointments, someone else watching the other kids or being an extra support person at the appointment (PT).”* Two service providers also mentioned that *“Mennonite and Hutterite families seem to do better because they have support from their community in caring for their infant (DP2 and Neonatologist)”* and noted similarities among Indigenous (First Nations, Metis, Inuit) families. Despite how important service providers felt social support was, most parents felt that having a child in the NFUP did not change how supported they felt by their social network (51.0%). Indeed, only 26.5% of parents said that it made them feel more supported. Moreover, parents felt that having an infant in the NFUP did not change how supported they felt by their partner (38.8%) or improved how supported they felt by their partner (38.8%). However, some parents discussed the importance of trustworthy childcare, illustrating agreement with service providers perspective that social support is protective as a form of needed social support while in the NFUP.

Support from the Healthcare System. Beyond interpersonal support, a few service providers identified that parents who feel supported and connected to the healthcare system tended to be more optimistic and engaged than parents who do not. Service providers defined connectedness to the healthcare system as parents having regular access to services and providers (e.g., family physicians or social workers). However, service providers noted that healthcare connectedness is often not possible for families, in part because services are overwhelmed. One service provider stated,

“I think the lack of support when they’re discharged from the hospital and exhaustion. You bring a new baby home and a baby who often is less on a schedule than a term baby going home, probably more demanding, less settled. So, the demands of parenting and the stress on the family is there (DP1).”

Additionally, it was noted that service providers perceive parents as not knowing what services they need to access for their infant until after their first assessment in the NFUP. This is particularly concerning during COVID-19, as 79.6% of parents noted that the pandemic increased their stress around accessing services for their infant.

Religion and Faith. In addition to healthcare support, two service providers noted that parents who discussed feeling connected to their religion or faith seemed more optimistic than parents who did not. One provider saw a connection to faith as such an important protective factor against worsening mental health that they have changed their family practices around religion to map onto this. This service provider noted,

“It [referring to parents’ connectedness to religion/faith] is so important that I was telling my mom the other day, I want my kids to go, I’m Catholic, I want them to go through the first communion because we see in clinic how important faith is for families and how we can

choose the outcomes, you know. That's a huge one (DP2)."

Parental Coping Styles. All service providers discussed how they see a breadth of mental health coping strategies among parents while their high-risk infant is attending the NFUP. Based on their descriptions, three parent coping styles were categorized: the seekers, attenders, and avoiders. Service providers described parents who fell under the category of "seekers" as those who actively seek out more education and support resources for their child and themselves than what is offered while in the NFUP. One service provider captured this by explaining how some parents *"really seek out a lot of resources, they love checklists and are on it the whole time, their whole day is therapy, enrichment, all that (OT)."* Parents who participate in what is offered but do not seek extra resources or support fall under the coping style labelled as "attenders." Finally, service providers perceived that some parents cope with their mental health while in the NFUP through avoidance. When describing how some parents are overwhelmed by hearing about their infant's health in NFUP appointments, one service provider explained, *"attending appointments for them might be hard because they have to face all those things (OT)."*

Parental Mental Health Service Use in NFUP

Service providers were asked to describe their current approach to addressing parents' mental health in the NFUP. This discussion revealed two subthemes named after quotes from service providers: (1) There is no process or person in place, and (2) where do we refer parents?

There is no Process or Person in Place. All service providers discussed that there is no parental mental health screening tool or process within their program and no preventative process to help mitigate worsening parental mental health despite a desire for such as process. Their current approach involved briefly asking parents how they are doing during appointments and only discussing mental health further with parents who express that they are not doing well,

which they noted rarely occurs as parents are often focused on absorbing the information related to their child during the appointment. One service provider explained their approach to asking parents about their mental health, stating,

“I think I would touch on it, but I don’t know that I would go into crazy depth by acknowledging like, Oh gosh, you have all these kids at home, you have all these appointments. That’s a lot and how are you kind of thing. And I guess there are some cases where we know it’s not good, and we will try, but there are probably others that are just sort of under the radar, and we’re not getting too deep into it. So only like the real obvious severe struggling families, we are getting into it a bit more deeply (PT).”

Another service provider explained, *“I think with not having those supports readily available, and with all resources being stretched, we’re very likely not exploring it to the need that it needs to be explored for the family. If the family gives a hint, then definitely, we’ll explore. We’ll ask how things are. And when you come to see a physician or maybe a therapist, you may say fine. Right? And it’s not fine. But if the family doesn’t open up, we may not have the time ability to fall in this as you would if you had somebody as part of the program who could contact them and say how things are going and discuss (DP1).”*

Further, another service provider expressed how they, *“sigh with relief (Neonatologist)”* when parents respond to their mental health check-in by saying that they are doing fine because they are unsure of how to address parental mental health, which was met with agreement (nods and statements such as “yes”) by the other service providers.

Where do we Refer Parents? Beyond their program, service providers discussed a lack of availability and options for referrals to address parental mental health. This was captured by one provider who stated, *“I don’t have a person or program I can refer them to relatively easily*

(DP1).” When asked to expand on parent mental health referrals, the service providers described a professional, a community program, and psychoeducation resources. Service providers talked about how no social worker is connected to their NFUP as social workers are limited and stretched, though are to other NFUPs in the country. They described referring some families to community programs that incorporate addressing parent mental health into their programming, such as the Families First program, though noted lengthy waitlists. One provider said, “*Even for families where the children have lots of needs, medical needs, developmental needs, you do make referrals to those supports like children’s disability services and Families First, but they sit on a waitlist for ages (DP1).*” Service providers also mentioned that they would offer parents psychoeducational resources such as brochures explaining mental health programs that offer sliding scales (e.g., Aurora). Though parental mental health programs do exist and are needed by parents, less than 50% of this sample of parents reported using a mental health service.

NFUP Parents Mental Health Service Use. Of the full sample of parents, 22 (44.9%) reported using at least one mental health service, with eight (16.3%) accessing formal services only, six (12.2%) accessing informal services only, and eight (16.3%) using both formal and informal services. Individual therapy was the most used formal mental health service ($n = 14$, 28.6%), and accessing mental health information online was the most common informal mental health service used ($n = 11$, 22.4%). Demographics of parents who used mental health services (both formal and informal, formal, or informal) or did not use services can be found in Table 5. Of note, 80% of participating fathers and 52% of mothers did not use mental health services.

Mental Health Service Use by Mental Health Concern.

Among this parent sample, the majority ($n = 36$, 73.5%) endorsed mental health severity warranting mental health service use. Half of the 36 parents experiencing one or more mild –

severe mental health concerns did not use a mental health service. Among the 18 parents who needed services and used services, 7 (14.3%) used both formal and informal services, 6 (12.2%) used formal services only, and 5 (10.2%) used informal services only. Interestingly, 4 (11.1%) of the 13 parents who did not need mental health services (i.e., did not endorse one or more mild – severe health concerns) reported using services anyway, suggesting that there are additional mental health concerns among NFUP parents that warrant mental health service use (e.g., stress).

Most parents experiencing mild depression or anxiety did not use services (64.3%) or formal services (14.3%). Both formal and informal services were most commonly used among parents with moderate (33.3%) and severe (45.5%) depression or anxiety, and clinically significant PTSD (38.5%; see Table 6 for breakdown of mental health service use by mental health severity). Further, most parents experiencing comorbid mild-severe mental health conditions ($n = 21$, 42.9%) used a mental health service ($n = 13$, 61.9%). Among those with comorbid mental health conditions that did use services, 7 (53.8%) used both formal and informal services, 2 (15.4%) used formal services only, and 4 (30.8%) used informal services only. Such findings suggest that there is room to improve parents' and service providers' mental health literacy around which services are most appropriate based on the severity of their mental health. Parents with mild concerns may be able to manage their symptoms through informal services alone, freeing up formal services for those with moderate or severe concerns.

Looking at specific mental health conditions, there was no association between whether a parent endorsed mild – severe depression and whether they used a mental health service ($\chi^2(1) = 1.34, p > .05$). There was also no significant association between whether a parent endorsed mild – severe anxiety and whether they used a mental health service ($\chi^2(1) = 2.54, p > .05$). However, moderate – severe depression ($\chi^2(1) = 5.82, p < .05$) and anxiety

($\chi^2(1) = 5.58, p < .05$) were each associated with MHSU. Based on the odds ratio, the odds of parents using mental health services were 5.95 times higher if they endorsed moderate – severe depression and 5.66 times higher if they endorsed moderate to severe anxiety than if they did not. Similarly, there was a significant association between whether a parent endorsed posttraumatic stress symptoms and whether they used a mental health service ($\chi^2(1) = 7.34, p < .05$). The odds of parents using mental health services were 7.54 times higher if they endorsed posttraumatic stress symptoms than if they did not.

Mental Health and Service Use by NFUP Eligibility Reason. Further, mental health service use among parents grouped by their infants' health concern(s) that made them eligible for the NFUP was determined. Groups are not mutually exclusive. Parents whose infants had neurological concerns reported accessing the most services for their infant and their infant having the most diagnoses. Across all eligibility reasons, most parents endorsed at least one mild-severe mental health concern, with depression being the most common. Parents whose infant was admitted due to prematurity most endorsed depression. Parents whose infant was premature, had a low birth weight, or had cardio-respiratory concerns most used both formal and informal mental health services. Among those whose infant had neurological concerns, informal mental health services were most used, and those whose infant was admitted for other reasons (e.g., syphilis or being small for their gestational age) most used formal mental health services. All subgroups except those whose infant had neurological concerns stated that they would prefer to access in-person mental health services for themselves, whereas those whose infant had neurological concerns preferred virtual services via the telephone. This information is useful in informing a national approach to addressing parental mental health, as eligibility reasons are standard across the 26 tertiary NFUPs in Canada. The results of mental health severity and

service use among parents who needed services within these parent subgroups can be found in Table 7. Though some parent subgroups reported using mental health services, all parents identified experiencing barriers to their use of mental health services.

Barriers to Parents Mental Health Service Use

Both parents and service providers discussed their perception of barriers to parental mental health service use within the NFUP. The service provider's discussion regarding the barriers to parental mental health service use in their program revealed two subthemes: (1) parent and (2) organizational barriers. Such perceptions were based on observations made during their lived experience working with parents in the program.

Parent Barriers. Service providers discussed three factors related to the parents that they perceived as barriers to them using mental health services: a) a parents' readiness, b) attitudes and beliefs about mental health, and c) reduced capacity for service involvement.

Readiness. All service providers discussed that a parents' lack of readiness for accessing mental health services was a key barrier to their mental health service use. Service providers explained that parents are so heavily focused on caring for their infant and meeting their complex demands that they are often not in a place where they are ready to focus some of their energy on themselves.

Attitudes and Beliefs About Mental Health. In addition to not feeling ready to use mental health services for themselves, service providers perceived parents' attitudes and beliefs about mental health as a key barrier to their use of mental health services. Service providers discussed how a family's culture could be a barrier to them using mental health services. One provider explained this, saying,

"Some cultures are not as inclined to go to mental health services. I always talk to the

immigrant community and tell them you know that in Canada, it's more common than in some countries. And so, some cultures are not as prone to going to counselling. They see it as though, oh well, people will identify me as being, you know, very sick mentally or something like that (DP#2)."

Service providers also discussed how families from certain cultures seem to experience stigma toward using mental health services, which serves as an additional barrier. One service provider explained,

"we have a big proportion of First Nations communities, and to me, with First Nations, they are very afraid of that stigma, and they don't want to be seen as having issues. So, you need another approach, maybe more culturally refined, so that could be another barrier that the different communities need a different approach (Neonatologist)."

Stigma was of concern to some among the full parent sample, with one parent saying they were *"Afraid of friends and colleagues knowing (ID 30)."* Moreover, service providers discussed that low mental health literacy, defined as the "knowledge and beliefs about mental disorders which aid their recognition, management or prevention (Jorm, 2000, p. 396)," among parents' served as a barrier to them using related services, evident through parents being unable to recognize or communicate when they were struggling with their mental health despite providers noticing symptoms (e.g., parents seeming less engaged in appointments or overwhelmed). This perspective was echoed by parents. Parents identified feeling unsure how to access mental health services (18.4%). One parent captured this, describing their biggest barrier to accessing mental health services as *"finding something suitable as I'm not 100% what type of counselling I may benefit from (ID 85)."* Not believing that a service was needed (22.4%) or that it would not be able to help (10.2%) were also identified by parents as barriers to them using mental health

services.

Reduced Capacity for Service Involvement. Beyond parents' attitudes and beliefs about mental health, service providers described that resource insecurity reduced their capacity for service involvement. Key resources identified by service providers as necessary for parents to participate in mental health services included the parent having time for themselves, finances to cover the cost of mental health services, childcare so that they can attend mental health services, and transportation to services. Service provider's perspectives were supported by parents both through quantitative and qualitative responses. Not having the time or energy was identified as the biggest barrier to parents accessing mental health services (38.8%), followed by cost (18.4%). Not having the time or energy was connected to prioritizing the child by a few parents, with one saying, "*Just not wanting to put in the effort to take the time for myself to go and do it even though I know I feel better after. Always putting myself and my needs at the bottom of the barrel (ID 102).*" Childcare and transportation were also identified by parents as resources needed to attend mental health services. Table 8 shows the integration of quantitative and qualitative data on parents' perspectives on barriers to using mental health services.

Organizational Barriers. In addition to speaking about their perception of the barriers to parental mental health service use, service providers talked about barriers at the organizational level that prevent them from being able to connect parents to mental health services. Such barriers were based on their own experiences rather than their perception of others' experiences (i.e., parents). Organizational barriers identified by service providers included a) providers' lack of training in adult mental health, b) appointment time and demands, c) a lack of mental health resources, and d) the program's structure of care.

Provider's Lack of Training. All service providers discussed that they lack training in

adult mental health which they perceived as a barrier to parents being able to use mental health services. All service providers stated that they desire training to recognize common mental health concerns among parents, when to connect parents to mental health supports, and where to refer them for mental health. One service provider stated, *"I always think that there's more I can do, and I don't know how (Neonatologist)."*

Appointment Time and Demands. In addition to lacking training in adult mental health, all service providers explained that even if they knew how to recognize and address parental mental health, they are limited by the length of assessment appointments. All service providers discussed how their assessments are limited to one hour, during which they have multiple demands to meet. One service provider explained,

"We have an appointment that is one hour long. And during the appointment, I feel that sometimes I have to do so many things because this is well, doing all the questions about health issues, examining the baby, talking to their families, doing trying to assess and make a diagnosis, doing their referrals, and then because we are part of research projects, taking their consent for research. And so, by the end of the appointment, it's like the hour is gone (Neonatologist)."

Further, service providers explained how they experience scheduling constraints, given that they can only see families during business hours and the limited number of service providers that work within the NFUP ($N = 5$). This was particularly concerning to service providers, as they noted,

"COVID-19 has caused our waitlist to increase, so babies that we would have seen like for sure within a month of discharge are sometimes waiting for two, three-four months to see us. So, there's more of a gap between getting in (PT)."

COVID-19 presented nuanced challenges, such as connection issues making one-hour

appointments even shorter, and families being distracted during appointments due to other family members or children who were in the home. COVID-19 also impacted the availability of external referrals for parental mental health

Lack of Mental Health Resources. All service providers noted that they perceived they lacked mental health resources for parents, which they perceived as a barrier to parents using mental health services. Lacking mental health resources included staff within the program with the time and training to address parental mental health (e.g., a nurse, psychologist, or social worker). One provider explained,

"I think the biggest thing is that we don't have social support for these families. We don't have mental health support here in the clinics or when they leave. It's not something, there's no preventative program to help with family stress. We don't have a social worker attached to the program. Social work resources are very limited and stretched. And so, we don't have access to them to be sort of preventative (DP1)."

Service providers explained that there is a lack of funding to integrate a mental health professional into the NFUP. Beyond lacking internal parent mental health resources, service providers explained that they perceived a lack of external resources, with one saying, *"I don't have a place that I can, somebody that I can refer them to relatively easily or a program relatively easily (DP1)."* Further, service providers described having to rely on external agencies to support parents' mental health as difficult, as they perceived it as difficult to communicate between agencies and follow-up, meaning that families often end up stuck on waitlists. One service provider captured this, saying, *"I mean, we can refer out to other programs, but there's a few things out there. But they've been limited with COVID too, and they have their own restrictions or some barriers to accessing some of those also (PT)."*

NFUP Structure of Care. Service providers also noted that the structure of care served as a barrier to parents using mental health services. Service providers noted that the disconnect between the NICU and the NFUP added challenges they perceived as hindering parents' mental health services use. The first was that due to being in separate locations, service providers from the NICU are unable to share knowledge regarding parents that may be struggling with their mental health and supports they may be accessing with NFUP service providers. One service explained this, stating,

"The fact that we're at a different spot now from the NICU is presumably a bit of a barrier. So, I think that before we were all crowded at children's hospitals, so perhaps even for the therapy, it was easier to know about the babies who were in NICU and were coming because the therapist might have lunch with you and might be in the place. And so, you had this sense of who the child was. You had a sense of perhaps the families, and you presumably had a sense of a little bit of the urgency of one over the other. And that is, I'm sure, lacking now because they're not we're not there. They come as a new child (DP1)."

The second was that the disconnection between programs hinders continuity of support for parents.

"We are separate from the NICU, a separate location, different separate program. So, we don't have knowledge of the support that they had in NICU, nor can we refer them back to the social worker who was involved with them in NICU. So, we don't know their trajectory and what might be available (DP1)."

Informing the Development of Parental Mental Health Services in the NFUP

Service providers and parents provided insight that informs the development of parental mental health services or adaptation of current services to address parents' unmet mental health

needs. The service providers' discussion related to this topic revealed four subthemes: (1) service modality preferences, (2) bridging the gap between NICU and NFUP, (3) parent support groups, and (4) psychoeducation for service providers and parents. Parents' responses to the online survey were integrated within these subthemes to consolidate both perspectives.

Service Modality Preferences. Service providers and parents spoke about their preferences for mental health service modalities. Service providers noted that formal services could be implemented by a social worker, nurse, or psychologist, through in-person or virtual administration. One service provider suggested that it may be easier for parents to attend if the mental health service was virtual, based on attending virtual appointments during COVID-19. This was supported by some parents, with 22.4% expressing that they prefer to access mental health services via telephone and 12.2% prefer virtual via video. Findings from the online survey supported service providers' perception, as parents specified that they would access various types of mental health services, with the most desired informal service being obtaining mental health information online ($M = 23.65$, $SD = 40.97$) and formal service being individual therapy ($M = 31.78$, $SD = 45.13$). Service providers also expressed that in-person mental health service integrated into the NFUP may also be desirable to parents. Integrated services would involve parents attending mental health services for themselves while providers were seeing their infant in the NFUP. All service providers also supported integrated parental mental health services. Parents supported the use of integrated mental health services (71.7%), with 65.3% saying that they would prefer to attend in-person.

Bridge the gap between NICU and NFUP. All service providers discussed the possibility of bridging the gap between the NICU and NFUP to address organizational barriers to parental mental health services in NFUP. All service providers supported the idea of bridging the

gap between these two programs through developing a mental health screening program that begins at NICU discharge and connects parents to supports while waiting to begin the NFUP and during the NFUP. Parental mental health screening at NICU discharge was highlighted as important for early intervention by all service providers, with one stating, *“maybe you could help them even more if you assess in NICU and then you follow them right after they go home. You can help them more than letting them stay for six months (Neonatologist).”* All service providers agreed that it was important to have a professional who specializes in adult mental health conduct the parent mental health screens, with one provider saying, *“having somebody that would do the screening either with a tool or somebody knows more about mental health would be important (DP2).”* Further, another provider described how the mental health professional would serve as

“a link between the NICU program and the NFUP where they help with that communication and warning us like this is one we’re aware of, they might have trouble with attending. This is the support we’re providing. You can call me if you need help with your appointments, that kind of thing (PT).”

Further, all service providers felt that stigma around accessing mental health supports could be mitigated by making mental health screening standard for all parents being discharged from NICU and accessing NFUP.

A process for ensuring continuity of parental mental health care was developed through discussion among service providers. Service providers noted the infant’s pediatrician could be provided the results of the parents’ mental health screen and referral recommendations, as this would be the service provider families would see while waiting to begin the NFUP. When the infant is of age to begin the NFUP (6 – 8 months), the pediatrician could then inform the NFUP

of the results of the parents' mental health screen results and any supports that the parent is currently accessing, waitlisted for, or in need of further supports from the NFUP program. Once a family begins the NFUP, service providers noted that having a mental health professional (e.g., social worker, public health nurse, or psychologist) who is integrated into their program and continues to screen parents' mental health again, connect parents to referrals, and conduct wellness checkins in line with their infant's therapy appointments would be ideal.

Parent Support Groups. All service providers discussed how having peer-led peer support group at each major transition may help mitigate the risk of transition periods worsening parental mental health. Service providers perceived the social connection fostered within peer support groups as a benefit and protective against worsening parental mental health. One service provider suggested developing a peer mentorship program where parents waiting to begin the NFUP are paired with parents who are already attending the NFUP. Such partnership would allow new parents to access social support early and mitigate uncertainties regarding entering the NFUP by having someone they can contact to share experiences and ask questions. One service provider captured this, stating, *"I'm thinking one way to improve the disconnection between NICU and NFUP is if we had the parent groups. Because we do have parent groups in NICU. I know those could be connected to parent groups in the follow-up. (Neonatologist)."*

Psychoeducation for Service Providers and Parents. All service providers discussed wanting psychoeducation resources regarding parental mental health, both for themselves and to provide to parents. Desired resources included brochures explaining common mental health concerns, identifying them, and resources to address them. Additionally, service providers noted wanting access to books that explain mental health concerns that parents in their program experience, such as anxiety, depression, and posttraumatic stress, both for themselves and to

recommend to parents. Finally, service providers noted that they wanted additional training regarding mental health concerns experienced by parents in their program, with one stating, “*if we are going to spend more time exploring mental health, then some staff development on the best way to do that is needed. You know, the benefits, the limitations, some parameters (DP1).*”

Discussion

Despite a two – four times higher prevalence of mental health concerns among NFUP parents than the general population, the Manitoba NFUP lacks an integrated approach and referrals to support parental mental health leaving unmet needs. Overall, 36 (73.5%) of NFUP parents met criteria for at least one mental health concern, though half of these parents were not accessing a mental health service despite a need and expressed interest. A significant association was found between moderate – severe depression, anxiety, and posttraumatic stress symptomology and parents’ use of mental health services, though not mild – severe depression or anxiety and mental health service use. Several barriers to parental mental health service use were identified by both parents and service providers, with the most predominant being resource insecurity among parents (e.g., time, energy, cost, childcare) and the organization (e.g., staffing, time, referral sources). Finally, opportunities to meet NFUP parents’ mental health needs were discussed by parents and service providers, and perspectives were integrated to inform mental health service recommendations that consider parents’ needs and preferences and what can be feasibly implemented by service providers.

Parental Mental Health

Findings from the parent survey determined that a large proportion of parents were experiencing a mental health concern warranting use of a mental health service (30.6%), which is almost twice as high as among parents of non-high risk infants (18.2%; Stambaugh et al., 2017).

Further, 42.4% of parents within this sample reported experiencing comorbid mental health concerns, which is over triple general postpartum rates (~13%; Ramakrishna et al., 2019).

Depression was the most endorsed mental health concern among NFUP parents, followed by PTSD symptomology and anxiety. Findings regarding parental mental health in NFUP serve to fill the gap in literature assessing parental mental health at 18 – 24 months postpartum and beyond when families are in the NFUP.

Depression. Within the present study, 29 (59.2%) of parents endorsed a need for mental health services for depression, with 17 (34.7%) endorsing mild depression, 4 (8.2%) endorsing moderate depression, 4 (8.2%) endorsing moderately severe depression, and 4 (8.2%) endorsing severe depression. These results support those of previous studies finding that prevalence of depression among mothers of high-risk infants who stayed in NICU (20 – 63%; Miles et al., 2007, Vigod et al., 2010) is nearly double the rate of population norms among non-NFUP postpartum parents (10-24%; Kendall-Tackett, 2017). Depression affected the largest proportion of parents grouped by infant health concern. These findings support considering infant health concerns as a risk factor for certain mental conditions across Canada, given that eligibility concerns are consistent across Canadian NFUPs. Service providers noted that some parents attending their appointments present as withdrawn, which coincides with previous studies on parents experiencing depression while in the NFUP (Garel et al., 2007). These results extend those of previous studies, illustrating that the prevalence of depression remains high among this parent population beyond NICU and one year postpartum, with 87.8% of parents having an infant who is one-year old or over (infant age $M = 2.31$ years, $SD = 1.40$).

Anxiety. Anxiety was the second most endorsed mental health concern among this parent sample, with 25 (51.0%) of NFUP endorsing levels that warrant mental health service use.

Among these parents, 11 (22.4%) endorsed mild anxiety, 7 (14.3%) endorsed moderate anxiety, and 7 (14.3%) endorsed severe anxiety. These findings were in line with previous research, which has found that mothers of high-risk infants are two times more likely than mothers of non-high-risk infants to experience postpartum anxiety (18 – 43% and 11 – 21%; Dennis et al., 2017; Fairbrother et al., 2015; Fairbrother et al., 2016; Voegtline et al., 2010). Further, the content of worry among the present sample was found to be similar to that of previous studies (Garel et al., 2007; Johansson et al., 2020) in that this sample of parents were worried about their infant's health and development and mothers and one father expressed worrying about the adequacy of their parenting. The present study expands upon these studies, elucidating other areas of worry, including interpersonal relationships (e.g., partner and other family members), resources insecurity (e.g., finances, childcare for other children), and their ability to manage role demands (e.g., homeownership, work, large to-do lists, caring for other children).

Postraumatic Stress. Finally, PTSD was found to be the third most endorsed mental health concern, with 13 (26.5%) of NFUP parents endorsing levels of PTSD that warrant mental health service use. These findings supported previous literature finding that mothers of high-risk infants experience a prevalence of PTSD symptoms that is over double the rate of postpartum population norms (26.5% versus 0 – 8%; Alcorn et al., 2010). Similar to previous studies, the NICU experience was identified as a trauma context among parents in the NFUP, supporting that the impact of the NICU experience goes beyond the length of NICU stay (Sabnis et al., 2019). Other trauma contexts identified by parents within the NFUP included previous perinatal loss, the birth experience, and receiving concerning news regarding their infant's health and development and prognosis (e.g., another surgery being needed or the possibility of the infant not surviving). The results of this study expand upon the current literature, as previous literature

looking at PTSD beyond 14 months postpartum in parents of high-risk infants is lacking and most parents within the present study were beyond 14 months postpartum (85.9%).

NFUP Parents' Mental Health Service Use

Consistent with previous studies in Canada (Provincial Council for Maternal and Child Health, 2017) and (Hall et al., 2015; McGowan et al., 2017), service providers within the current study discussed how mental health screening and services for parents are not integrated into their program, leaving parents with unmet mental health support needs. The majority of Manitoba NFUP parents desired integrated mental health services ($M = 54.16/100.00$, $SD = 33.90$) and needed services (73.5%), though only half of parents who needed services were using them. These findings follow a similar pattern to national findings (Provincial Council for Maternal and Child Health, 2017). Further, within the present study, 14.3% of parents with mild depression or anxiety used both informal and formal services, and a high portion of parents with moderate (26.7%) or severe (27.3%) anxiety or depression or clinically significant PTSD (23.1%) did not use services. These findings suggest that there is room to improve parents' and service providers' mental health literacy around which services are most appropriate based on the severity of their mental health. Parents with mild concerns may be able to manage their symptoms through informal services alone, freeing up formal services for those with moderate or severe concerns.

All service providers perceived a lack of referral options, with the few available being overwhelmed and having long waitlists. This coincides with previous research finding that NICU service providers perceived a lack of psychological support for parents and that 53.6% felt referrals were rarely made for parents (Twohig et al., 2016). Service providers from the NFUP discussed how they perceived mental health services as needed for parents transitioning from NICU discharge to home and then home to the NFUP. However, psychological support during

these transitions does not exist, nor for transitioning out of the NFUP. These findings coincide with previous research looking at NICU service provider perspectives, which found that 45.6% perceived that mental health services were not offered to parents upon discharge from the NICU (Twohig et al., 2016).

Findings regarding parental mental health service use are additive to the literature, as they inform unmet mental health service needs among NFUP parents. Of this sample ($N = 49$), 22 parents (44.9%) used mental health services, with formal services being used more than informal. Individual counselling was the most used formal service, and seeking online mental health information was the most common informal service used by parents. Parental mental health service use varied by infant health concern. A combination of formal and informal services was the most common form of mental health service use among parents whose infant was premature, had a low birth weight, or had cardio-respiratory concerns. Informal mental health services were most used among those whose infant had neurological concerns, and formal mental health services were most used among those whose infant was admitted for other reasons (e.g., small for their gestational age). These findings support considering NFUP infant health when screening parental mental health, given that eligibility criteria are consistent across Canadian NFUPs. Additionally, a significant association between anxiety, depression, or PTSD and parental mental health service use was only found when symptoms were moderate – severe, not when mild - severe. This finding suggests that there is room to improve mental health literacy and early intervention strategies to address mild symptoms through less intensive informal services (e.g., online psychoeducation platforms or wellbeing apps), rather than only addressing symptoms once moderate – severe.

Barriers to Parental Mental Health Service Use

The results from both parents and services providers shed light on barriers to parents using mental health services. Barriers were categorized as those related to the parent and those related to the organization. The biggest barrier related to the parents was lacking resources to facilitate mental health service use. Key resources included time, energy, cost, childcare, and transportation if services were in person, consistent with previous research (Cameron et al., 2020; Glazebrook et al., 2007; Lean et al., 2008; Kantrowitz-Gordon, 2013). Cost was particularly concerning, as 20.3% of families identified as low income (\$0 – \$40,000). Further, factors related to low mental health literacy, such as lacking an understanding of when mental health support is needed, what supports should be accessed, and how to access such services, were a barrier among parents and service providers, consistent with previous literature among NICU and general postpartum mothers (Ballantyne et al., 2014; Cameron et al., 2020).

Service providers noted additional barriers related to the organization, including limited resources such as an integrated mental health professional, time within appointments to address parental mental health, mental health screening tools, and referral options, in line with previous research (Dykes et al., 2016; Mosqueda et al., 2013; Twohig et al., 2016). Service providers also expressed their lack of training in adult mental health as a key barrier despite the average number of years working within the program being $M = 8.3$ years, $SD = 5.81$ years. This finding was contrary to a previous study which found that NICU providers' competence was positively correlated with years of experience (Twohig et al., 2016). Changes in healthcare organizations have been found to be a barrier to parents attending NFUPs in Canada (Ballantyne et al., 2014), in line with the perspectives of Manitoba service providers in the present study who viewed the change in location of their NFUP as a barrier causing disconnection between the Manitoba NICU and NFUP. Finally, service providers' discussion of parental mental health coping styles

(seekers, attenders, and avoiders) provides a nuanced view to findings from previous literature that healthcare provider and parent perspectives on barriers to service use are not always congruent (Ballantyne et al., 2014). Results within the present study suggest that fear of bad news regarding their infants' prognosis may only be a barrier for "avoiders," whereas "seekers" and "attenders" may be unaffected or motivated by fear.

Informing the Development of Parental Mental Health Services in the NFUP

Parents and service providers identified strategies to mitigate parent and organizational barriers to address parents' unmet mental health support needs. Parents' service modality preferences indicated that mental health services should aim to be in-person, or if virtual, then by telephone. Parents' also expressed interest in couples or family therapy and wellbeing apps. Manitoba service providers expressed a desire for a mental health screening program implemented by a trained professional (e.g., social worker, nurse, psychologist) at NICU discharge, given that this transition was noted as a risk factor for worsening parental mental health. The trained professional would be integrated into the NFUP, allowing them to bridge the gap between the Manitoba NICU and NFUP by connecting the parent to mental health supports and following up with families once they enter the NFUP. While some NFUPs across Canada have an integrated social worker, findings from previous studies support the development of such a program, with one review noting that mental health screening and support at NICU discharge are lacking and needed (Purdy et al., 2015).

Additionally, service providers suggested the development of peer support groups to mitigate worsening parental mental health during key transition points (e.g., NICU discharge, waiting for NFUP, end of maternity leave). Most parents felt that having a child in the NFUP did not change how supported they felt by their social network (51.0%) or partner (38.8%) or even

improved while in the NFUP. Previous literature has found that perception of social support and depression severity are higher among NICU parents with post-secondary education (high school diploma and higher; Kara et al., 2013). Thus, no change or an improvement in perceived social support among the present parent sample may be explained by the majority experiencing depression and reporting education level at or beyond a high school diploma.

An online platform (app, website, forum, podcast) offering such peer support may be particularly helpful in developing a national initiative addressing parental mental health across Canadian NFUPs. Such an online platform would meet parent service modality preferences fostering their engagement while mitigating barriers related to limited parent and organization resources that facilitate in-person mental health support. A secure website could be developed, with access given to families continuing to NFUPs when their infant is discharged from NICU. Such a website could house peer support forums organized by child diagnosis and age group (e.g., infant, toddler, school age, pre-teen, teenager, adult), allowing continued support beyond the NFUP and throughout the child's life. Additionally, making such a website a national initiative would allow for interprovincial support, which is beneficial for families with a child with a rare condition not experienced by many others in their province. Ensuring that the website is only provided to NFUP families and not open to the public would help to mitigate concerns regarding privacy within forums.

In addition to peer support forums, a nationally available website could house carefully curated psychoeducational resources to increase parental mental health literacy and provide empirical information regarding child development to mitigate uncertainties. Such information could be curated by mental health professionals working within Canadian NFUPs, and researchers and service providers from the Canadian Neonatal Network. This website would also

allow Canadian NFUP researchers to share their research findings and could be used to recruit families who have consented to be contacted regarding research in their website membership profile. This approach would help mitigate recruitment challenges within the present study, as NFUP families did not respond to recruitment through indirect means (e.g., social media postings) but were willing to participate when directly contacted.

The development of an online peer support platform is further supported in the literature with one qualitative study finding that parents of high-risk infants desired mobile platforms that connect them with peer support and information to mitigate isolation and improve trust in providers (Liu et al., 2011). Development of online platforms that offer psychoeducation and support to NFUP parents is supported in the literature, with previous studies finding better mental health outcomes among NICU parents who used interventions incorporating both psychoeducation and psychosocial support as opposed to psychoeducation alone (Benzies, 2013). Finally, providers discussed the importance of fostering resiliency among parents through mental health service use. One provider noted, *“If they are more resilient, you’re going to have better engagement with their own child with all the service providers and better follow-through. That’s to their and their child’s benefit, for sure (PT).”*

Limitations

The findings in this study should be considered with their limitations. Service providers and parents were recruited from one NFUP, making it unclear whether the developed considerations are generalizable across Canadian NFUPs. Determining generalizability is needed to fill the national service gap addressing parental mental health in NFUPs. Though demographics were determined for parents grouped by infant NFUP eligibility criteria that is standard across Canadian programs, expected cell sizes were too small to determine whether

certain subgroups of parents of infants with different conditions are more or less vulnerable to mental health concerns and, if so, whether there are differences in their mental health service use. Parents of infants with more complex conditions tend to have worse mental health outcomes and lower mental health service use compared to parents of infants with less complex health concerns (Lean et al., 2018), warranting research that compares the mental health and related service use of such parent subgroups to inform a national approach to mental health screening in Canadian NFUPs. Further, expected cell sizes from Study 1 were too small to conduct chi-square analyses that compare scores on key demographics among parents who accessed mental health services versus those who did not. Research on dimensions of health inequities has shown that families lacking economic and social capital resources have worse mental health outcomes and more barriers to using mental health services, making this important to analyze (Colton et al., 2015). Finally, given the small sample size within Study 2, each service provider's perspective cannot be considered representative of other providers from their field. Further, the perspectives of NFUP nurses are lacking within the present study, as their contact information was not provided for recruitment. Nurses play a critical role within NFUPs and should be included within future research expanding the present study to inform a national approach to addressing parental mental health in NFUPs.

Implications

Despite these limitations, the results of this two-part study expanded our understanding of the parent and service provider perspectives on the mental health service use and needs of parents of high-risk infants attending a Manitoba NFUP. Prevalence of mental health concerns being 2 – 4 times higher among NFUP parents and the majority not using mental health services signifies unmet parental mental health support needs. Consolidating the perspectives of NFUP

parents and service providers allowed for several strategies to address parents' unmet mental health support needs to be developed that foster parent engagement and are feasible to implement. Resource insecurity among parents (time, energy, cost, childcare) and the organization (staff, time, referrals) was the biggest barrier to parents using mental health services, followed by parent and provider mental health literacy. This finding, along with the result that looking for mental health information and support online was the most commonly used informal mental health support by parents, lends support for developing online psychoeducational resources such as webpages, blogs, apps, or podcasts to meet parents' mental health needs. Further, developing peer support groups in-person or online would allow parents to share information, experiences, and support. Finally, integrating a mental health screening program and referral process at NICU discharge is needed to bridge the parental mental health support gap between the NICU and NFUP. Once in the NFUP, developed mental health supports could include integrated, individual or couples therapy based on parents' and providers' expressed preferences. Such therapy could employ a trauma-informed and CBT-focused approach, given literature to support the use of these approaches to mitigate worsening mental health among NFUP parents (McGowan et al., 2017; Shaw et al., 2013). The 26 tertiary NFUPs that exist across Canada employ similar family eligibility criteria and multidisciplinary teams of service providers (Albaghli et al., 2019), allowing for the integrated findings to be applied and expanded upon to inform a national approach to addressing parental mental health in NFUPs.

Next Steps Through Knowledge Translation

Following the study's completion, the findings will be shared with parents, service providers, and government policymakers. Findings will be shared with parents through developing a poster that illustrates study findings and is displayed to parents in NFUP

assessment rooms. Additionally, an in-person and video-recorded presentation will be given at SSCY Centres' Breakfast at SSCY monthly event to disseminate the results to SSCY parents and service providers. NFUP service providers will be provided with a one-page resource summarizing the prevalence of mental health concerns, barriers to parental mental health service use, and a mental health recommendations list (see Appendix C). Within Manitoba, the results will be shared with government and policy stakeholders in Shared Health to justify increased funding for parental mental health resources in SSCY Centre's NFUP. A summary of the findings will be provided to the Canadian Neonatal Network, along with an offer to give a virtual presentation to members to begin conversation across provinces regarding the development of a national approach. Additionally, a poster or oral presentation at relevant academic conferences. Finally, the manuscript will be uploaded to MSpace as part of the University of Manitoba's Faculty of Graduate Studies Procedures and submitted for publication in a relevant journal such as the *Journal of Maternal and Child Health*, *Journal of Perinatology* or *Advances in Neonatal Care*. Once published, SSCY will add a link to the publication along with a lay summary (see Appendix C) to SSCY Centre's and Rehabilitation Centre for Children's websites for ease of access by parents, service providers, and government policymakers.

Future Directions

Given the small number of non-birthing parents within this sample, the unmet mental health support needs of non-birthing parents remain unknown. Future research looking at the mental health service use, related facilitators and barriers, and mental health service modality preferences among non-birthing parents of high-risk infants attending the NFUP is needed to ensure nuances in high-risk infant caregivers' mental health support needs are met. Similarities and differences in the mental health service use barriers, motivators, and preferences of birthing

and non-birthing parents of high-risk infants within NFUP programs also remain unknown and should be studied to expand considerations for addressing NFUP parental mental health.

Research comparing whether subgroups of parents of infants with different conditions are more or less vulnerable to mental health concerns and, if so, whether there are differences in their mental health service use is also warranted to inform a national approach to parent mental health screening in Canadian NFUPs. Additionally, the generalizability of the findings across Canadian NFUPs is unknown, warranting future research that expands considerations to a national level.

Conclusions

Despite a two – four times higher prevalence of mental health concerns among NFUP parents than the general population, the Manitoba NFUP lacks an integrated approach and referrals to support parental mental health mental leaving unmet needs. Consolidated perspectives of service providers and parents informed opportunities to address unmet parental mental health support needs that foster parent engagement and are feasible for providers to implement. Both service providers and parents supported the development of a mental health screening integrated into the NFUP to bridge the mental health service gap between the NICU and NFUP, peer support groups for key transition periods (e.g., NICU discharge to waiting for NFUP), and the integration of psychoeducation for both parents and providers, to help mitigate risk that poor parental mental health poses to the parent, infant, and family at large. Future research should expand upon the developed considerations for addressing parental mental health in NFUPs by including multiple Canadian NFUPs. Doing so would improve generalizability and allow for the development of a national approach to addressing parental mental health in NFUPs, filling the related nation-wide service gap.

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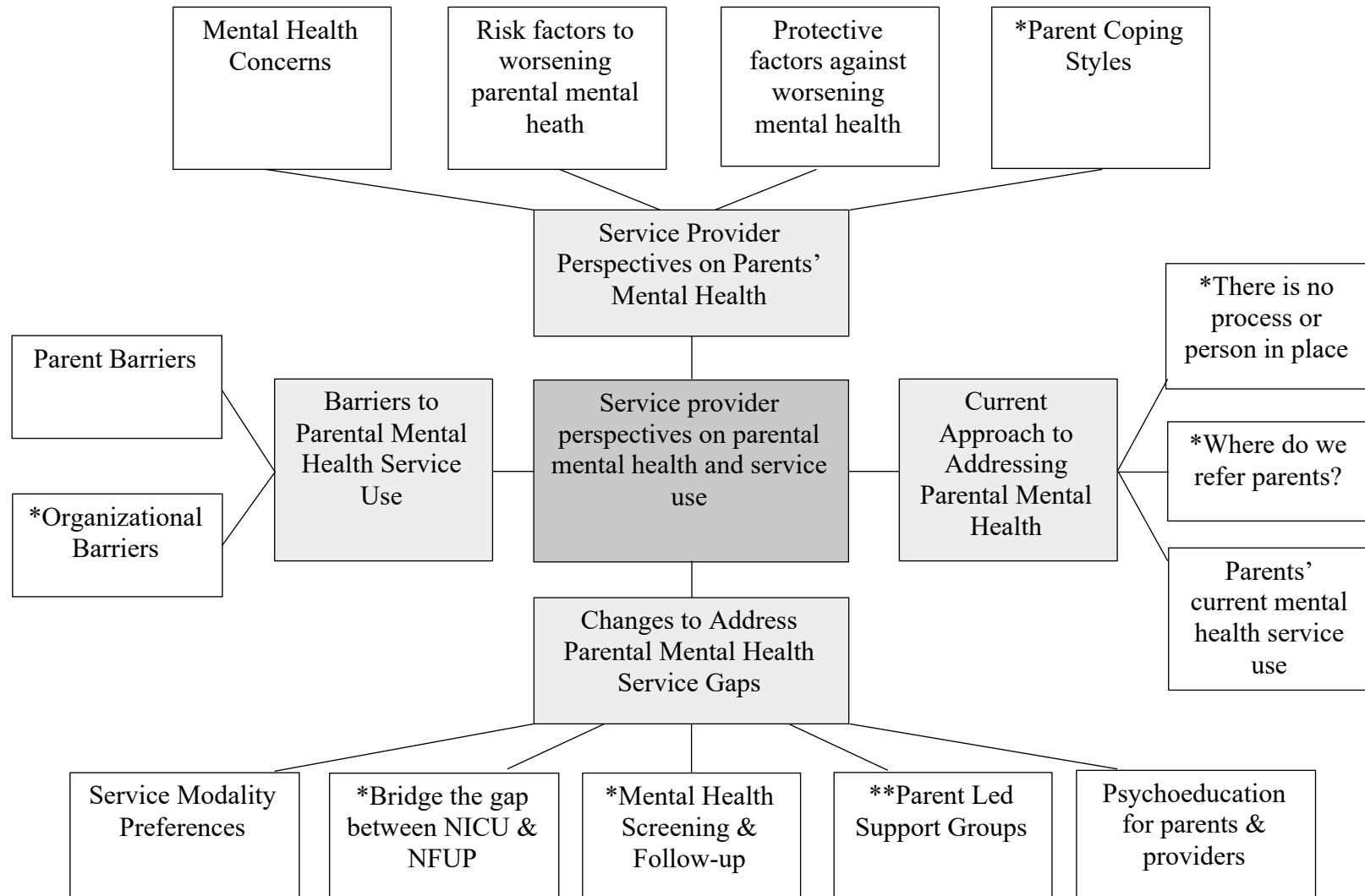
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Figure 1

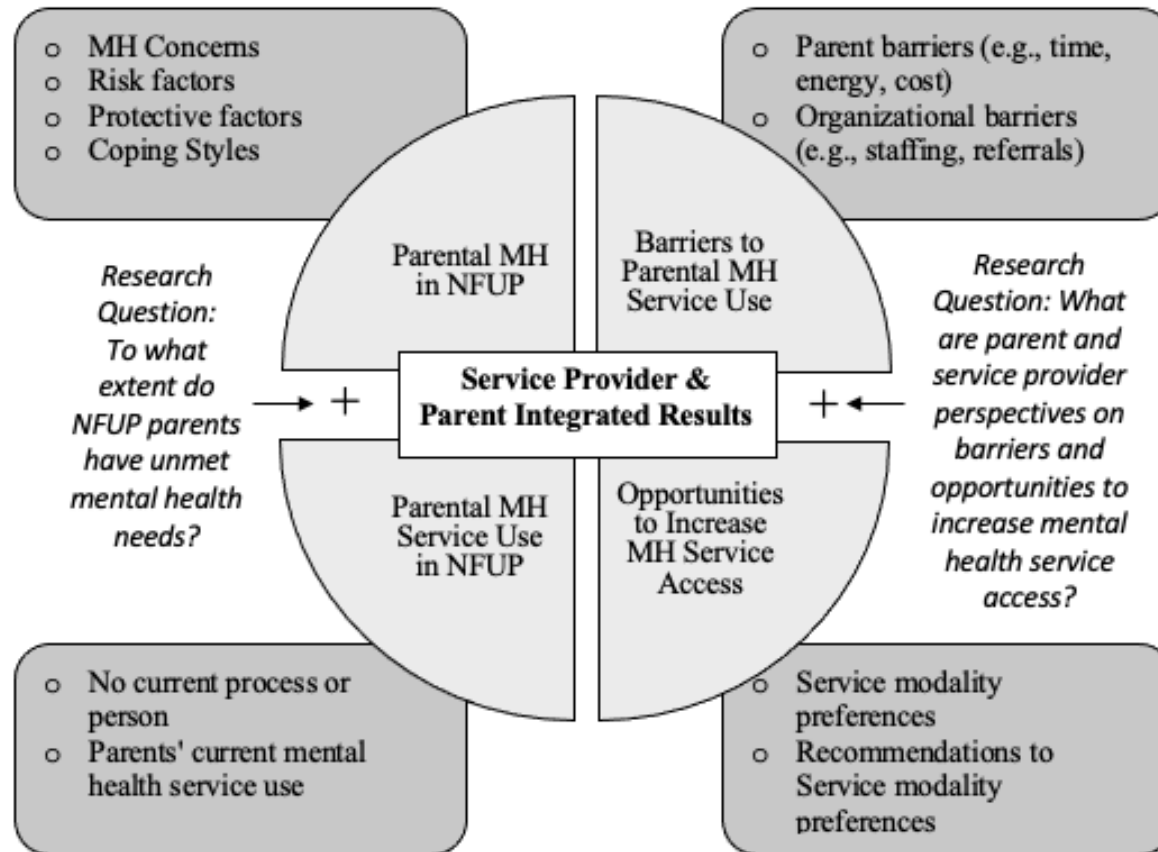
Integrated Findings Showing Main and Subthemes, and Where Perspectives were Similar or Different



Note. Light grey = main theme, white = subtheme, * = only providers discussed, ** = where perspectives differed.

Figure 2

Overview of Integrated Findings to Guide the Integrated Results Section.



Note. Light grey = main theme, dark grey = subthemes

Table 1**Parent Recruitment Strategies**

Recruitment Strategies	
Direct Methods	Indirect Methods
Calling families who had attended the Neonatal Follow-up Program within the last five years and provided verbal consent to be contacted regarding research to ask if they were interested in the present study.	Posting hard copies of the study brochure in the research corner at SSCY Centre.
Recruiting families in the waiting room at SSCY before their appointments began.	Providing copies to the program to have at their reception desk.
Having an administrative staff within the clinic ask families for their verbal consent to be contacted about the study during phone calls to schedule their Neonatal Follow-up Program appointments.	Promoting the survey on SSCY Centre's and the Hearts and Minds Laboratory social media accounts as well as through the Family Network Newsletter. Snowball sampling was used to recruit partners. The final question within the survey asked whether their partner would be willing to complete a similar questionnaire. If yes, they were asked to provide their partner's email so that a similar questionnaire could be provided.

Table 2Parent Sociodemographic Information ($N = 49$)

Sociodemographic	Mean & SD or n (Frequency)
Age	$M = 32.46, SD = 6.79$
Gender	
Female	44 (89.8%)
Male	5 (10.2%)
Marital Status	
Married/Common Law	43 (87.8%)
Single	6 (12.2%)
Number of Children	$M = 2.14, SD = 1.14$
Race/Ethnicity	
Indigenous Origins	7 (16.7%)
European Origins	23 (54.8%)
Caribbean Origins	1 (2.4%)
Latin, Central, and South American	2 (4.8%)
African Origins	1 (2.4%)
Asian Origins	8 (19.0%)
Education	
High school	12 (24.5%)
College/Technical	17 (34.7%)
Bachelors	14 (28.6%)
Masters or Professional Degree	6 (12.2%)
Employment Status	
Full-time	18 (36.7%)
Part-time	11 (22.4%)
Not Working	20 (40.8%)
Income	
\$0 - \$40,000	10 (20.4%)
\$40,001 - \$80,000	12 (24.5%)
\$80,001 - \$120,000	13 (26.5%)
\$120,000+	14 (28.6%)

Table 3Service Provider Sociodemographic Information ($N = 5$)

Sociodemographic	Mean & SD or n (Frequency)
Age	$M = 50.4, SD = 13.576$
Gender	
Female	5 (100%)
Race/Ethnicity	
European Origins	3 (60%)
Latin, Central, and South American Origins	2 (40%)
Education	
Bachelor's degree	1 (20%)
Professional degree	3 (60%)
PhD	1 (20%)
Occupation	
Developmental Pediatrician	2 (40%)
Neonatologist	1 (20%)
Occupational Therapist	1 (20%)
Physiotherapist	1 (20%)
Years Working in Field	$M = 22.80, SD = 9.68$
0 – 10	1 (20%)
11 – 20	2 (40%)
31 – 40	2 (40%)
Employment Status	
Full-time	5 (100%)
Years Working in the Neonatal Follow-up Program	$M = 8.30, SD = 5.81$
0 – 10	3 (60%)
11 – 20	2 (40%)

Table 4

Integrated Service Provider and Parent Data Supporting Each Theme

Main and Subthemes	Service Provider's Perspectives (<i>N</i> = 5)	Parents' Perspectives (<i>N</i> = 49)			
		Qualitative Reflexive Thematic Analysis	Quantitative Data	Qualitative Content Analysis	
			Hits	Themes	
Main Theme 1: Parental mental health in Neonatal Follow-up					
Parental mental health concerns	Anxiety	GAD-7 (<i>M</i> = 6.63, <i>SD</i> = 5.94) Clinically significant (<i>n</i> = 14/49; 28.6%)		34	
	Depression	PHQ-9 (<i>M</i> = 7.38, <i>SD</i> = 6.45) Clinically significant (<i>n</i> = 29/49; 59.2%)		21	
	Posttraumatic Stress	PCL-5 (<i>M</i> = 21.35, <i>SD</i> = 17.86) Clinically significant (<i>n</i> = 13/49; 26.5%)		12	Context: NICU, perinatal loss, birth experience, child custody, car crash, ill family member
Risks to worsening mental health	Stressed and overwhelmed	PSI (<i>M</i> = 40.44, <i>SD</i> = 9.58)		8	
	Transitions	NA		0	
	Exhaustion from managing multiple demands	NA		4	Managing role demands
	Interpersonal relationships	NA		9	Doing things right/doing enough
				7	Interpersonal relationships
				40	Child's health and development and prognosis

	Social disparities	NA	12	Resource insecurity
Protective factors against worsening mental health	Social support, support within the healthcare system, community support, and religion and faith	NA	10	Time and energy
			7	Trustworthy childcare
			2	Social support
Coping	Seekers, Attenders, and Avoiders	NA	NA	
Main Theme 2: Current approach to parent MHSU				
There is no process or person in place	Lack of process for addressing parental mental health in NFUP	NA	NA	
Where do we refer parents?	Limited availability of and options for referrals	NA	15	Waitlists, service availability, and unsure who to contact
Parents MHSU	Parents are not using mental health services	Any MHSU (<i>n</i> = 22, 44.9%) Both formal and informal (<i>n</i> = 8, 16.3%) Formal MHSU (<i>n</i> = 8, 16.3%) Informal MHSU (<i>n</i> = 6, 12.2%) No MHSU (<i>n</i> = 27, 55.1%)	NA	
Main Theme 3: Barriers to parental mental health service use				
Parent barriers	Attitudes and beliefs about mental health	Do not believe it would help (<i>n</i> = 5; 10.2%) No perceived need (<i>n</i> = 11; 22.4%) Unsure how to access services (<i>n</i> = 9; 18.4%) Stigma (<i>n</i> = 2)	6	External pressure, inability to open-up, fear, not caring enough about their wellbeing, not believing services would help

Organizational barriers	Readiness for mental health service use	Not interested in seeking services ($n = 9$; 18.4%)	8	Not interested
	Lack of parent resources to participate (Time, cost, childcare, transportation)	Do not have time or energy ($n = 19$; 38.8%) Too costly ($n = 9$; 18.4%) Childcare ($n = 9$; 18.4%)	26	Time and energy, cost, transportation
	Lack of adult mental health training for service providers	NA	NA	
	Time and managing appointment demands	NA	NA	
	Lack of mental health resources (e.g., funding, staffing, and referrals)	NA	15	Waitlists, service availability and how to determine who to contact
	Structure of care (NICU & NFUP disconnected, NFUP is at two hospitals)	NA	NA	
Main Theme 4: Changes to address parental mental health service gaps in Neonatal Follow-up Program				
Bridge the gap between NICU &	Screen families when leaving NICU, inform pediatrician, inform NFUP at 6mo old	Motivators to using mental health services: Cost effective ($M = 43.41$, $SD = 30.44$) Easy to access ($M = 59.04$, $SD = 29.26$) Time and energy ($M = 56.31$, $SD = 31.46$)	3	Short waitlists and simpler process
Mental health screening and follow-up	Basic screening tools and a professional to conduct screens and connect parents to resources	Believed I needed services ($M = 55.96$, $SD = 29.51$)	NA	
Parent-led support groups	Parent-led support groups for transitions (NICU to home, home to NFUP support group, NFUP peer mentor)	NA	NA	
Psychoeducation	Desire brochures, books, and training	Belief it would help ($M = 55.96$, $SD = 29.51$) Interest in seeking services ($M = 48.06$, $SD = 29.11$)	2	Information on services and mental health

Integrated mental health services	Providers desire integrated mental health service (100% agreed)	Interest in accessing mental health services or supports if they were integrated into the NFUP ($M = 54.16, SD = 33.90$)	NA	
Desired service types	Social worker, clinical psychologist, nurse practitioner	Individual therapy ($n = 15, 30.6%$) Group-based therapy ($n = 11, 22.5%$) Couples therapy ($n = 17, 34.7%$) Family therapy ($n = 17, 34.7%$) e-mental health services ($n = 17, 34.7%$) calling a crisis line ($n = 11, 22.4%$) online mental health information ($n = 14, 28.5%$) Wellbeing phone apps ($n = 20, 40.9%$)	NA	
Service modality preferences	Mix of in-person and virtual (telephone and video) based on parent preference	In-person: ($n = 32, 65.3%$) Virtual via telephone ($n = 11, 22.4%$) Virtual via video ($n = 6, 12.2%$)	11	Virtual would make it easier (phone, zoom calls, phone app, online, podcast)

Table 5**Key Parent Demographics that Impact Mental Health Service Use (MHSU) by Type of Parental MHSU**

Key Demographic Variables (NEM-II Episode Base)	MHSU (<i>n</i> = 22)			No MHSU (<i>n</i> = 27)
	Formal & Informal (<i>n</i> = 8)	Formal without Informal (<i>n</i> = 8)	Informal (<i>n</i> = 6)	
	<i>n</i> (Frequency)	<i>n</i> (Frequency)	<i>n</i> (Frequency)	<i>n</i> (Frequency)
Age	<i>M</i> = 29.63, <i>SD</i> = 6.50	<i>M</i> = 34.25, <i>SD</i> = 6.76	<i>M</i> = 32.67, <i>SD</i> = 3.61	<i>M</i> = 32.72, <i>SD</i> = 7.44
Gender				
Female (<i>n</i> = 44)	7 (15.9%)	8 (18.2%)	6 (13.6%)	23 (52.2%)
Male (<i>n</i> = 5)	1 (20.0%)	0	0	4 (80.0%)
Marital Status				
Married/Common Law (<i>n</i> = 43)	7 (16.3%)	7 (16.3%)	4 (9.3%)	25 (58.1%)
Single (<i>n</i> = 6)	1 (16.7%)	1 (16.7%)	2 (33.3%)	2 (33.3%)
Number of Children				
One child (<i>n</i> = 16)	2 (12.5%)	3 (18.8%)	3 (18.8%)	8 (50.0%)
Two children (<i>n</i> = 18)	2 (11.1%)	1 (5.6%)	1 (5.6%)	14 (77.8%)
Three + children (<i>n</i> = 15)	4 (26.7%)	4 (26.7%)	2 (13.3%)	5 (33.3%)
Race/Ethnicity (<i>N</i> = 42)				
Indigenous Origins (<i>n</i> = 7)	3 (42.9%)	0	2 (28.6%)	2 (28.6%)
European Origins (<i>n</i> = 23)	3 (13.0%)	7 (28.0%)	3 (13.0%)	15 (65.2%)
Caribbean Origins (<i>n</i> = 1)	0	0	0	1 (100.0%)
Latin, Central, South American (<i>n</i> = 2)	2 (100.0%)	0	0	0
African Origins (<i>n</i> = 1)	0	1 (100.0%)	0	0
Asian Origins (<i>n</i> = 8)	0	0	1 (12.5%)	7 (87.5%)
Education				
High school (<i>n</i> = 12)	2 (16.7%)	2 (16.7%)	2 (16.7%)	6 (50.0%)
College/Technical (<i>n</i> = 17)	3 (17.6%)	2 (11.8%)	2 (11.8%)	10 (58.8%)
University (<i>n</i> = 20)	3 (15.0%)	4 (20.0%)	2 (10.0%)	11 (55.0%)
Employment Status				
Full-time (<i>n</i> = 18)	1 (5.6%)	2 (11.1%)	2 (11.1%)	13 (72.2%)

Part-time (<i>n</i> = 11)	4 (36.4%)	2 (18.2%)	2 (18.2%)	3 (27.3%)
Not Working (<i>n</i> = 20)	3 (15.0%)	4 (20.0%)	2 (10.0%)	11 (55.0%)
Income				
\$0 - \$40,000 (<i>n</i> = 10)	4 (40.0%)	1 (10.0%)	1 (10.0%)	4 (40.0%)
\$40,001 - \$80,000 (<i>n</i> = 12)	1 (8.3%)	1 (8.3%)	2 (16.7%)	8 (66.7%)
\$80,001 - \$120,000 (<i>n</i> = 13)	2 (15.4%)	2 (15.4%)	1 (7.8%)	8 (61.5%)
\$120,000+ (<i>n</i> = 14)	1 (7.1%)	4 (28.6%)	2 (14.3%)	7 (50.0%)

Note. Key demographic variables refer to known variables that impact a persons' mental health service use as defined in the episode base from the Network Episode Model – II. Percentages were determined based on the total number of parents in each row.

Table 6

Mental Health Service Use (MHSU) Among Parents who Needed Mental Health Services

Services Used	Depression or Anxiety Severity			PTSD
	<i>Mild (n = 28)</i>	<i>Moderate (n = 15)</i>	<i>Severe (n = 11)</i>	<i>Clinically Significant (n = 13)</i>
No MHSU	18 (64.3%)	4 (26.7%)	3 (27.3%)	3 (23.1%)
Both	3 (10.7%)	5 (33.3%)	5 (45.5%)	5 (38.5%)
Formal	4 (14.3%)	2 (13.3%)	2 (18.2%)	1 (7.7%)
Informal	3 (10.7%)	4 (26.7%)	1 (9.1%)	4 (30.8%)

Note. Need for services was operationalized as endorsing at least one mild – severe mental health concern. The measure used to assess PTSD does not interpret scores based on severity. Rather, those endorsing clinically significant PTSD are understood as needing mental health services.

Table 7**Mental Health Severity and Mental Health Service Use by Infants' Neonatal Follow-up Program Eligibility Reason**

Key Demographic Variables	Premature (<29 weeks; <i>n</i> = 21)	Low Birthweight (<2,000g; <i>n</i> = 26)	Cardio-Respiratory Concerns (<i>n</i> = 13)	Neurological Concerns (<i>n</i> = 8)	Other (e.g., syphilis, SGA; <i>n</i> = 8)
	<i>n</i> (Frequency)	<i>n</i> (Frequency)	<i>n</i> (Frequency)	<i>n</i> (Frequency)	<i>n</i> (Frequency)
Infant Health Complexity					
# of Infant diagnoses	<i>M</i> = 2.48, <i>SD</i> = 1.97	<i>M</i> = 1.42, <i>SD</i> = 1.36	<i>M</i> = 2.00, <i>SD</i> = 1.83	<i>M</i> = 3.63, <i>SD</i> = 2.97	<i>M</i> = 1.63, <i>SD</i> = 1.92
# of Current Services	<i>M</i> = 2.57, <i>SD</i> = 2.29	<i>M</i> = 1.92, <i>SD</i> = 2.02	<i>M</i> = 2.00, <i>SD</i> = 1.63	<i>M</i> = 3.63, <i>SD</i> = 2.77	<i>M</i> = 1.13, <i>SD</i> = 1.55
Parent Mental Health (clinically significant)					
One or more mental health concerns	15 (71.4%)	20 (76.9%)	10 (76.9%)	6 (75.0%)	5 (62.5%)
Depression	13 (61.9%)	17 (65.4%)	9 (69.2%)	4 (50.0%)	5 (62.5%)
Anxiety	7 (33.3%)	8 (30.8%)	3 (23.1%)	3 (37.5%)	0
Posttraumatic stress	7 (33.3%)	7 (26.9%)	5 (38.5%)	4 (50.0%)	1 (12.5%)
MHSU among parents who needed services					
Formal & Informal Services	5 (31.3%)	4 (20.0%)	3 (33.3%)	2 (33.4%)	0
Formal Services	2 (12.5%)	4 (20.0%)	0	0	2 (33.3%)
Informal Services	2 (12.5%)	2 (10.0%)	1 (10.0%)	2 (33.3%)	1 (16.7%)
No Service Use	7 (43.8%)	10 (50.0%)	6 (66.7%)	2 (33.3%)	3 (50.0%)
Service Modality Preferences					
In-Person	13 (61.9%)	17 (65.4%)	6 (46.1%)	3 (37.5%)	4 (50.0%)
Virtual telephone	6 (28.6%)	5 (19.2%)	4 (30.8%)	4 (50.0%)	3 (37.5%)
Virtual video	2 (9.5%)	4 (15.4%)	3 (23.1%)	1 (12.5%)	1 (12.5%)

Note. Cutoffs for prematurity and low birthweight are based on standardized eligibility criteria across the 26 tertiary Neonatal Follow-up Programs in Canada. Parents in need of mental health services were defined as those with one or more mild – severe mental health concern warranting service use of varying intensity.

Table 8

Parents' Perspectives on Barriers to Mental Health Service Use: Integration of Quantitative and Qualitative Data

Barrier	<i>n</i> (Frequency)	Hits	Quotes
Resource Insecurity			
Do not have time or energy	19 (38.8%)	18	Just not wanting to put in the effort to take the time for myself to go and do it even though I know I feel better after. Always putting myself and my needs at the bottom of the barrel (ID 102).
Too costly	9 (18.4%)	5	
Childcare	NQ	5	Having my child and no one to care for him while accessing mental health services (ID 34).
Transportation	NQ	1	
Attitudes and Beliefs			
Mental Health Literacy			
Do not believe I need services	11 (22.4%)	4	
Unsure of how to access mental health services	9 (18.4%)	10	Finding the right service: Finding someone that wants to take on the depth of my issues (ID 70). Finding something suitable as I'm not 100% what type of counseling I may benefit from (ID 85).
Do not believe it would help	5 (10.2%)	3	Unsure if I could benefit (ID 72). Timing, good fit with service provider, a service provider who specializes in the area of concern, believing that it will work. (ID 79)
Stigma	NQ	2	Afraid of friends and colleagues knowing (ID 30).

NQ = not in quantitative data

Appendix A

**Parents will not see the titles of measures, as these will not be built into the REDCap survey.*

a. Family Socio-demographics Form

What country do you live in? _____ **What province do you live in?** _____

What neighbourhood and/or town do you live in? _____

Are you new to Canada (moved to Canada within the past five years)?

Yes No Prefer not to answer

Relation to the child receiving services from the Neonatal Follow-up Program at SSCY*:

Mother Father Grandparent Other: _____

**If you have more than one child who is receiving services from SSCY between the ages 0 and 5 please answer for the child who requires the most support*

Household size (on a regular basis): # of Adults _____ # of Children _____

Your age in years _____

Age of 0-5 year old child receiving services from SSCY, in months* _____

Ages of any other children in the family (in months): _____

What is your gender?

Female Male non-Binary Other Prefer not to answer

If other, please describe your gender. _____

Legal Marital Status:

Married/Common Law Widowed
 Divorced Single (never married)
 Separated Prefer not to answer

Race/ethnic origin:

Indigenous Origins (1) European Origins (2)
 Caribbean Origins (3) Latin, Central, and South American (4)
 African Origins (5) Middle Eastern (6)
 Asian Origins (7) Oceania Origins (Australian, New Zealander, Pacific Islands) (8)
 Other (9) _____ Prefer not to answer (10)

If other, please describe your race/ethnic origin? _____

Education Level:

- | | |
|---|---|
| <input type="checkbox"/> Some high school | <input type="checkbox"/> Master’s Degree |
| <input type="checkbox"/> High school diploma | <input type="checkbox"/> Professional Degree |
| <input type="checkbox"/> College/Technical school | <input type="checkbox"/> PhD |
| <input type="checkbox"/> Bachelor’s degree | <input type="checkbox"/> Prefer not to answer |

Employment Status:

- | | |
|--|---|
| <input type="checkbox"/> Full-time | <input type="checkbox"/> Not employed |
| <input type="checkbox"/> Part-time | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> On some type of leave | |

Household Income:

Which of the following categories best describes your household annual income:

- | | |
|--|--|
| <input type="checkbox"/> \$1 - \$10,000 | <input type="checkbox"/> \$80,001 - \$90,000 |
| <input type="checkbox"/> \$10,001 - \$20,000 | <input type="checkbox"/> \$90,001 - \$100,000 |
| <input type="checkbox"/> \$20,001 - \$30,000 | <input type="checkbox"/> \$100,001 - \$110,000 |
| <input type="checkbox"/> \$30,001 - \$40,000 | <input type="checkbox"/> \$110,001 - \$120,000 |
| <input type="checkbox"/> \$40,001 – \$50,000 | <input type="checkbox"/> \$120,001 – \$130,000 |
| <input type="checkbox"/> \$50,001 - \$60,000 | <input type="checkbox"/> \$130,001 - \$140,000 |
| <input type="checkbox"/> \$60,001 - \$70,000 | <input type="checkbox"/> \$140,000+ |
| <input type="checkbox"/> \$70,001 - \$80,000 | <input type="checkbox"/> Prefer not to answer |

What is your postal code? _____

Do you live within Winnipeg’s city limits?

- Yes No

Do you receive assistance from any governmental or other agencies?

- Yes No

If yes, which services? Check as many that apply:

- | | |
|--|---|
| <input type="checkbox"/> Child and Family Services (CFS) | <input type="checkbox"/> Manitoba Housing - Social Housing |
| <input type="checkbox"/> Rent Assist | <input type="checkbox"/> Employment and Income Assistance (EIA) |
| <input type="checkbox"/> Child Care Subsidy | <input type="checkbox"/> Child DisABILITY Services |
| <input type="checkbox"/> Family Conciliation | <input type="checkbox"/> Disability and Health Supports Unit |
| <input type="checkbox"/> Manitoba Child Benefit | <input type="checkbox"/> Other. Please describe: _____ |

b. Child Disorder Checklist/Services Accessed

Child Diagnoses*:

**If you have more than one child receiving services from the Neonatal Follow-up Program at SSCY between the ages 0 and 5 please answer the following sections on child diagnosis and service use for the child who requires the most support*

Which of the following developmental and behavioural disorders has your child been diagnosed with or is currently being assessed for? (Check as many as apply):

Disorder	Diagnosed	Being Assessed
Attention-Deficit Hyperactivity Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Autism Spectrum Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Down Syndrome	<input type="checkbox"/>	<input type="checkbox"/>
Enuresis/Encopresis	<input type="checkbox"/>	<input type="checkbox"/>
Fetal Alcohol Spectrum Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Global Developmental Delay	<input type="checkbox"/>	<input type="checkbox"/>
Intellectual Development Disorder (Intellectual Disability)	<input type="checkbox"/>	<input type="checkbox"/>
Oppositional Defiant Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Selective Mutism	<input type="checkbox"/>	<input type="checkbox"/>
Separation Anxiety Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Specific Learning Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Speech/Language Delay	<input type="checkbox"/>	<input type="checkbox"/>
Tic Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>
Obsessive Compulsive Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Cerebral Palsy	<input type="checkbox"/>	<input type="checkbox"/>
Motor Problems	<input type="checkbox"/>	<input type="checkbox"/>
Hearing Problems	<input type="checkbox"/>	<input type="checkbox"/>
Vision Problems	<input type="checkbox"/>	<input type="checkbox"/>
Sensory Sensitivity	<input type="checkbox"/>	<input type="checkbox"/>
Born Pre-term	<input type="checkbox"/>	<input type="checkbox"/>
Cardiac (heart) conditions	<input type="checkbox"/>	<input type="checkbox"/>
Syphilis	<input type="checkbox"/>	<input type="checkbox"/>
Brain injury and seizures	<input type="checkbox"/>	<input type="checkbox"/>
Hypoxic-ischemic encephalopathy (HIE)	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>

Services Accessed for Child:

Which of the following developmental and behavioural disorders is your child been treated (or waitlisted for treatments) for? (Check all that apply):

Disorder	Receiving Services	Waitlisted
Attention-Deficit Hyperactivity Disorder	<input type="checkbox"/>	<input type="checkbox"/>

Autism Spectrum Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Down Syndrome	<input type="checkbox"/>	<input type="checkbox"/>
Enuresis/Encopresis	<input type="checkbox"/>	<input type="checkbox"/>
Fetal Alcohol Spectrum Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Global Developmental Delay	<input type="checkbox"/>	<input type="checkbox"/>
Intellectual Development Disorder (Intellectual Disability)	<input type="checkbox"/>	<input type="checkbox"/>
Oppositional Defiant Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Selective Mutism	<input type="checkbox"/>	<input type="checkbox"/>
Separation Anxiety Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Specific Learning Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Speech/Language Delay	<input type="checkbox"/>	<input type="checkbox"/>
Tic Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>
Obsessive Compulsive Disorder	<input type="checkbox"/>	<input type="checkbox"/>
Cerebral Palsy	<input type="checkbox"/>	<input type="checkbox"/>
Motor Problems	<input type="checkbox"/>	<input type="checkbox"/>
Hearing Problems	<input type="checkbox"/>	<input type="checkbox"/>
Vision Problems	<input type="checkbox"/>	<input type="checkbox"/>
Sensory Sensitivity	<input type="checkbox"/>	<input type="checkbox"/>
Born Pre-term	<input type="checkbox"/>	<input type="checkbox"/>
Cardiac (heart) conditions	<input type="checkbox"/>	<input type="checkbox"/>
Syphilis	<input type="checkbox"/>	<input type="checkbox"/>
Brain injury and seizures	<input type="checkbox"/>	<input type="checkbox"/>
Hypoxic-ischemic encephalopathy (HIE)	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>

Service for Infant	Currently Accessing	Previously Accessed
Physiotherapy	<input type="checkbox"/>	<input type="checkbox"/>
Occupational Therapy	<input type="checkbox"/>	<input type="checkbox"/>
Speech Language Pathology	<input type="checkbox"/>	<input type="checkbox"/>
Ophthalmology	<input type="checkbox"/>	<input type="checkbox"/>
Emergency Room	<input type="checkbox"/>	<input type="checkbox"/>
Children’s Hospital	<input type="checkbox"/>	<input type="checkbox"/>
Surgeon	<input type="checkbox"/>	<input type="checkbox"/>
Other		

Average hours per week that your child spends accessing these services per week? _____

To what extent has COVID-19 increased your stress around accessing services for your child?

- Significantly stressed (1)
- Somewhat stressed (2)
- Moderately stressed (3)
- No change (4)
- Prefer not to answer (5)

To what extent has having a child(ren) with additional support needs (from the Neonatal Follow-up Program) changed how supported you feel by your social network (e.g., friends, family, etc.)?

- Much worse (1) Worse (2) No change (3) Better (4) Much better (5)

How has the birth of your child(ren) in the Neonatal Follow-up Program impacted your relationship with you partner?

- Much worse (1) Worse (2) No change (3) Better (4) Much better (5)

c. SSCY Neonatal Follow-up Program Additional Demographic Items*:

**Please answer the following questions based on your child needing the most support who is attending the Neonatal Follow-up Program at SSCY Centre.*

1a. Did you have difficulty getting pregnant with this child?

- Yes No Prefer not to say

1b. If yes, please briefly describe the difficulties that you experienced. _____

2. At what week in your pregnancy was your child born? _____

3. What was your child's birthweight? _____

4a. Is your child a multiple (e.g., twin, triplet, etc.)?

- Yes (1) No (2) Prefer not to answer (3)

4b. If your child was a multiple, did all infants from this pregnancy survive?

- Yes (1) No (2) Prefer not to answer (3)

4c. If your child was a multiple, are any of the other children from this pregnancy attending the Neonatal Follow-up Program?

- No (1) One (2) Two (3) Three (4) Three+ (5) Prefer not to say (3)

The remaining questions in this section pertain to other pregnancies you may have had.

5. Have you ever experienced a termination?

- Yes No Prefer not to say

6. Have you ever had difficulty getting pregnant?

- Yes No Prefer not to say

7. If you answered “yes” to the previous question: Can you please explain the difficulties that you experienced in trying to conceive: _____

8a. Have you ever experienced a neonatal loss (e.g., miscarriage, stillbirth)?

- Yes No Prefer not to say

8b. If yes, how many neonatal losses (e.g., miscarriage, stillbirth) have you experienced?

8c. At what time-point did you experience each neonatal loss (week in pregnancy)? _____

9. Have you experienced complications during labour in a previous pregnancy (obstetric complications, emergency cesarian, etc.)?

- Yes No Prefer not to say

d. Parental Mental Health Measures

1. In general, how has your mental health been throughout your life?

- Poor (1) Fair (2) Good (3)
 Very good (4) Excellent (5) Prefer not to answer (6)

2. Have you previously experienced a problem with anxiety in your life?

- Yes (1) No (2) Prefer not to answer (3)

2a. Have you previously sought help for a problem with anxiety in your life?

- Yes (1) No (2) Prefer not to answer (3)

3. Have you previously experienced a problem with depression in your life?

- Yes (1) No (2) Prefer not to answer (3)

3a. Have you previously sought help for a problem with depression in your life?

- Yes (1) No (2) Prefer not to answer (3)

4. Have you previously experienced posttraumatic stress disorder in your life?

- Yes (1) No (2) Prefer not to answer (3)

4a. Have you previously sought help for posttraumatic stress disorder in your life?

- Yes (1) No (2) Prefer not to answer (3)

5. Did your mental health worsen during pregnancy?

- Yes (1) No (2) Prefer not to answer (3)

5a. If yes, what changes did you notice in your mental health? _____

5b. Have these changes improved?

- Yes (1) No (2) Prefer not to answer (3)

5bi. If yes, when did you notice that these changes improved? _____

6. Did your mental health worsen during the postpartum period (labour – 12 months after)?

- Yes (1) No (2) Prefer not to answer (3)

6a. If yes, what changes did you notice in your mental health? _____

6b. Have these changes improved?

- Yes (1) No (2) Prefer not to answer (3)

6bi. If yes, when did you notice that these changes improved? _____

7. When you find yourself worrying, what types of things do you tend to be worried about?

8. To what extent has COVID-19 worsened your mental health?

- Significantly (1) Somewhat (2) Moderately (3) No change (4) Prefer not to answer (5)

Generalized Anxiety Disorder 7-Item (GAD-7) Scale

	Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all sure	Several days	Over half the days	Nearly every day
1.	Feeling nervous, anxious, or on edge	0	1	2	3
2.	Not being able to stop or control worrying	0	1	2	3
3.	Worrying too much about different things	0	1	2	3
4.	Trouble relaxing	0	1	2	3
5.	Being so restless that it's hard to sit still	0	1	2	3
6.	Becoming easily annoyed or irritable	0	1	2	3
7.	Feeling afraid as if something awful might happen	0	1	2	3

	Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
If you have checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?	0	1	2	3

PATIENT HEALTH QUESTIONNAIRE - 9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?
(Use to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING 0 + + +
=Total Score:

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all <input type="checkbox"/>	Somewhat difficult <input type="checkbox"/>	Very difficult <input type="checkbox"/>	Extremely difficult <input type="checkbox"/>
--	--	--	---

PTSD Checklist (PCL) - 5

Name: _____

Date: _____

Instructions: Below is a list of problems that people sometimes have in response to a very stressful experience. Please read each problem carefully and then circle one of the numbers to the right to indicate how much you have been bothered by that problem in the past month.

In the past month, how much were you bothered by:	Not at all	A little bit	Moderately	Quite a bit	Extremely
1. Repeated, disturbing, and unwanted memories of the stressful experience?	0	1	2	3	4
2. Repeated, disturbing dreams of the stressful experience?	0	1	2	3	4
3. Suddenly feeling or acting as if the stressful experience were actually happening again (as if you were actually back there reliving it)?	0	1	2	3	4
4. Feeling very upset when something reminded you of the stressful experience?	0	1	2	3	4
5. Having strong physical reactions when something reminded you of the stressful experience (for example, heart pounding, trouble breathing, sweating)?	0	1	2	3	4
6. Avoiding memories, thoughts, or feelings related to the stressful experience?	0	1	2	3	4
7. Avoiding external reminders of the stressful experience (for example, people, places, conversations, activities, objects, or situations)?	0	1	2	3	4
8. Trouble remembering important parts of the stressful experience?	0	1	2	3	4
9. Having strong negative beliefs about yourself, other people, or the world (for example, having thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted, the world is completely dangerous)?	0	1	2	3	4
10. Blaming yourself or someone else for the stressful experience or what happened after it?	0	1	2	3	4
11. Having strong negative feelings such as fear, horror, anger, guilt, or shame?	0	1	2	3	4
12. Loss of interest in activities that you used to enjoy?	0	1	2	3	4
13. Feeling distant or cut off from other people?	0	1	2	3	4
14. Trouble experiencing positive feelings (for example, being unable to feel happiness or have loving feelings for people close to you)?	0	1	2	3	4
15. Irritable behavior, angry outbursts, or acting aggressively?	0	1	2	3	4
16. Taking too many risks or doing things that could cause you harm?	0	1	2	3	4
17. Being "superalert" or watchful or on guard?	0	1	2	3	4
18. Feeling jumpy or easily startled?	0	1	2	3	4
19. Having difficulty concentrating?	0	1	2	3	4
20. Trouble falling or staying asleep?	0	1	2	3	4

Total _____

In answering the above questions, please check off whether you were thinking of any of the following situations (Check all that apply).

- Mental health
- Physical health
- Accessing the Neonatal Follow-up Program
- Distress around higher risk birth outcomes
- Possible emerging development delays
- Other
- Decline to answer

Please describe the stressful situation you were thinking of in more detail.

e. Parent Mental Health Service Utilization

1. The following are a number of mental health services that you may have accessed. Please check the box for each service you have accessed in the past year.

- Individual counselling/therapy
 - In-person Virtually
- Group-based counselling/therapy
 - In-person Virtually
- Couples Counselling/therapy
 - In-person Virtually
- Family counselling/therapy
 - In-person Virtually
- e-Mental Health services (e.g., online therapist-guided self-help, online chat support, online peer- or therapist-coaching)
- Mental health crisis line (e.g., Crisis Services Canada)
- Seeking mental health information online
- Well-being phone apps (e.g., guided meditation)
- Other: _____

2. If you have NOT accessed any mental health services

Please indicate the reasons why you have not accessed mental health services (select all that apply):

- Too costly
- Do not believe it would help
- Unsure of how to access mental health services
- Do not have time or energy
- Not interested in seeking services
- Do not believe I need services
- Decline to Respond
- Other: _____

**The following item will appear as a sliding scale (continuous variable)*

To what extent do you find each of the following to be a barrier to you using mental health services?

- Too costly
- Do not believe it would help
- Unsure of how to access mental health services
- Do not have time or energy
- Not interested in seeking services
- Do not believe I need services

3. Describe some of the things that are getting in the way of you accessing mental health services: _____

4. What’s the biggest barrier of you accessing mental health services? _____

5. Describe some things that might make it easier for you to take care of your mental health or access services:

6. If you have sought services, what motivated you to get help? _____

7. If you DID access mental health services

Please indicate the reasons why you accessed mental health services (select all that apply):

- Cost effective
- Believe it would help
- Easy to access mental health services
- Felt like I had the time or energy
- Was interested in seeking services
- Believed I needed services
- Decline to Respond
- Other: _____

**The following item will appear as a sliding scale (continuous variable)*

8. To what extent do you find each of the following to be a motivator to you using mental health services?

- Cost effective
- Believe it would help
- Easy to access mental health services
- Felt like I had the time or energy
- Was interested in seeking services
- Believed I needed services
- Important for my family

How interested would you be in accessing [insert for each service in Q1 above] service for yourself?

- Not at all interested (1)
- A little interested (2)

- Neutral (3)
- Somewhat interested (4)
- Very interested (5)

What format would you prefer to access mental health services for yourself?

- In-person Virtually via telephone Virtually via video

How interested would you be in accessing [insert for each service in Q1 above] service if it were integrated into the Neonatal Follow-up Program? *on a sliding scale*

- Not at all interested (1)
- A little interested (2)
- Neutral (3)
- Somewhat interested (4)
- Very interested (5)

e. Gift Card Entry Form

To what extent were you being careful and honest in answering the questions in this survey?

- Not at all honest and careful (1)
- Slightly honest and careful (2)
- Mostly honest and careful (3)
- Completely honest and careful (4)
- Refuse to answer (5)

Would your partner be willing to complete a similar version of this questionnaire?

- Yes (1) No (2) Prefer not to say (3)

If yes, please provide their email. **Their email will be used to send the questionnaire.*

Gift Card Entry:

If you would like to be entered into a draw for a \$100 e-gift card and/or if you would like to be contacted for future studies in our lab, please click this link to be redirected to a secured form to submit your email address: (link to be inserted)

Appendix B

Semi-Structured Focus Group Procedure: Service Provider Sample**Greeting and Consent**

Hello! My name is Shayna. I want to welcome you and thank you for taking the time to meet with me today.

- I see from your email that you sent on [date] that you have agreed to participate in this focus group (or interview)
- Can everyone please confirm that this is correct?

I am very grateful that you are willing to share your experiences working with families who have infants attending the Neonatal Follow-up Program. We are very interested in hearing your perspectives on the risk factors that are negatively affecting parent/caregiver mental health for these families and what additional supports you think they need.

I want to remind you that anything you say will not be linked with your name. All names will be removed from the transcript later. As you have read in the consent form, I am audio recording the focus group, the audio recording will be transcribed which will help us to find common themes in the group's comments.

Your participation here is voluntarily and you can also decide which questions you want to answer and which you don't want to answer. Also, there are no wrong answers, I want you to feel safe to share your views on your experiences. Your experience might be a little bit different than others, and this can help to provide us with a lot of varied information.

Does anyone have any questions or concerns at this time? [*Answer any questions.*]

Do I have your consent to start the audio-recording? Ok I am starting the recording now and we will start with our questions. (See Questions, below)

[These questions will serve as guidelines for the discussion. We may also share some of the data from the online survey to get their perspectives on the results. We want to allow the participants to make some decisions on which questions and issues are important to discuss.]

Closing

Thank you so much for making yourself available and sharing your thoughts, it is greatly appreciated.

Brief REDCap Service Provider Demographic Survey
**To be completed prior to focus group*

1. What is your gender?

- Female Male non-Binary Other Prefer not to answer

1a. If other, please describe your gender. _____

2. Age: _____

3. Race/ethnicity:

- | | |
|---|---|
| <input type="checkbox"/> Indigenous Origins (1) | <input type="checkbox"/> European Origins (2) |
| <input type="checkbox"/> Caribbean Origins (3) | <input type="checkbox"/> Latin, Central, and South American (4) |
| <input type="checkbox"/> African Origins (5) | <input type="checkbox"/> Middle Eastern (6) |
| <input type="checkbox"/> Asian Origins (7) | <input type="checkbox"/> Oceania Origins (Australian, New Zealander, Pacific Islands) (8) |
| <input type="checkbox"/> Other (9) _____ | <input type="checkbox"/> Prefer not to answer (10) |

3a. If other, please describe your race/ethnicity? _____

4. Education Level:

- | | |
|---|---|
| <input type="checkbox"/> Some high school | <input type="checkbox"/> Master's Degree |
| <input type="checkbox"/> High school diploma | <input type="checkbox"/> Professional Degree |
| <input type="checkbox"/> College/Technical school | <input type="checkbox"/> PhD |
| <input type="checkbox"/> Bachelor's degree | <input type="checkbox"/> Prefer not to answer |

5. Employment Status:

- | | |
|--|---|
| <input type="checkbox"/> Full-time | <input type="checkbox"/> Not employed |
| <input type="checkbox"/> Part-time | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> On some type of leave | |

6. What field do you work in?

- | | |
|---|---|
| <input type="checkbox"/> Occupational Therapy | <input type="checkbox"/> Nurse |
| <input type="checkbox"/> Physiotherapy | <input type="checkbox"/> Other |
| <input type="checkbox"/> Developmental Pediatrician | <input type="checkbox"/> Prefer not to answer |

6a. If other, please write the title of your field.

7. How long (in years) have you worked in your field? _____

8. How long (in years) have you worked at SSCY Centre's Neonatal Follow-up Program?

9. Please describe your role within SSCY Centre's Neonatal Follow-up Program.

Questions to be included in Focus Group

General Parent Mental Health Questions

- Can you describe the negative mental health symptoms or challenges that you see in the parents that you work with?
- In your experience, what factors do you think contribute to parent stress and negative mental health outcomes?
 - Are there any factors that you see help protect parents mental health?
 - What are the risk factors for poor parental mental health that you notice?

Perception of Motivators and Barriers to Parental Mental Health Service Use

- What factors do you think contribute to parents' likelihood of seeking mental health support (e.g., cost effective, believed it would help, easy to access, had time and energy, interested in seeking services, believed they needed services, others)?
- What barriers do you perceive parents in your program experience when trying to access mental health services/resources (e.g., cost, belief it would help, unsure how to access, no time or energy, no interest, do not believe they need mental health services, others)?
- How might current services be adapted to mitigate these barriers?

Current Organizational Service Model:

- What supports are currently in place to help parents manage stress and/or mental health while in the NFUP? Any barriers within your organization to making improvements?
- Are there resources outside of your organization that you refer parents/caregivers to for extra support? If yes, what are they?
- What resources do you wish your organization had to support parent mental health?
- Would you want to see parent mental health services integrated into the NFUP?
 - What type (e.g., resources, individual therapy, group therapy)?
 - What format (e.g., in-person, virtual)
 - Pros to integrated parent mental health services?
 - Cons to integrated parent mental health services?

Covid-19 Service Disruptions:

- Have you experienced any disruptions in the way you provide mental health supports or referrals to parents since the beginning of the COVID-19 pandemic? Have these changes affected the families you provide services to?
 - Have you noticed a shift in the frequency in which families access your services?
 - If yes, what do you think contributes to this?

Conclusion Questions

- What are the benefits to infants and families when parent mental health is resilient?
- Is there anything that we have not discussed pertaining to parental mental health and related supports in your program that you would like to add?

Thank you for your time today. I really appreciate the information that you shared with me.

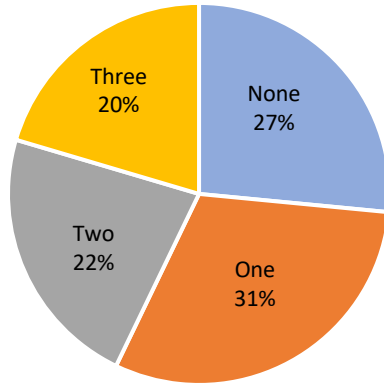
Appendix C

Lay Summary

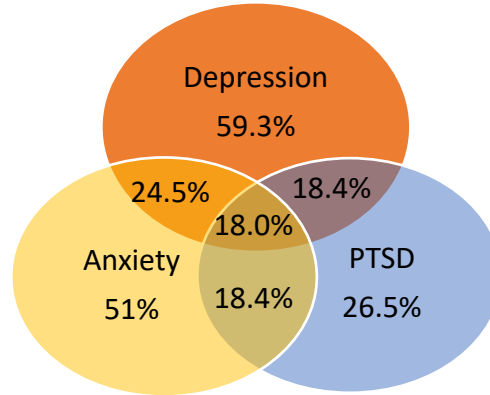
Parents of high-risk infants attend Neonatal Follow-up Programs so that their infant can keep getting care. These parents go through a lot of stress around their infant's health and are more likely to deal with depression, anxiety, and posttraumatic stress than parents who do not have a high-risk infant. Service providers feel that mental health support for these parents is lacking. They also think parents face barriers to getting help, leaving many parents without care. This project aimed to inform how the mental health needs of parents in this program can be met by bringing together parents' and service providers' thoughts. Forty-nine parents did an online survey asking about their mental health, service use, and what services they wanted. Two focus groups with five service providers from the program were run to ask how parent mental health is being handled and how we can improve the current approach. The results showed that parents need mental health support. Over half have depression, and many have anxiety or posttraumatic stress. But, under half of the parents said they used a mental health service. The parents who did not get help said they could not get support because they did not have time, could not afford it, or didn't know how. Service providers felt they did not have the time or training to help parents with their mental health even though they wanted to. Both groups had ideas of how to meet parents' mental health support needs. One was to have a mental health provider in the Neonatal Follow-up program who can talk to parents and help get them care. Another idea was to create peer support groups for parents waiting to join the program and parents in the program. Making programs that meet parents' mental health needs is vital for their health and the health of their infant and family.

Resource for Service Providers

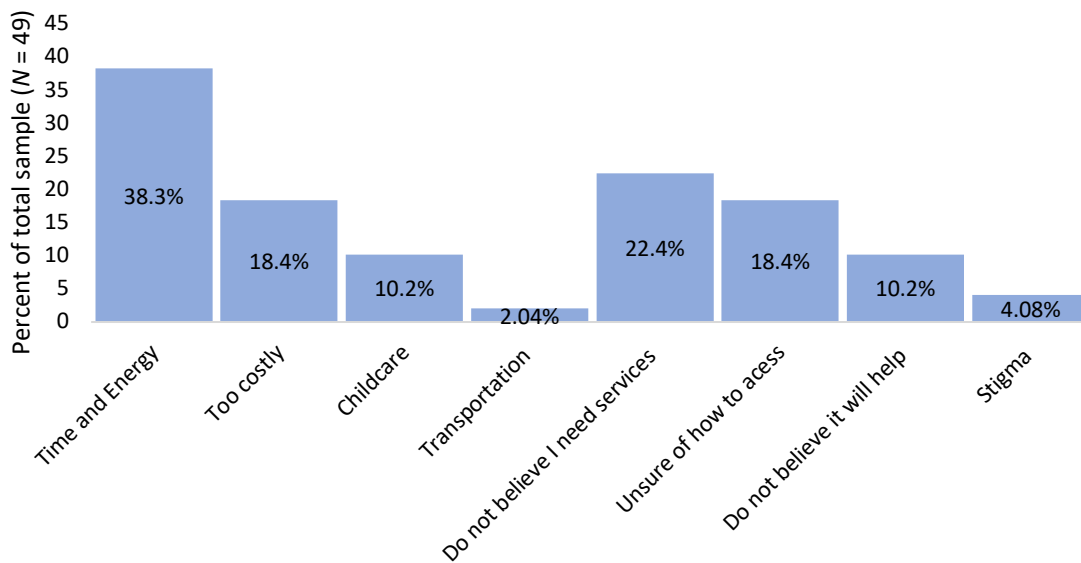
Number of Mental Health Concerns Endorsed by Parents



Parent Mental Health in NFUP

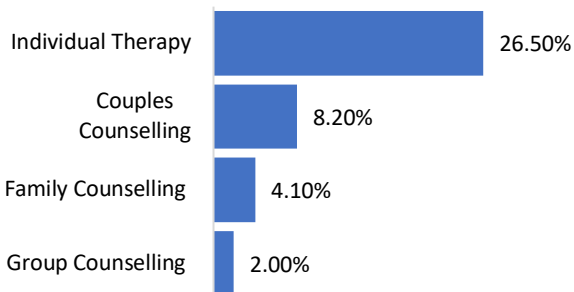


Barriers to Parental Mental Health Service Use

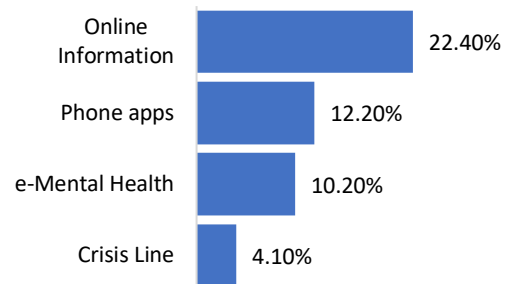


Mental Health Service Preferences

Formal Mental Health Services



Informal Mental Health Services



Online and Phone Psychological Services in Winnipeg

A link to this resource list will be provided at the end of the online survey. The list includes:

- Crisis lines
- Counselling and peer support resources (free and in sliding-scale)
- Free mindfulness meditations apps

Crisis Lines: Note: All of the following lines work 24/7 unless indicated otherwise.

- **Canadian Mental Health Association Crisis Services:** Toll free 1-888-617-7715
- **Crisis services Canada** (Ontario- based): Toll free 1-733-456-4566
Or www.crisisservicescanada.ca
- **Crisis Response Centre:**
Mobile crisis service: 204-940-1781 Community intake: 204-788-8330
- **Klinic Crisis Line:** ph: (204) 786-8686 Toll free: 1-888-322-3019
- **Kids Help Phone:** text/ call 1-800-668-6868 or visit <https://kidshelpphone.ca/>
- **Ma Mawi wi Chi Itata Centre** (Indigenous): Emergency kits delivered to your home, including food, baby supplies, and basic toiletries Contact:
McGregor location: 204-925-0330 or 204-9256816
Spence location: 204-925-0352 or 204-925-0348
- **Manitoba Suicide Prevention & Support Line:** Toll free: 1-877-435-7170
- **McDonald's Youth Services (MYS):** 204-949-4777 Toll Free: 1-888-383-2776
- **Sexual Assault Crisis Line:** 204-786-8631 Toll free: 1-888-292-7565
- **Trafficking Hotline:** Toll Free: 1-844-333-2211
- **Wahbung Abinooonjiiag** (Indigenous): Mon-Fri 9am to 5pm.
Call: 204-935-4610 or 4310554-8385
- **Willow Place:** For family violence crisis. 204-615-0311 Toll free 1-877-977-0007
- **Winnipeg Regional Health Authority (WRHA):**
 - WRHA Mobile Crisis Service – 204-940-1781
 - WRHA Mobile Crisis Service TTY Deaf Access Line – 204-779-8902
 - WRHA Crisis Stabilization Unit – 204-940-3633
 - WRHA Crisis Stabilization Unit TTY Deaf Access Line – 204-957-7101

Free counselling and peer support:

- **ADHD Peer support meetings:** Mondays at 6:30pm online through www.global.gotomeeting.com/join/412037549

- **Addictions Foundation of Manitoba:** MB Addictions Helpline at 1-855-662-6605
- **Aulneau Renewal Centre:** (French-English bilingual)
 - Wellness checks: We are facilitating wellness checks to help address any anxiety you may have due to COVID-19. Via a phone call, you will have access to a counsellor who can help you look at coping tools and resources to help you and your family during this difficult time. This service is free for all clients and community members. You do not need to be a client at Aulneau Renewal Centre for this service.
 - Call (204) 947-7090 and leave your name and phone number and a counsellor will call you back.
 - Intakes are still open for sliding scale counselling services. Fill the intake form online at www.aulneau.com. Currently Aulneau is offering phone and video sessions.
- **Canadian Mental Health Association (CMHA):** Winnipeg Phone Line – 204-982-6100
- **Critical Incident Reporting and Support Line (24/7): Ph: 204-788-8222**
- **Family Dynamics:** ph: 204-947-1401
 - In-person services still provided for those who do not have symptoms of illness and have not travelled in the past 14 days
 - Behavior support, counselling, family support for refugees, in home family supports
 - Also great resources for the entire family on their Facebook page
- **First Nations and Inuit Hope for Wellness Help Line: Toll Free 1-855-242-3310**
 - **Counselling available in English and French. Upon request, counselling available in Cree, Ojibway, and Inuktitut.**
- **Gambling Helpline (24/7): Toll free: 1-800-463-1554**
- **Klinic Community Health Centre:** General inquiries at (204)-784-4090
- **Jewish Child and Family Counselling Services** (open to all faiths, cultural groups and ages): 204-477-7430
 - Currently serving by appointment only. Phone services available and payments in a sliding scale format
- **Learning Disabilities Association of Manitoba:**
 - For general information call: 204-786-0987
 - Help lines: 204-560-1464; 204-560-1461; 204-560-1466

- **Manitoba Farm, Rural & Northern Support Services:** Monday to Friday: 10am – 9pm
ph: 204-571-4180 Toll free: 1-866-367-3276 or online at www.supportline.ca
- **Manitoba Schizophrenia Society:** 204-786-1616
 - Talk to a peer support worker. Leave a message and they will call you back
- **McDonald’s Youth Services (MYS):** Phone counselling by appointment Mon-Fri 10am to 3pm
 - Call 1-844-452-0551 or email familynavigator@mys.mb.ca to book.
 - 24/7 confidential support for youth by texting MYS to 1-800-686868
 - General questions about current services available at 204-477-1804
- **Mood Disorders Association of Manitoba:**
 - Baby Blues & Better Days warm line (peer support for post partum depression) 1pm to 9pm, 7 days a week, text or call: 204-391-5983
- **Mount Carmel Clinic:**
 - Phone counselling available for North End residents through 204-589-9477
- **North End Women’s Centre:** 204-589-7347 for information about counselling services
 - Good resources and information through Facebook
- **Recovery of Hope:** Offering appointments through video-conference or telephone whenever possible
 - Book by calling **204-477-4673, 866-493-6202, or emailing info@recoveryofhope.ca**
- **Sara Riel – Seneca Respite:**
 - General information at 204-231-0217
 - Seneca Warm Line (peer support, 24/7): 204-942-9276
- **Seniors Abuse Support Line (9am – 5pm): Toll free: 1-888-896-7183**
- **Worker’s Compensation Board Distress Line (24/7): Phone: (204) 786-8175**
Toll free: 1-800-719-3809
- **Winnipeg Regional Health Authority (WRHA) Community Mental Health**
Services: General information at 204-788-8330

Free mindfulness and meditation apps

- **Smiling mind** – mindfulness meditations for children and adults.
- **Insight timer** – mindfulness meditations and soothing background music, meditations available in 42 languages.
- **Calm in the storm** – available for iPhones only
- **Stop, Breathe, Think** – 34 free meditations and a kid’s friendly version available