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EXECUTIVE SUMMARY

Introduction

The primary aim of this report was to examine the association of the InSight mentoring program with the long-term outcomes of its participants and their children across health and social spheres.

The InSight mentoring program, provided through Healthy Child Manitoba, provides support and advocacy through outreach and intensive case management. It is aimed at preventing future fetal alcohol spectrum disorder (FASD) births for women who are pregnant or postnatal and have substance use problems, but are not effectively using community services. Each woman is assigned a mentor who works intensively one-to-one with her and her family. Mentors work within a harm-reduction framework to help women set and achieve their own goals, while weaving in the overall program goals of reducing alcohol use, making healthy choices about family planning, and connecting with social services. Over the course of the three years of the program, mentors encourage women to develop confidence to advocate for themselves, to achieve self-efficacy, and to access resources and supports in their communities. There is a growing body of research demonstrating that interventions, such as mentoring programs, that address the complex social determinants of women's health may have greater effectiveness at preventing FASD than programs strictly targeting alcohol use (Clarren, 2011; Ospina, 2011).

Approximately 11% of Canadian women consume alcohol during pregnancy. However, not all women who drink during pregnancy will give birth to children with FASD, due to a variety of reasons. Prenatal alcohol exposure places children at risk for adverse health effects, including intellectual and learning disabilities, facial dysmorphism, and social and emotional difficulties (Astley, 2010; Bertrand, Floyd, & Weber, 2005; Burd, Cotsonas-Hassler, Martsolf, & Kerbeshian, 2003; Chudley et al., 2005). These disabilities may be diagnosed under the umbrella of FASD. Women whose children are diagnosed with FASD are often marginalized, having a history of mental illness, poverty, substance abuse issues in themselves or their social network, a history of physical and sexual abuse, and being subject to the residual effects of historical colonization (Astley, Bailey, Talbot, & Clarren, 2000). Estimates of FASD prevalence vary, but a recent comprehensive study generated a midpoint of 3.6% (May et al., 2014). It represents a significant financial burden, estimated at \$5.3 billion in Canada alone (Stade et al., 2009; Stade, Ungar, Stevens, Beyen, & Koren, 2007).

Methods

This evaluation used information from the InSight program database as well as information available in the Population Health Research Data Repository (Repository) housed at the Manitoba Centre for Health Policy. The Repository includes multiple de-identified databases covering health and social-service data for the population of Manitoba. The InSight database included 525 women who were enrolled in the program at some point since 1999. Participants in the InSight program were included in this evaluation if they were 18 years of age or over, enrolled between April 1, 2001 and June 30, 2008, and had a valid personal health identification number (PHIN), which, after scrambling, allowed their InSight record to be linked to data in the Repository. This resulted in a cohort of 226 InSight participants for this evaluation. The target pregnancy was identified as the pregnancy during which the participants were enrolled or, in the case of participants enrolled postpartum, the pregnancy that immediately preceded entry to the program. Results are presented for the InSight participants before, during, and after the program. Statistical modeling was used to contrast the outcomes with a comparison group of women who had reported alcohol use during a pregnancy and had received income assistance.

Objectives

This report had six objectives:

1. Describe the characteristics of InSight participants before and at program entry using all available data sources.
2. Describe key FASD-prevention indicators, taken from the InSight database, for InSight participants during and at program exit.
3. Compare outcomes of InSight participants before, during, and after the program with a comparison group of women who did not participate, in the areas of:
 - a. use of healthcare services;
 - b. pregnancy outcomes (including prenatal care);
 - c. substance use in pregnancy;
 - d. mental health outcomes; and
 - e. use of social services.
4. Contrast outcomes before, during, and after the program for the children of InSight participants and the children of a comparison group of women who did not participate, in the areas of:
 - a. neonatal outcomes;
 - b. involvement with Child and Family Services; and
 - c. FASD assessments.
5. Examine the agreement between data available in the Repository and the InSight database.
6. Identify data limitations and suggest ways to improve data collection by the InSight Program, to allow for ongoing and improved program evaluation.

Results

Objective 1: Characteristics of the InSight Participants

Our findings confirm the vulnerability of InSight participants. Using the InSight entry interview and data from the Repository, we identified multiple unmet needs and risk factors for poor outcomes identified in this group of women. Results for the 226 participants revealed:

- Young age at initiation of alcohol use:
 - 59.1% initiated use at 13 years of age or younger; and
 - 45.9% started binge drinking at 13 years of age or younger.
- High-risk-alcohol-use patterns both during pregnancy and when not pregnant:
 - 7.8% reported consuming alcohol daily in the month before enrolment;
 - 80.6% reported high-risk alcohol use in their target pregnancy; and
 - alcohol use was reported in 50.4% of pregnancies before the program.
- High rates of mental health disorders and mental health services need and use:
 - 76.4% reported a history of anxiety or depression;
 - 48.8% reported a need for mental health services; and
 - 36.7% met the definition criteria for a mood or anxiety disorder at least once before the program, as identified by administrative data in the Repository (physician and hospital visits).
- Poor connection to social services (with the exception of the Healthy Baby Community Support programs and the Healthy Baby Prenatal Benefit):
 - 57.1% reported an unmet need for social housing;
 - 26.1% reported an unmet need for food bank use;
 - 25.0% reported an unmet need for intimate-partner-violence services; and
 - 25.0% reported not receiving income assistance in the month before program entry, despite very few reporting income from employment.

Key Message

InSight participants represent a highly vulnerable population not adequately connected to social services. This program is reaching the population it was intended to reach.

Objective 2: Program Outcomes Taken from the InSight Database

Outcomes important for the prevention of FASD include the following:

- Lower alcohol use and higher rates of abstinence during and at exit from the program, compared to the period before program entry:
 - 21.3% of women achieved at least six months of abstinence during the program;
 - 54.5% of women achieved at least six months of abstinence during the program, allowing for a brief relapse; and
 - 42.8% of women had achieved at least 30 days of abstinence at the time of program exit.
- An increased percentage of women reporting reduced alcohol use (captured as “no alcohol use” or “low risk alcohol use”) improved in subsequent pregnancies compared to the target pregnancy:
 - No alcohol use was reported in 9.6% of target pregnancies versus in 56.7% of subsequent pregnancies.
- Use of reliable contraception increased during the program from 6.8% of participants to 32.6% of participants reporting reliable use at all assessments; 73.8% reported use of reliable contraception at half or more of their assessments.
- Identification of need for and connection to social services increased for multiple types of social services, as measured at program exit compared to entry.

Key Message

The findings suggest that the InSight program had a significant impact during participation in its key focus areas.

Objectives 3 and 4: Long-term Outcomes for InSight Participants and their Children Compared to Women who did not Participate in the InSight Program

In these comparisons, a group of InSight participants who received income assistance (n=214) was compared to a group of women who did not participate in InSight but who disclosed alcohol use in a pregnancy and who received income assistance (n=2,163). These comparisons used a statistical method that adjusts for differences to make the groups appear more similar at baseline to enable an apples-to-apples comparison. Outcomes were measured over three periods: (1) before the program, (2) during the program, and (3) after the program. Outcomes were available for variable lengths of time, depending on how recently the InSight participants finished the program.

Differences between the InSight participants and the comparison group were examined for an overall difference in the change over time and for differences between periods.

We looked for statistical differences in the pattern of change over time for the entire period as a whole between the InSight participants and the comparison group. A significant result for this comparison provides strong evidence of a program effect. We also looked for statistical differences between the InSight participants and the comparison group for each time period (before, during, and after) and between time periods for the InSight participants (e.g., during vs. before). Significant differences for these comparisons provide moderate evidence of a program effect; they could also be due to confounding variables (as noted above) or the passage of time by itself.

Statistically significant differences were seen in one or more of these comparisons for several indicators:

- Overall the aim is to increase physician visits and decrease hospitalizations in this high-risk population. This effect is seen during the program but was not sustained after program exit:
 - Hospitalization rates for all cause (excluding pregnancy), mental health, and injury showed a different change over time. Rates decreased during the program then increased after program exit in the InSight participants, while continuing to decrease in the comparison group.
 - Physician-visit rates for all causes (except pregnancy) showed a different change over time. Rates were lower and did not increase as quickly over time for the InSight participants.
- In this highly vulnerable population it is not reasonable to expect full transition off of income assistance. InSight participants demonstrated increased use over time, which can be seen as beneficial in that it increases financial security. The comparison group stayed relatively stable over time.
- A goal of the program was to empower participants to make informed choices about using contraception; this was achieved as live birth rates demonstrated a different change over time, with rates approaching equivalence in the period after the program.
- InSight participants demonstrated the largest gains during the program in the uptake of prenatal care, with improved rates relative to the comparison group across multiple indicators of use. These gains, however, were lost after program exit, which strongly suggests the program has a beneficial effect—however, one which does not persist after program support is removed.
 - The largest improvement was seen for the percentage of InSight participants initiating prenatal care in the first trimester, relative to the comparison group.
 - A decrease in breastfeeding initiation was seen during the program for InSight participants. This may indicate an appropriate clinical decision for women who continue to use substances, or it may indicate inappropriate stigmatization or discouragement of women from breastfeeding.
 - Breastfeeding initiation rates in the period after InSight were similar to before.
- Patterns of having children taken into care of CFS revealed mixed results, which require further investigation. More infant apprehensions (in the first 72 hours) may reflect an increase in the identification of high-risk situations (a surveillance bias). Lower rates of having children taken into care overall may represent InSight participants' increased ability to parent safely. Among InSight participants we observed:
 - overall higher rates of CFS involvement in all periods, despite adjustment;
 - higher rates of infants taken into care in the first 72 hours during, compared to before and after the program;
 - decreased rates of having children taken into care overall during the program;
 - a relatively smaller rate decrease over time than for the comparison group (rates decreased over time in both groups); and
 - stable rates of smoking during pregnancy that were higher than the comparison group's rates, which decreased over time.
- Higher rates of social isolation, increasing over time, were observed for all periods in the unadjusted results. This merits attention in planning program delivery and post-program support.
- Decreased use of alcohol during pregnancy is suggested but could not be confirmed in this sample. The differences between the groups in the period before InSight, despite statistical adjustment, highlight the difficulty of achieving a fair comparison. Small sample size also inhibited our ability to draw firm conclusions.
 - Alcohol use in pregnancy was assessed using multiple indicators and was relatively higher for the InSight participants vs. the comparison group, across all periods and indicators.
 - There were trends towards equivalent rates due to lower use in the InSight participants on some indicators.
 - Significantly higher relative differences in high-risk alcohol use before pregnancy were observed before and during the program, with no relative difference after (i.e., rates became similar to the comparison group).

- Increased FASD-assessment rates for children born to the InSight participants is an important outcome because it helps assess appropriate interventions for these children to improve their outcomes.
 - Rates for children of the InSight participants increased and thus were higher than those of the comparison group during the program. Rates decreased again after the program, but trended toward remaining higher relative to the comparison group. Numbers are low overall due to the capacity of the assessment clinic.
- High rates of Families First screens in this population reflect opportunities to identify families in need of support.
 - Rates for the InSight participants did not change over time; however, they trended toward being higher after the program relative to the comparison group.
- Good connection to social housing was demonstrated.
 - Increased use of social housing was observed for InSight participants during the program (compared to before), and a relatively higher rate than the comparison group was observed before and during the program. (The period after program exit could not be examined because of data issues.)
- The InSight participants had higher uptake of the Healthy Baby prenatal benefit and the pre/postpartum community support groups in all periods relative to the comparison group, with no changes between periods for the InSight participants.
- Increasing rates of mood-disorder diagnoses over time may reflect improved connection to services—as this indicator measures treatment prevalence—or a true increasing incidence.
 - There was a trend toward increasing rates of mood-disorder diagnoses over time for the InSight participants, who had relatively higher rates in all periods vs. the comparison group.

Key Messages

Increasing or stable connection to many services was demonstrated. However, for some participants this did not persist after program exit. Some findings require further interpretation within the context of participant goals and individual circumstances.

Our ability to interpret results around substance and alcohol use in pregnancy was limited by sample size.

Despite the employment of sophisticated statistical techniques to ensure the groups appeared similar at baseline, differences between the InSight participants and the comparison group persisted. Therefore, differences over time and between groups could be an effect of the program, or they could be the effect of differences between the two groups of women—i.e., confounding variables—that were not taken into account.

Recommendations

1. Extension of the program in length, development of a step-down program after program exit. The lack of sustained effect in the following areas suggests that ongoing mentor support is needed or further work on helping the participants to develop their own self-efficacy is required. This is supported by:
 - a. the gains demonstrated during the program such as reduced alcohol use outside of pregnancy, connection to social services and use of reliable contraception;
 - b. the gains in prenatal care which were lost after program exit;
 - c. the suggestion of increased social isolation after program exit; and
 - d. the suggestion of less high-risk alcohol use prior to pregnancy and less use during pregnancy.
2. Discussion of these results with this study's advisory group led to a recommendation for increased ability for the program to help participants identify and seek treatment for disabilities that require ongoing support, such as FASD. It may be unrealistic to expect all participants to sustain gains without external support.
3. Re-evaluation of the program in the future to test whether the areas where no effect was seen was due to lack of effect or other factors. Specifically a repeated evaluation would benefit from:
 - a. a larger sample, due to both program expansion and elapsed time, with longer follow-up available, especially for studying the outcomes of children;
 - b. improved collection of participant start and exit dates;
 - c. possible inclusion of women who were eligible for the InSight program, and for whom we have some basic information (such as the PHIN), but who declined to enrol or were only briefly enrolled, who could act as a comparison group; and
 - d. inclusion of information from participants using updated data collection forms addressing some of the issues with current and past forms.

This evaluation used multiple sources of information to show outcomes for InSight participants and their children, covering the periods before, during, and after program participation. The value of this report is that it provides a first look at previously unrecorded outcomes in this vulnerable population, especially those after program exit, and with the context of a comparison group. However, our ability to make fair comparisons was hampered by difficulty identifying a satisfactorily similar control group. While we observed improvement in some areas, many areas did not demonstrate changes. Whether this was due to the small sample sizes, data quality, or a true lack of program effect is unclear. This report demonstrates some improved outcomes, and suggests hypotheses for future study. Future evaluation of this program would benefit from a mixed-methods analysis that includes both qualitative and quantitative aspects, and incorporates further detail about the characteristics of the participants themselves and how they relate to outcomes achieved. With the ability to link outcomes to participants' individual goals, or the ability to study the trajectory of individual participants over time, a better understanding of the program's strengths and successes could be reached.

CHAPTER 1: INTRODUCTION

There is a growing body of research demonstrating that interventions that address the complex social determinants of women's health—such as mentoring programs—may have greater effectiveness at preventing fetal alcohol spectrum disorder (FASD) than programs that only address alcohol use (Clarren, 2011; Ospina, 2011).

Description of the InSight Mentoring Program

The InSight mentoring program¹ provides outreach and intensive case management, support, and advocacy for women who are pregnant or postnatal, have substance use problems, and are insufficiently connected to other community programs and services. The ultimate goal of InSight is to reduce the prevalence of drinking during pregnancy and the number of children born with FASD. Espousing a harm-reduction philosophy, the program works to achieve its goal by supporting women and their families in a variety of areas to improve family health and wellbeing.

InSight replicates the model of the Parent-Child Assistance Program, which proved very successful at preventing FASD in Seattle, Washington (Grant, Ernst, Streissguth, & Stark, 2005). Funded by Healthy Child Manitoba, InSight began in 1998 with two locations in Winnipeg and was expanded to include sites in Thompson and The Pas in 2001. In 2002, the capacity of the two Winnipeg sites was increased by 50% and in 2008 the program was expanded again to the communities of Portage la Prairie, Dauphin, and Flin Flon.

The program operates out of two community health centres, two regional health authorities and a Friendship Centre. Each site has a program coordinator who manages the site, is responsible for community outreach, education, and program referrals, and who supervises two or three mentors. Mentors are well-trained, paid staff who have significant experience working with vulnerable populations. Each mentor may work with up to 15 women at a time, which gives InSight a total program capacity of 240 women. Women are eligible for the program if they are

- aged 18 years or older;
- pregnant or up to 12 months postpartum;
- experiencing substance-use problems;
- not well-connected to community resources; and
- living within a one-hour radius of a program site.

The program works with women whether or not they have custody of their children and whether or not they are abstinent from drinking.

At program entry, each woman is assigned a mentor who works intensively with her and her family for up to three years. Mentors help women build and maintain healthier lifestyles in a supportive, non-judgmental way using motivational interviewing, trauma-informed and harm-reduction practices. Mentors routinely help women set their own goals for the program and help them to achieve these goals, while integrating broader program goals. In this way, services are tailored to each woman and her specific situation, and can include a broad range of supports.

Mentors work with women to connect with community services, get transportation to appointments, and overcome barriers to service. Mentors facilitate access to services, including housing, prenatal care, and healthcare for women and their children, parenting support, spiritual and cultural teaching, substance-use treatment, family-planning services, and services that address intimate-partner violence and trauma. Mentors advocate for clients and assist clients to advocate for themselves as they seek financial security, address child custody or care issues, legal and criminal justice issues and healthcare issues.

1 For information on the InSight mentoring program, see: <http://www.gov.mb.ca/healthychild/fasd/insight.html>

Over the course of the program's three years, mentors encourage women to develop the confidence to advocate for themselves, to achieve self-efficacy, and to know where in the community to seek help when needed, so that they can maintain gains in health and well-being beyond their time in InSight.

Background on Alcohol Use in Pregnancy and FASD

Prenatal alcohol exposure places children at risk for adverse health effects including intellectual and learning disabilities, facial dysmorphology, and social and emotional difficulties (Astley, 2010; Bertrand et al., 2005; Burd et al., 2003; Chudley et al., 2005). These disabilities are collectively termed FASD. Due to the range of expression and disability related to prenatal alcohol exposure it is a difficult condition to diagnose. There is also immense stigmatization associated with prenatal alcohol use that results in underreporting and failure to seek a diagnosis. The Canadian Maternity Experiences Survey (2009) indicated that approximately 63% of women reported drinking alcohol pre-conception, and 11% reported alcohol consumption during pregnancy (Walker, Al-Sahab, Islam, & Tamim, 2011). Exact population incidence and prevalence of FASD in Canada and internationally are unknown. Estimates of FASD prevalence vary but a recent comprehensive study generated a midpoint of 3.6% (May et al., 2014) and it represents a significant financial burden, estimated at \$5.3 billion for Canada alone (Stade et al., 2009; Stade et al., 2007).

Because of the complex interplay of environment and genetics, not all women who drink during pregnancy will give birth to children with FASD. Women whose children are diagnosed with FASD are often marginalized with a history of mental illness, poverty, substance abuse issues (their own or in their social network), a history of physical and sexual abuse, and the effects of colonialism. These women often come from lower socioeconomic backgrounds, have lower education levels, and poor nutrition (Astley et al., 2000).

Study Objectives

The primary aim of this study was to examine whether InSight is associated with any long-term effects after program exit over multiple domains for clients and their children. The specific objectives of this evaluation were to:

1. Describe the characteristics of InSight participants before and at program entry using both the InSight Database and the Population Health Research Data Repository (Repository).
2. Describe the results for key indicators of FASD prevention for InSight participants during and at program exit.
3. Contrast outcomes before, during, and after program exit of clients with a comparison group of women who did not participate in the InSight program in the areas of:
 - use of healthcare services;
 - pregnancy outcomes (including prenatal care);
 - substance use in pregnancy;
 - mental health indicators; and
 - use of social services.
4. Contrast outcomes before, during, and after program exit for the children of InSight participants and the children of a comparison group of women who did not participate in the InSight program in the areas of:
 - neonatal outcomes;
 - involvement with Child and Family Services; and
 - FASD assessments.
5. Examine the agreement between variables available in both information sources (Repository and InSight)
6. Identify areas of data limitations and provide suggestions to improve data collection by InSight, to allow for ongoing and improved program analysis.

These objectives were accomplished by identifying a group of InSight participants who had completed the program and who were able to be linked to a valid personal health identification number (PHIN), which allowed InSight data to be linked to the Repository housed at the Manitoba Centre for Health Policy. To assess the impact of the program, a comparison group of women who did not participate in InSight, but had received income assistance and disclosed alcohol use in pregnancy was drawn from data in the Repository.

Report Structure

Chapter 2 contains a detailed description of the methods used to identify an appropriate group of InSight participants and a comparison group for analysis, and gives an overview of the data sources used. This chapter also describes the indicators used to compare outcomes within the group of InSight participants as well as between them and the comparison group.

Chapter 3 addresses Objective 6 and contains a discussion of data quality. During this research project several areas for improvement in data collection were identified. A detailed description of missing variables and their importance is included, as are suggestions for ways to streamline data collection. The most significant limitations of this report are small sample sizes and the difficulties in capturing drug and alcohol use and social-service use in the Repository.

Chapter 4 addresses Objectives 1 and 5 and contains information drawn from both the InSight database and the Repository to describe the characteristics of the InSight participants before and at program entry. Where a variable was available from both sources a direct comparison is shown.

Chapter 5 addresses Objective 2 and contains information on alcohol use in both pregnant and non-pregnant participants, use of contraception, and connection to social services as drawn from the InSight database for the InSight participants described in Chapter 3. This information is gathered over the three years of the program and at program exit.

Chapter 6 addresses Objectives 3 and 4 and presents indicators drawn from the Repository over three time periods: before, during, and after InSight. It reports rates and unadjusted comparisons between time periods for InSight participants and their children. Additionally, the same indicators are reported for a comparison group of women (including their children) who were not program participants. Statistical adjustment was used to compare results between these two groups (see Chapter 2 for methodology). Chapter 6 contains indicators from multiple areas, including healthcare usage, pregnancy outcomes and prenatal care, substance use in pregnancy, mental health outcomes, use of social services, neonatal health, FASD assessments, and contact with Child and Family Services.

Chapter 7 summarizes the key results and presents recommendations arising from this evaluation.

CHAPTER 2: METHODS

Study Groups

Two study groups were used in this report: one of InSight participants and a comparison group of women who did not participate in InSight.

InSight Study Group

The InSight database that MCHP received for analysis included data from 1999 to 2012. Our criteria for retaining individuals in the study population were decided to retain the highest number of participants for whom data quality was sufficient for analysis and who had finished the program early enough for one year of post-program outcomes to be measured.

We received information on 525 women. The study cohort's development is described in Figure 2.1. Women were excluded (n=177) from the study population if they:

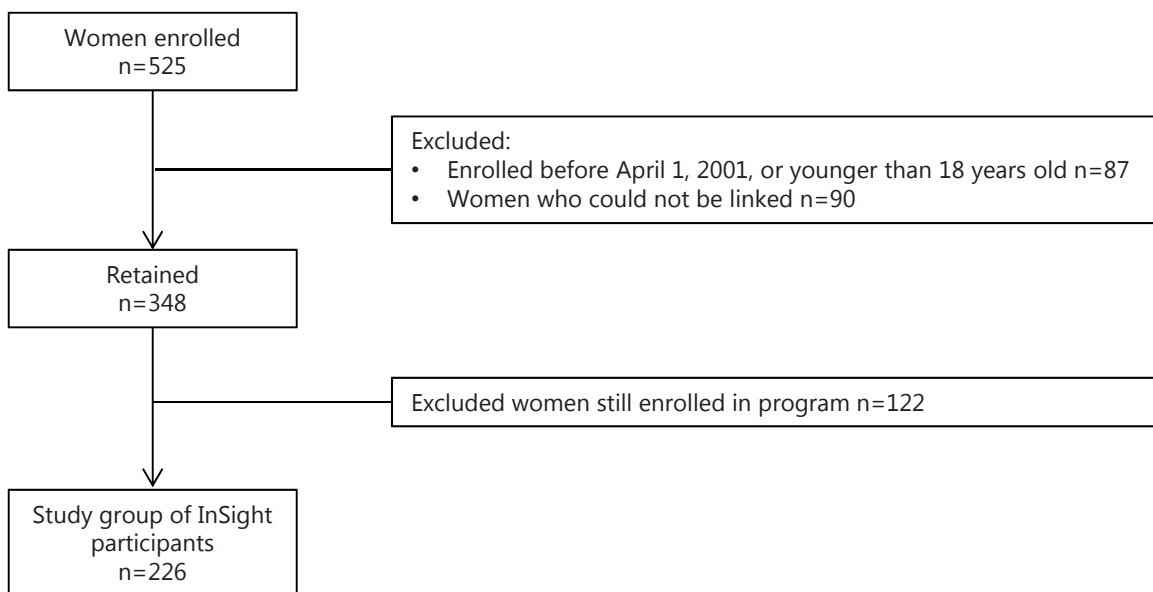
- were younger than 18 years of age (this program targeted adults and the number of teenagers enrolled was very low (fewer than six), such that they could not be grouped separately);
- enrolled prior to April 1, 2001 (before this date InSight data were very incomplete, thus not enough information was available to include them in the analysis); or
- had a record that Manitoba Health, Healthy Living and Seniors (MHLS) could not associate with a PHIN (a valid PHIN is required to link to other Repository data).

The excluded participants were similar on most characteristics other than program centre and time of enrolment. (These results are presented in Chapter 3.) Please note that women without a recorded PHIN would still have a number available to them and would not be denied access to medical services.

The most recently established centres—Portage la Prairie, Dauphin, and Flin Flon (all started in 2008—were not operating long enough to have women complete the program, and so were not included in the cohort. Despite longer-running programs in the Winnipeg-based centres, issues with the quality of early data collection limited the numbers of InSight participants included (e.g., missing PHINs and completion of Addiction Severity Index intake forms). Details of the cohort's development, including exclusions, are given in Chapter 3.

There were 122 women still enrolled in the program on March 31, 2012, the date that the data were abstracted and processed. These women were excluded because they did not have at least one year of post-program outcome data available. The final study cohort included 226 InSight participants enrolled between April 1, 2001 and June 30, 2008. For some of these women, data are incomplete or missing for certain variables. These will be noted throughout this report. When subpopulations are analyzed, such as those with a pregnancy or those with a Families First Screen, the sample size is even smaller. This is noted in the applicable analyses. For the analyses in Chapter 6, the sample was limited to InSight participants who had received income assistance before entry (n=214).

Figure 2.1: Development of the InSight Study Group



Comparison Group (Women who did not Participate in InSight)

In Chapter 6 we use several indicators to compare the InSight participants with a group of women who did not participate in InSight but who reported alcohol use in a pregnancy between Jan. 1, 2001 and June 30, 2008 and received income assistance at any point before that birth (n=2,163). The birth date of that child (referred to as the target child) was used in lieu of a program start date when required for comparisons. A statistical method called Inverse Propensity Treatment Weighting (IPTW) adjusted for differences between the two groups to allow for comparisons between them. Details on how the IPTW works and how to interpret the results are given in Chapter 6.

Data Sources

This report describes the results of a retrospective evaluation of the InSight mentoring program in Manitoba. This means that the information used was collected before the start of the evaluation. In addition to the InSight database provided by the Healthy Child Manitoba office, the analyses for this report used administrative and clinical databases in the Repository at MCHP. Most of these data are derived from administrative claims data collected by Manitoba Health, Healthy Living and Seniors (MHHLs) and other government agencies in order to administer the universal healthcare system and other services within Manitoba.

All data files in the Repository are de-identified, which means that names and other identifying fields are not available. A unique scrambled identifier based on the PHIN is used by MHHLs to allow linkage across files and follow-up over time. Data in the Repository have been extensively documented and validated for this kind of research (Roos, Gupta, Soodeen, & Jebamani, 2005; Roos & Nicol, 1999). All data management, programming, and analyses were performed using SAS® statistical analysis software, version 9.3.

InSight Database

Data maintained by the Healthy Child Manitoba office in the InSight database include information on all women who have joined the program, as well as information on their children (as reported by participants). Data are collected at intake, at six-month assessments, periodically as goals are reassessed, for specific events such as births and deaths, and upon exit from the program. The intake and exit evaluations provide information on birth-control history, past pregnancies, childhood history, housing stability, history of drug and alcohol use, connection to

MCHP Databases

The following data from the Repository were used for our analyses:

- Cadham Provincial Laboratory (for information on laboratory tests such as sexually transmitted diseases);
- Canadian Census (public-use files);
- Child and Family Services Applications (intake and CFSIS, child daycare, education (enrolment, marks, and assessments));
- Families First Screening (FFS) and Home Visiting Program;
- Healthy Baby (Manitoba Prenatal Benefit, Community Support programs);
- Hospital Discharge Abstracts;
- MCHP Research Registry;
- Manitoba Fetal Alcohol Spectrum Disorder;
- Manitoba Immunization Monitoring System (MIMS);
- Manitoba Maternal Serum Screening Program;
- Medical Claims;
- Employment and Income Assistance program (income assistance or IA); and
- Social Housing (Tenant Management System, Shelter Benefit, and Rent Supplement).

For descriptions of these databases please visit the MCHP website: http://umanitoba.ca/faculties/medicine/units/community_health_sciences/departmental_units/mchp/resources/repository/datalist.html.

Additional Reports

Additional information on some of the indicators used and variables reported on in this deliverable, and the impact of some of the services to which the women were connected can be found in the following reports:

- The Experiences of Women Involved with Mentoring: Summary of NAT 4 Research Projects, 2011–12. (Burnside, McDermott, Gough, Tanchak, & Reinink, 2012)
- Perinatal Services and Outcomes in Manitoba, 2012 (Heaman et al., 2012).
- Evaluation of the Healthy Baby Program, 2010 (Brownell, Chartier, Au, & Schultz, 2010).
- Next steps in the provincial evaluation of the BabyFirst program: Measuring early impacts on outcomes associated with child maltreatment, 2007 (Brownell M, Santos R, Kozyrskyj A, Roos N, Au W, Dik N, Chartier M, Girard D, Ekuma O, Sirski M, Tonn N, Schultz J, 2007).
- Please see Reference List for complete reference.

Indicators and Time Periods Used in this Report

The outcomes of the InSight participants are reported using several indicators from the InSight data and databases in the Repository over different time periods. Table 2.1 contains a list of the indicators used in this report as well as the time period during which they were captured and the data sources from which they were drawn. Detailed technical descriptions of the indicators used in this report are given in Appendix Table 1.1.

Table 2.1: Indicators Used in this Report

Time period in which they were available and data source

	Before	At Program Entry	During	At Program Exit	After	Data Source
Descriptive Variables						
Program Centre		X				I
Enrollment Year		X				I
Self Reported Ethnicity		X				I
Income Quintile		X				R
Socioeconomic Factor Index		X				R
Area of Residence		X				R
Preferred Substance		X				I
Income Sources Other than Income Assistance		X				I
Self Reported Chronic Medical Condition		X				I
Age at First Birth		X				R
Legal Status		X				I
Maternal Age		X				B
Education Level		X				B
InSight participants' outcomes						
Alcohol Use Outside of Pregnancy	X	X	X	X	X*	B
Mood Disorder Diagnoses	X	X	X	X	X	B
Social Services Other than Housing		X		X		I
Hospitalisation Rates	X		X		X	R
Physician Visit Rates	X		X		X	R
Social Housing	X	X	X	X		B
Receipt of Income Assistance	X	X	X	X	X	B
Use of Contraception		X	X			I
Social Isolation	X*		X*		X*	R
Healthy Baby Group Participation - Pre or Post Natal	X*		X*		X*	R
Alcohol Use in Pregnancy	X	X	X	X	X	B
Birth Rates	X		X		X	R
Receipt of Prenatal Care	X		X		X	R
Receipt of Families First Screening	X		X		X	R
Smoking During Pregnancy	X		X		X	R
InSight participants' Children's Outcomes						
Number of Children	X	X	X	X	X	B
Size for Gestational Age	X		X		X	R
Prematurity	X		X		X	R
Neonatal Intensive Care Unit Admission	X		X		X	R
Breastfeeding	X		X		X	R
Contact with Child and Family Services	X	X	X	X	X	B
Fetal Alcohol Spectrum Disorder Assesments	X		X		X	R

R indicates data from the Population Health Research Data Repository (Repository)

B indicates data from both InSight and the Repository

I indicates data from InSight dataset

* measured in pregnancy, only available for women with a FFS in that pregnancy

In this report, the results of comparisons of the InSight participants to themselves over time as well as the comparisons at each time period between the InSight participants and the comparison group are reported as relative risks with 95% confidence intervals; significance is set at $p < 0.05$ with adjustments for multiple comparisons. A p-value of 0.05 means that there is a 5% probability that differences were due to chance alone. When the patterns of change over time were compared between the two groups, we looked for a statistical interaction, which requires a larger sample size to achieve significance than single variables analyses. After weighing the risk of missing a true difference, against the risk of falsely assuming a difference where one does not exist, we set the significance for this test at $p < 0.15$. Further detail on the interpretation of the statistical results is given in Chapter 6.

CHAPTER 3: DATA QUALITY IN THE INSIGHT DATABASE

Data Quality

When evaluating any program, the quality of the data available and its ability to capture the outcomes of interest will affect the conclusions that can be drawn. In this chapter, we discuss the general areas in which data quality and availability affected our ability to conduct this evaluation, and give suggestions for improving the data collection process in the future. The focus is on the InSight database.

Unrecorded PHINs

As discussed in Chapter 2, when preparing the InSight data for linkage with the MCHP Repository data, the first challenge was the lack of consistently recorded maternal PHINs. This was discussed with the program centres and an effort was made to fill in some of the missing PHINs. Following this, 27.4% of PHINs were still missing. Further analysis revealed that these unrecorded PHINs were not randomly distributed. Table 3.1 shows the unrecorded PHINs by program site and time period. Participant records could not be linked to the Repository without a PHIN, so we could not evaluate the long-term outcomes of these women. This reduced the sample size considerably. The majority of unrecorded PHINs were from earlier years, before 2001. Therefore, we excluded women who entered the program before this date. In addition to their effect on our ability to study long-term outcomes, the missing data. Also differentially excluded women based on the program site they attended, thereby reducing the generalizability of results. Conversely, excluding women enrolled early in the program, when it was newly implemented and sites may have been of variable quality may make the results more representative of those of newer participants. An additional challenge was that a significant number of PHINs belonging to the target children were not recorded (47.4% of the 525 expected target children). Due to this low number we could not reliably identify the target children in the Repository.

Table 3.1: Distribution of Missing PHINs by Site and Year

	Before April 2001	April 2001 to June 2002	July 2002 to June 2004	July 2004 to June 2006	July 2006 to June 2008	After June 2008	Total
Site 1	20	s	s	s	s	s	31
Site 2	s	s	s	s	0	0	9
Site 3	36	18	11	s	s	12	91
Site 4	s	0	s	s	6	s	13
Total	58	23	18	18	11	17	145

s indicates data suppressed due to a value of 5 or less

Of those InSight participant records missing a PHIN, many were also missing other variables. Participants without a recorded PHIN were compared to participants with a PHIN on several variables within the InSight dataset. Only a few differences were noted. Women excluded from the analysis were more likely to be married ($p=0.047$), more likely to report a chronic medical problem ($p=0.012$), and more likely to have had depression or anxiety at some point in their lifetime ($p=0.010$). They did not differ significantly on all other variables assessed: education, drug of choice, employment income, depression or anxiety in the last 30 days, use of social housing, use of or need for intimate-partner-violence services, food bank services or mental health services, and receipt of income assistance in the last 30 days.

Suggestions for Improvement

Discussion with our Advisory Group identified the common reasons for unrecorded PHINs as:

- program-site staff’s lack of an understanding of the importance of gathering this information;
- concerns of staff and participants about privacy and stigmatization in an already marginalized population; and
- participants not being able to provide this information readily; the extra work to obtain it was a deterrent.

Strategies to improve the collection of PHINs should include education about its importance for studying program outcomes (e.g., evaluating the impact of InSight and ensuring true representation of program sites in research such as this). Further education around privacy legislation and how anonymity is maintained during this research would also be beneficial. Special attention should be given to gathering the PHINs for the children born to participants. This can be difficult when children are not in the custody of their mothers. An understanding of how PHINs are used and protected during research should reduce concerns about the extra time or effort required to obtain this information when participants are not able to provide it readily. Additionally, helping participants obtain a Manitoba Health Card if they have lost theirs would enable them to more easily access services for which it is required.

Missing Variables and Outcomes

InSight data were missing in two general ways: individual variables were unrecorded/missing, or whole forms were missing. Many women did not have a complete set of forms and thus were missing data for all the variables from the specific missing form. For example, while all the InSight participants had an intake form, only 52.7% (n=119) had all six 6-month assessments and an exit-interview form. When data were missing for situational forms, such as the Notification of Subsequent Birth, it was sometimes unclear whether this was because this was not an outcome or because the form was not completed. It is also possible that forms were completed but not entered electronically.

Even when forms were available electronically, data were often missing for individual variables. Data for a variable could be missing in two ways: there could have been no value in the database field or the variable could have been coded as missing or unknown. This resulted in different numbers of women used for different analyses. There was a substantial number of missing values for individual variables (Table 3.2). This lack of data limited the sample size available for evaluating a variable, the use of these variables to compare by subgroup, and the ability to examine the relationship among variables.

Table 3.2: Percentage of Descriptive Data Missing from the InSight Database, by Variable

InSight Variables	n	%
Site Location (n=226)	0	0.0
Enrolment Years (n=223)	3	1.3
Preferred Substance at Program Enrolment (n=179)	47	20.8
Anxiety or Depression in Past 30 Days (n=169)	57	25.2
Anxiety or Depression at any Point in Life (n=178)	48	21.2
Chronic Medical Problem which Interferes with Life (n=177)	49	21.7
Receipt of Income Assistance (n=171)	55	24.3
Income from Employment at Program Enrolment (n=161)	65	28.8
Living in Social Housing at Program Enrolment (n=105)	121	53.5
Marital Status (n=82)	144	63.7
Food Bank (n=161)	65	28.8
Mental Health Services (n=160)	66	29.2
Domestic Violence Services (n=160)	66	29.2

Suggestions for Improvement

Discussion with our Advisory Group identified the reasons for missing variable information, including:

- The requested information was of a sensitive nature, and the request may be intrusive, especially when it is early in the mentor-participant relationship.
- An overwhelming quantity of variables and forms were required.
- Many questions had options of “missing” or “unknown” as potential responses on the forms. This option may have made it easier for mentors to avoid probing participants.
- There was insufficient database/data-entry validation.
- Participants don’t always engage consistently throughout the three years of the program, which means that information is unavailable for certain periods.

Discussion also yielded suggested strategies for decreasing the number of missing outcomes or variables. These include separating requests for information that is required for program evaluation from that required to identify participant needs and provide services. This would reduce the quantity of data gathered at any one time. Intrusive questioning, which is primarily designed to identify participant needs, could be moved from intake to later in the program to allow for a mentor-participant rapport to develop. Some of these suggestions have already been incorporated into the program. Wherever possible, the use of “missing” or “unknown” as responses should be avoided. The importance of program evaluation should be supported by providing adequate administrative support to allow for accurate data collection.

Type of Data Gathered

Inconsistent Measurement Across Time

One of the strengths of InSight is that it follows women over time, collecting information from before entry and at multiple points across the three-year program. Unfortunately, several of the variables are not measured in the same way at each time point (such as alcohol use in pregnancy and out of pregnancy and the use of social services). For example, at both entry (on ASI Intake Interview) and exit (ASI Exit Interview) 22 questions cover 19 areas of

community-service use. However, fewer areas are covered at the six-month intervals, the questions are asked differently, and they are divided between the target child and the participating mother. Thus, it is not possible to compare social service usage reliably over time. For contraceptive use, the questions differ at intake from the six-month assessments, and are not asked on the exit interview.

Information about alcohol use is gathered using different questions throughout the program, which makes results not directly comparable. For example questions differ when the target pregnancy is compared to subsequent pregnancies, when use is captured in and outside of pregnancy, or before the program to during the program.

Additionally, the intake and exit forms are completed via direct interview by the program director, but the six-month assessments are completed by the mentor using their knowledge of the participant. It is unknown whether the responses would be the same, even if the questions were similar at all time points as the relationship of the program director to the participants differs from that of the mentor and the participants.

Specific Relevant Data not Gathered

A few specific and highly relevant data points were not captured in the database. Women who enrol in the program are either pregnant or recently postpartum. This information is not captured directly on the intake form, although it can be derived from the target child's birthdate if it is recorded. One of the most significant challenges when we first started working with the InSight database was determining whether the women with missing forms had stayed in the program. Recently a form was added to capture information about participant retention and reasons for leaving. However, its use in this report was limited because only 12.8% of our sample had this form available.

Even though the InSight program works around a harm-reduction philosophy, harm reduction was not well-captured in the database. Questions around alcohol use tended to focus on total abstinence and were not sensitive to reductions in use. The questions on some of the forms also captured all substance use together as an all-or-none quantity; they did not differentiate between substances, and were not sensitive to changing patterns of use or the priority of substances used.

Suggestions for Improvement

These issues can be addressed by realigning the information gathered during the program with the evaluation objectives and program philosophy. This will require changing the forms, which would not allow for continuity between past and future participants. However, the increased utility of newly designed forms outweighs this drawback.

With this in mind, we make the following specific recommendations:

- Questions about alcohol use should be separate from questions about other substance use. Consideration should be given to gathering information on the most commonly used substances individually. Less commonly used substances could be grouped together to reduce the amount of data gathered overall.
- The same questions about the quantity and frequency of use for each substance of interest should be asked at every time point during and outside of pregnancy.
- Efforts should be made to make information gathered on InSight forms comparable to information gathered by other Healthy Child Manitoba initiatives such as the Families First Screen (FFS), and during routine prenatal care on the Manitoba Prenatal Record.
- InSight administrators should identify evaluation goals in other areas, such as contraceptive use, and ensure that this information is captured at all time points.
- Attention must be given to collecting PHINs, as well as the start and end dates for program involvement for all participants, to ensure they can be identified for study in the MCHP Repository.
- A field for pregnancy status should be added to the intake form.

Summary

The data-quality issues outlined above had a cumulative effect on the analyses that could be undertaken for this report. The exclusion of earlier years of data for unrecorded PHINs reduced the sample size overall and shortened the length of follow-up after program exit, which reduced the sample size for specific outcomes, particularly those related to pregnancy. This was compounded again when not all pregnancies could be linked to a further data source such as the FFS. Initially, we had planned to study long-term outcomes stratified by program outcomes such as abstinence from alcohol or receipt of different social programs. However, limitations in the sample size and the InSight database made this impossible. Improvement of the information gathered in the InSight database as well as in other program-delivery areas would allow more detailed research longer term follow-up of the results found in this report.

Table 4.3: Descriptive Characteristics of the InSight Participants from the Repository

	n	%
Mother's Age at First Birth (n=224)		
17 and under	88	39.3
18-19	68	30.4
20 and older	68	30.4
Lifetime Mood or Anxiety Disorder (n=226)		
Yes	83	36.7
No	143	63.3
Income Quintile (n=224)		
Winnipeg income quintiles 1-2	104	84.6
Winnipeg income quintiles 3-5	19	15.4
Rural income quintiles 1-2	44	43.6
Rural income quintiles 3-5	57	56.4
SEFI Score (n=225)		
Very low SES	59	26.2
Other	166	73.8
Area of Residence (n=226)		
Winnipeg	123	54.4
Rural	103	45.6
Child and Family Services Involvement (n=226)		
Yes	171	75.7
No	55	24.3
Maternal Age (n=226)		
18-19	24	10.6
20-24	76	33.6
25-29	79	35.0
30-34	34	15.0
35 and older	13	5.8
Education Level (n=149)		
Less than grade 12	117	78.5
Grade 12	32	21.5
Number of Previous Children (n=226)		
0	26	11.5
1	40	17.7
2	39	17.3
3 or more	121	53.5
Income Assistance in Last 30 Days (n=226)		
Yes	169	74.8
No	57	25.2
Child and Family Services Contact at Enrolment (n=226)		
Yes	171	75.7
No	55	24.3
Social Housing (n=226)		
Yes	34	15.0
No	192	85.0

Table 4.4: Descriptive Characteristics of InSight Participants from Both the InSight Database and the Repository
Agreement between sources

Variables	InSight		Repository		Kappa
	n	%	n	%	
Maternal Age (n=179)					
18-19	18	10.1	18	10.1	1.0000
20-24	58	32.4	58	32.4	
25-29	66	36.9	66	36.9	
30-34	26	14.5	26	14.5	
35 and older	11	6.1	11	6.1	
Education Level (n=122)					
Grade 12	14	13.0	25	20.5	0.4889
Less than grade 12	94	87.0	97	79.5	
Social Housing (n=160)					
Yes	45	28.1	23	14.4	0.3099
No	115	71.9	137	85.6	

Demographic Characteristics

InSight participants were distributed relatively equally across the four program centres included in this study—the two Winnipeg centres (Aboriginal Health and Wellness Centre and Nor’West Co-op Community Health) and the two outside of Winnipeg (The Pas and Thompson) (Table 4.2). Data for enrolment years show an unequal distribution of women across the four periods (Table 4.2). Enrolment of 39% of the women after July 2007 limited our ability to examine longer-term follow-up. There were just five years of follow-up or less for 52% of participants (a breakdown of participants by follow-up length is given in Table 2.2).

Self-reported ethnicity was available for 180 of the InSight participants, with 94.4% (n=170) identifying as Aboriginal.

Socioeconomic Status (SES)

We used multiple variables to describe the SES of InSight participants:

Area of residence: defined in the Repository by the six-digit postal code. To preserve anonymity the exact address of the women was not available for analysis. Postal codes were used to assign participants to a census dissemination area (DA). This is the smallest area (about 400 residents) for which the Canada Census reports multiple non-medical social determinants of health, including average household income, percent of single parent households, unemployment rate, and high school completion rate.

Just over half of InSight participants resided in Winnipeg (54.4%); all others were considered as rural-dwelling (see Table 4.3).

Social Economic Factor Index (SEFI): a composite score of SES developed by researchers at MCHP that incorporates all of the non-medical social determinants of health described above. Scores at less than two standard deviations below the mean represent very low SES. Statistically, we would expect only 2.5% of the population to be very low SES. However, 26.2% of the InSight participants were classified as having very low SES (Table 4.3).

Income quintiles: the average household income of the DA alone can also be used as a marker of SES, and each DA can be grouped into quintiles, with rural and urban quintiles reported separately. One fifth (20%) of the population is in each quintile, which are numbered 1–5. The quintile with the lowest SES is 1 and the highest is 5. The majority of Winnipeg participants (84.6%) lived in the two lowest income quintiles. For rural participants where the DA is larger and encompasses a wider spread of household income the relationship between individual household income and area level income is not as tightly correlated. Thus for rural participants 43.6% of women lived in the two lowest rural quintiles (Table 4.3).

- Receipt of income assistance in the past 30 days (30 days before program entry): this data was available from the InSight database (n=171), which captured self-reported receipt of income assistance from both federal and provincial sources, and from the Repository, which captures only provincially administered income assistance. This resulted in a small, but expected discrepancy: 84.8% of the InSight participants reported receiving income assistance at program entry (Table 4.5).
- Repository data showed that 74.9% of participants were receiving income assistance.
- The kappa for these two data sources was 0.4457, which indicates a moderate level of agreement. This was within the expected range as the self-report captures more sources of income assistance.

Table 4.5: Data-Source Comparison: Income Assistance Received within 30 Days before Enrolment, InSight Participants

		InSight Database		
		No	Yes	Total
Repository	No	19	24	43
	Yes	7	121	128
	Total	26	145	171

Kappa = 0.4457

Alcohol Use at and before Enrolment

InSight seeks to enrol women with significant alcohol use who are inadequately connected to services. Multiple variables pertaining to alcohol use were gathered as a baseline and to characterize the extent of the participant’s problems with alcohol:

Preferred substance: During the intake process women were asked their preferred substance or drug of choice. The InSight database contained responses for 179 participants (Table 4.2). However, many women use multiple substances and significant amounts of alcohol even when they identify another substance as preferred (J. Isbister, written communication, November 2013).

- 63% (n=112) identified alcohol as either the sole or one of the primary preferred substances.
- 37% (n=67) women did not identify alcohol as their drug of choice.

Age of initiation of alcohol use: Earlier ages at initiation of use are associated with alcohol addiction. This variable captures the age at which alcohol was used for effect. Data were available for 159 participants (Table 4.6). The mean age of initiation of alcohol use in Canada has been reported at 15.6 years of age (Finnerty, Perron, & Pieterston, 2007).

- 70% of InSight participants reported their first significant use of alcohol was before 15 years of age.
- Over 50% of InSight participants reported they started binge drinking before they were 15 years of age.

Frequency of alcohol use in the 30 days before enrolment (Table 4.7): This self-reported information was collected at the intake interview and was available for 179 participants. For comparison, a recent survey of Manitoba’s drinking behavior reveals that 2.5% of respondents report daily use of alcohol (Liquor and Gaming Authority of Manitoba, 2014).

- 8% of InSight participants report daily alcohol use at enrolment.
- A high proportion of participants report no or low alcohol use in the past 30 days, which may suggest a pattern of lower-risk drinking or reflect that some women primarily use drugs.

It is likely that alcohol use was under-reported, for several reasons. Some women enter the program during a period of abstinence or reduction in their alcohol use and are joining the program to maintain this pattern. Underreporting may also occur because alcohol use during pregnancy is highly stigmatized, and because the interview is conducted very early in the program before trust and confidence in the program are established; a participant may fear Child and Family Services (CFS) involvement in their pregnancy or at their birth. Women may also have been incarcerated, in addiction treatment, or otherwise involuntarily unable to use alcohol prior to the program start.

Table 4.6: Age at First Use of Alcohol, InSight Participants

Age	Age at First Use (%)	Age at First Binge Use (%)
≤10	10.1	6.9
11	11.3	6.9
12	24.5	17.0
13	13.2	15.1
14	10.7	9.4
15	10.1	13.2
16	6.3	8.8
17	5.0	5.0
18	3.8	7.6
≥19	5.0	10.1

Table 4.7: Number of Days Alcohol was Consumed in Past 30 Days, InSight Participants

Days	%
0	48.6
1	15.6
2	7.3
3 to 5	8.4
6 to 11	6.2
12 to 29	6.2
30	7.8

For details on alcohol use during the target pregnancy see Chapter 5. Further details on alcohol use before program entry and during pregnancy are given in Chapter 6 (within the context of a comparison group).

Health Status at Enrolment

Some information on health status is available from both sources, but is not directly comparable due to differences in the definitions between sources.

The InSight database information was examined to see if diagnoses of FASD in the participants could be derived. It was found to be impossible because of how information was gathered.

Significant anxiety or depression in the last 30 days, and at any point in life (Table 4.2): This self-reported information was gathered during the intake interview and was available for 169 and 178 participants, respectively. It describes symptoms sufficient to interfere with daily living.

Diagnosis of a mood or anxiety disorder (Table 4.3): This information came from the Repository. Participants were identified who met a validated definition for an anxiety or depressive mood disorder. This definition looks for specific diagnostic codes relating to physician visits, prescription drug use, or hospital services over the three years prior to enrolment. It has been previously demonstrated to identify a different population than survey methods (Martens PJ, Fransoo R, McKeen N, The Need to Know Team, Burland E, Jebamani L, Burchill C, DeCoster C, Ekuma O, Prior H, Chateau D, Robinson R, Metge C, 2004).

- 57.4% of InSight participants report significant anxiety or depression in the last 30 days.
- 76.4% report significant anxiety or depression during their lifetime.
- 36.7% meet the Repository criteria for a mood or anxiety disorder before enrolment.

Almost a quarter of women (24.3%) report having a chronic non-medical problem that interferes with their life, other than substance use or mental health issues (see Table 4.2).

Use of Social Services at Enrolment

A major goal of the InSight program is to help women connect with the social programs and services available to them. Questions on the intake form identify six categories of services often used or needed by this population: social housing, food bank usage, mental health services, and intimate-partner-violence services. The number of participant responses available for these questions were 105, 161, 160, and 160, respectively. Women answered either: “yes” to indicate they are using the service, or “no, not needed,” “no, but needed,” or indicate they are on a wait list. Women who reported being on a wait list were included with the “no, but needed” group for analysis because their numbers were small. Table 4.2 shows the breakdown of responses.

- Unmet needs for social services ranged from 25–57%.
- Due to the high number of missing responses, the need for services is likely underestimated (see Chapter 3).

Pregnancy Patterns before Program Entry

Number of children prior to entry: this information was available from both the InSight database (n=226) and the Repository (Table 4.8).

- The Repository identified 11.5% of participants as having no children prior to entry; the InSight database identified 19.0%.
- The Repository identified 53.5% of participants as having three or more children prior to entry; the InSight database identified 46.9%.

There is good agreement between the two sources; the discrepancy exists as whether the target child was classified as before or during the program depended on how it was reported by the participant, and may not be directly correlated with the birth date.

Table 4.8: Data-Source Comparison: Number of Children Prior to Enrolment, InSight Participants

		InSight Database				
		0	1	2	3+	Total
Repository	0	24	s	s	s	26
	1	10	26	s	s	40
	2	s	s	27	8	39
	3+	s	s	14	95	121
	Total	43	34	43	106	226

Kappa = 0.7081

Age at first birth: This information is captured only by the Repository. A younger age at first birth is associated with poor outcomes for both the woman and her children, even those born later in the mother’s life (Jutte et al., 2010). Results are given in Table 4.3.

- 39.3% of women had their first child at age 17 or under

Involvement with CFS in the three years before program entry: this information was available from the InSight database and the Repository, and results were available for 160 participants (see Table 4.9).

- Repository data reveals that 75.0% of participants had been involved with CFS.
- The InSight database shows that 68.7% of participants had been involved with CFS.
- The agreement between the sources is moderate ($\kappa=0.48$).

Table 4.9: Data-Source Comparison: Contact with CFS in Last Three Years, InSight Participants

		InSight Database		
		No	Yes	Total
Repository	No	28	12	40
	Yes	22	98	120
	Total	50	110	160

Kappa = 0.4769

Summary

The InSight participants exhibit many risk factors for poor health and social outcomes and meet the criteria established for the program. They have multiple markers of poor SES as measured at the individual and area level, including low income and education. They demonstrate high-risk use of alcohol including initiating use at a very young age and high-frequency use, information on use in pregnancy is given in Chapter 5. These women have high rates of mental health issues, both by self-report and objective measures, as well as low self-reported health. With the exception of income assistance, they are poorly connected to the social services available to them, and identify multiple unmet needs (a second criterion of the program). They tend to be young at the time of first birth and have high parity rates. Many have had contact with CFS. The pattern of characteristics seen in the InSight women and their children identifies numerous areas for support and interventions that would help meet the program objectives of reducing births of children with FASD and improving the health and welfare of these women and their families. The variability in agreement between self-report and administrative data sources in capture of information underlines the importance of using a mix of data sources in this type of research.

Key Message: InSight participants represent a highly vulnerable population not adequately connected to social services. This program is reaching the population it was intended to reach.

For further detail on the characteristics of women participating in InSight and other similar programs, including their qualitative experiences see Burnside et al. (2012).

CHAPTER 5: PROGRAM OUTCOMES

This chapter contains information taken from the InSight database to evaluate selected outcomes at program exit for the participants of the InSight program (Objective 2). The InSight database is a rich source of information that allows us to gauge a participant's status at program exit. To do this we chose to focus on three key areas targeted for prevention of FASD births: alcohol use, contraceptive use, and use of social services. It is important to note that program participants set their own goals with the support of their mentor. Because of this and because of constraints in the data-collection process, we were not able to identify whether the participants attained the goals they set, only which outcomes were attained.

A few challenges were encountered when assembling these data, the most significant being the lack of an exit interview form for many women. Of the 226 women in our sample, 39.4% were missing an exit-interview form. In some cases we could substitute their last six-month assessment; however, this was not always possible because the questions differ between the two forms. For further detail on missing data and other data-quality issues see Chapter 3.

Alcohol and Substance Use Outside of Pregnancy

Information on alcohol use outside of pregnancy is collected throughout the program on the six-month assessment form and the ASI Exit Interview. We used information gathered at participants' last six-month assessment and at program exit (Tables 5.1 and 5.2), as well as the longest period of abstinence recorded for a participant at any point in the program (Table 5.3).

We had information from the last six-month assessment—which was not necessarily from the end of the three-year program—for 185 women. Of this group, 36.8% reported abstinence for at least two weeks, 54.1% reported no abstinence, and 9.2% had unknown results. Table 5.1 gives details on the length of abstinence for participants who reported abstinence at their last six-month assessment. We were also able to measure abstinence from alcohol from the exit interview for 124 participants. At their exit interview 13.7% of these participants reported at least six months of abstinence (see Table 5.2).

Table 5.1: InSight Participants' Length of Abstinence from Alcohol at Last Six Month Assessment

When identified as abstinent, n=145

Months Abstinent (%)			
≤6	6 to 11	12 to 23	≥24
49.2%	24.6%	18.0%	8.2%

Table 5.2: InSight Participants' Length of Abstinence from Alcohol at Program Exit

All respondents, n=124

Days Abstinent (%)					
0	1 to 30	31 to 60	61 to 90	91 to 180	180+
18.5	38.7	14.5	5.6	8.9	13.7

Information was also captured on the longest period of abstinence from all substances—except cigarettes or methadone—either with or without a brief relapse (1–2 days) at any time during the program. This information is shown in Table 5.3. Only 15.8% of women for whom we have information failed to achieve a period of abstinence, which was defined as a least a two-week period; and 54.9% achieved at least six months with only short relapses.

Table 5.3: InSight Participants' Longest Length of Abstinence from All Substances
At any time during the program

	Months Abstinent (%)				
	0	1 to 5	6 to 11	12 to 23	24+
No Substance Use, No Relapse (n=171)	14.0	36.8	22.2	19.9	7.0
No Substance Use, Short Relapse (n=172)	15.8	29.7	25.1	19.3	10.5

Alcohol Use in Pregnancy

Target Child

Women can enrol in InSight while pregnant or up to twelve months postpartum; this is the target pregnancy, which results in the target child. Information on alcohol use during the target pregnancy was taken from the ASI Intake Interview Part B. This form was filled in for 80% (n=181) of the 226 InSight participants. Out of these forms, 18 were missing a birthdate for the target child; and in all but one of those 18 forms the pregnancy outcome was “other” or “missing,” which suggests that the pregnancy did not result in a live birth. We attempted to cross-check these findings with data from the Repository; however, we were unable to reliably distinguish the target child from previous or subsequent children due to the low number of PHINs available for target children. Using the 163 forms with a birthdate we see that 63.1% (n=103) of the target children were born during the program, with the remainder born before the program.

Alcohol use during the target pregnancy was recorded as: usual amount and frequency, with a question addressing use in the month preceding pregnancy and first trimester, as well as a question addressing use in the second and third trimesters. Respondents were assigned to either a low-risk profile or a high-risk profile of alcohol consumption by combining their frequency and amount of alcohol use (see Appendix Table 1.2 for method details).

This information was available for 156 of the target pregnancies and revealed that 78.2% of women drank in a high-risk pattern in the month preceding pregnancy and first trimester, and 51.3% drank in a high-risk pattern in their second and third trimesters. Of the 156 mothers with information on alcohol use during the target pregnancy, 80.6% demonstrated a high-risk pattern of use in any trimester. Only 19.4% maintained a low-risk pattern of drinking throughout pregnancy, with 15 (9.6%) of these participants reporting no alcohol use during their target pregnancy.

Subsequent Births

Information on women who have a subsequent pregnancy during their participation in the program is collected on the Notification of Subsequent Birth (NSB) form (revised 2006). Subsequent births are also captured on the six-month assessment forms. However, analysis of this data source revealed multiple inconsistencies, which suggested that one pregnancy was being captured on consecutive forms, making it difficult to establish a reliable pregnancy count. Thus, we were unable to confirm whether all the InSight participants' subsequent pregnancies during the program were captured on the NSB forms. We had information on 37 first-subsequent births, and fewer than six second-subsequent pregnancies from the NSB form. InSight participants were asked whether they had used no substances, used alcohol, or used other substances; participants were able to have answers in both categories of use. Of those with answers, 24.3% reported no substance use, 32.4% reported only drug use, 21.6% reported only alcohol use, and 21.6% reported use of both.

What these Findings Mean

The InSight program uses a harm-reduction philosophy and assists women participating in the program to set their own goals to reduce or discontinue their alcohol use both during and outside of pregnancy. Alcohol use is assessed in many different ways during the program but predominantly focuses on abstinence, and often captures all drug and alcohol use together. This makes it difficult to evaluate the effectiveness of reducing just alcohol and subsequent alcohol-related harms. Due to the variable time points and questions asked we did not undertake statistical comparisons; but the general pattern reveals that participation in the program is associated with longer periods of abstinence and reduced use both during and outside of pregnancy. These rates suggest possible short-term effectiveness of this intervention. However, there is a difference between measuring abstinence at a particular time point for all participants, such as the end of the program, versus at any time for each participant, which results in higher reduction rates. Relapse is very common with alcohol addiction, and this calls for ongoing support.

Use of Contraception

Mentors worked with the participants and encouraged them to set their own goals to reduce FASD births and improve their health and wellbeing. These goals may have included use of contraception. Contraceptive use is captured both at program entry and on the six-month assessment forms; however, the wording varies.

Participants were asked whether they were using contraception at the time of conception of the target child, and 21.8% of reported use of some method of contraception at least sporadically. Only 23.9% of this population—or 6.8% of all participants—reported using a reliable method of contraception (depo provera, IUD/IUS, or tubal ligation). All other methods, such as condoms, oral contraceptive pills, or diaphragms, were considered unreliable due to barriers to their effective use in vulnerable populations.

Information on contraception and sexual abstinence was also gathered at each six-month assessment. Those who reported sexual abstinence were counted as using reliable contraception. However, they represented only a very small percentage of responses. These results demonstrated increased use of reliable contraception, with only 4.1% of women reporting no use, 73.8% reporting use on at least three of their possible six assessments, and 32.6% reporting use in all six assessments.

No questions on contraception were asked at program exit.

What these Findings Mean

Increased use of reliable contraception is a key strategy to reduce FASD births in women who continue to consume alcohol. Active use of contraception reflects goal-setting, deliberate decision-making, and the ability to act on and maintain that decision, which in itself is a positive outcome. Use of many of the reliable contraceptive methods requires access to and attendance of a healthcare provider, which may be difficult for some patients due to previous experiences with the healthcare system, stigmatization, or a history of sexual violence. Because of our small sample and the kinds of questions used to gather information about contraceptive use, we were not able to determine whether contraceptive use differed in women who continued to consume alcohol versus those who did not, nor could we undertake meaningful statistical comparisons. Additionally we were not able to correlate participants' use of contraception with their goals in this area.

Connection to Available Social Services

A primary method through which the mentors aid the participants in meeting their goals is through improved use of available support services. Information on the need for and connection to services is gathered at intake and exit with one set of questions, and at each six-month assessment with a different set, making the six-month assessment results incomparable to participants’ reported experiences at intake and exit. Results reported in Chapter 4 show that InSight participants have a high need for services at program entry. At program exit only 20 women were listed as being on a wait list in any of the social services categories, almost exclusively for housing. Table 5.4 compares the need for services at program entry and exit. Due to the low number of exit forms completed (n=137) direct statistical comparisons were not undertaken. However, for participants who indicated a need for services, a general increase in use of mental health services, social housing services, and food banks was evident; some decreased use of intimate-partner-violence services was suggested.

Table 5.4: InSight Participants' Use of Social Services

	Yes (%)		No, But Needed (%)	
	Before InSight	After InSight	Before InSight	After InSight
Food Bank	31.1	51.2	26.1	9.5
Intimate Partner Violence	23.8	16.7	25.0	28.6
Mental Health	9.4	26.6	48.8	40.3
Social Housing	26.6	42.9	19.9	33.8

What these Findings Mean

Enrolment criteria for the InSight program include poor connection to available services, a characteristic of a high percentage of women at entry. At exit we observed an overall increase in the percentage of women accessing services. However, many have persistent unmet needs. It is unclear whether this reflects the lack of available services as only a very small number of women were reported as being wait-listed, and predominantly in one area (social housing). Information was not available to determine whether these persistent unmet needs were due to difficulties in accessing services, or because of some other reason. It is interesting that the percentage of women with an unmet need—those who answered “no, but needed”—remains relatively unchanged. This could reflect either that the program has helped women identify a need for these services but they have not accessed them, or that mentors’ interpretation of the need for services changed over time, particularly with respect to intimate-partner violence and mental health. One could conclude that InSight enables women to both identify the need for services and access these services, but the relative contribution of each to the pattern of results is unclear.

Summary

Analysis of outcomes in three key areas important for prevention of FASD was undertaken within the constraints of the data available and revealed areas of improvement, particularly in reduction in alcohol use in pregnancy and use of contraception. These findings are consistent with previous evaluations of outcomes at program exit of mentoring programs (Grant et al., 2005; Rasmussen et al., 2012). Available information on the need for and connection to social services was more difficult to interpret. The largest barrier to interpreting this data is its disconnect from the participants’ goals and our inability to measure successes as defined by the participants themselves.

Key Message: The findings suggest that the InSight program had a significant impact during participation in its key focus areas.

CHAPTER 6: LONG-TERM OUTCOMES OF THE INSIGHT PARTICIPANTS AND THEIR CHILDREN

This chapter compares InSight participants to a similar group of women not enrolled in InSight using several indicators in the following areas: use of health services, pregnancy rates and prenatal care, substance use in pregnancy, use of social services, neonatal outcomes, and children's outcomes. Data for these indicators were drawn from the MCHP Repository. Analysis results are presented for three time periods—before, during, and after the program—for the InSight participants versus the comparison group. Statistical methods are described below.

Developing the Comparison Group

One of the biggest challenges in estimating the impact of the InSight is not knowing what the outcomes would have been for participants were they not involved in the program. Any changes in the outcomes of InSight participants over time may be due to the program, to other influences in the women's lives, or simply to the passage of time. The best way to isolate these different possible causes is to run the intervention as a randomized controlled trial (RCT), in which eligible women are randomly chosen to participate and not to participate in the program. This usually ensures that all factors that could potentially affect outcomes outside of the program are similar for participants and non-participants alike. However, randomization is unappealing for interventions such as InSight, because it would mean withholding potentially beneficial services from people in need.

When an RCT is not employed, other methods can be used to control for the other factors that may influence outcomes. We chose to use a method that started with identifying women from the Repository who were not in the InSight program but were similar to them in important ways: they were living in poverty and had consumed alcohol during pregnancy. This comparison group contained 2,163 women who had a live birth between January 2001 and July 2008, for which they disclosed alcohol use during the pregnancy (from the Families First Screen or obstetric record), and who had received income assistance at some point prior to that birth. Note: 12 of the InSight participants had not received income assistance so to maintain similarity they were excluded from these analyses leaving a total of 214 in this group.

A statistical model was then created using the two groups combined—InSight participants and the comparison group—and as many measures as possible that predicted participation in InSight. The model assigned a score to each woman based on how well her characteristics matched these predictors. This score was then incorporated into the analyses to weight or adjust the results for each outcome using inverse probability of treatment weights (IPTW). InSight participants with a higher score contributed less to the analysis of outcomes than those with a lower score, and for the comparison group the reverse occurred: they were weighted higher if they had a higher score and lower if they had a lower score. The purpose of this method is to give greater weight to outcomes in women in the comparison group who were most similar to the InSight participants (i.e., more vulnerable), and less weight to those who were less similar (i.e., less vulnerable). This method adjusts for differences at baseline so that the two groups can be compared, ideally isolating the effect of the program. However, due to the extreme vulnerability of InSight participants and the limited number of relevant variables available in the Repository, some differences at baseline that represent residual confounders remain from the period before program entry.

In this report, the terms weighting and adjustment can be used interchangeably. Figure 6.1 demonstrates the dissimilarity of the groups before weighting and their similarity after adjustment. After weighting, almost all the variables have standardized differences of less than 15% between the groups, which means that the percentage of women scoring positive on each of the variables is similar across groups (Austin, 2011). For example, the last variable, "Mom's age at first birth," had a standardized difference between the groups of 25% before weighting and less than 10% after weighting. This means that the weighting successfully balanced the two groups for this variable (Austin, 2011).

Physician Visits

Indicators in this section were taken from physician billing records. Pregnancy-related care was excluded from all categories and reported separately (see Section 6.2). Visits are reported as all physician visits, all mental health, and all other.

Results are presented in person-years³ due to varying lengths of follow-up for each participant. The unadjusted rates (per person-year) for the InSight participants before program entry were 7.22 for all physician, 1.31 for mental-health-related, and 5.91 all other types of visits. For the comparison group the rates (per person-year) were 5.27 for all-cause, 0.58 for mental-health-related, and 4.69 for all other types.

Key Findings: Unadjusted Outcomes

Table 6.1: Unadjusted Rates of Physician Visits for InSight Participants

Rates per person-year, by time period

	Before	During	After
All Physician Visits	7.22	8.81	10.83
All Mental Health Physician Visits	1.31	1.90	2.43
All Other Physician Visits	5.91	6.90	8.38

Timing in relation to program delivery

Note: Pregnancy-related visits have been excluded.

Table 6.2: Unadjusted Relative Risks for Physician Visits for InSight Participants: Time Period Comparisons

95% confidence intervals

	During vs Before	After vs Before	After vs During
All Physician Visits	1.22 (1.04-1.43)	1.50 (1.28-1.76)	1.23 (1.05-1.44)
All Mental Health Physician Visits	1.45 (1.03-2.02)	1.85 (1.32-2.59)	1.28 (0.92-1.79)
All Other Physician Visits	1.17 (1.00-1.36)	1.42 (1.21-1.66)	1.22 (1.04-1.42)

bold indicates statistical significance for that time period

Timing in relation to program delivery

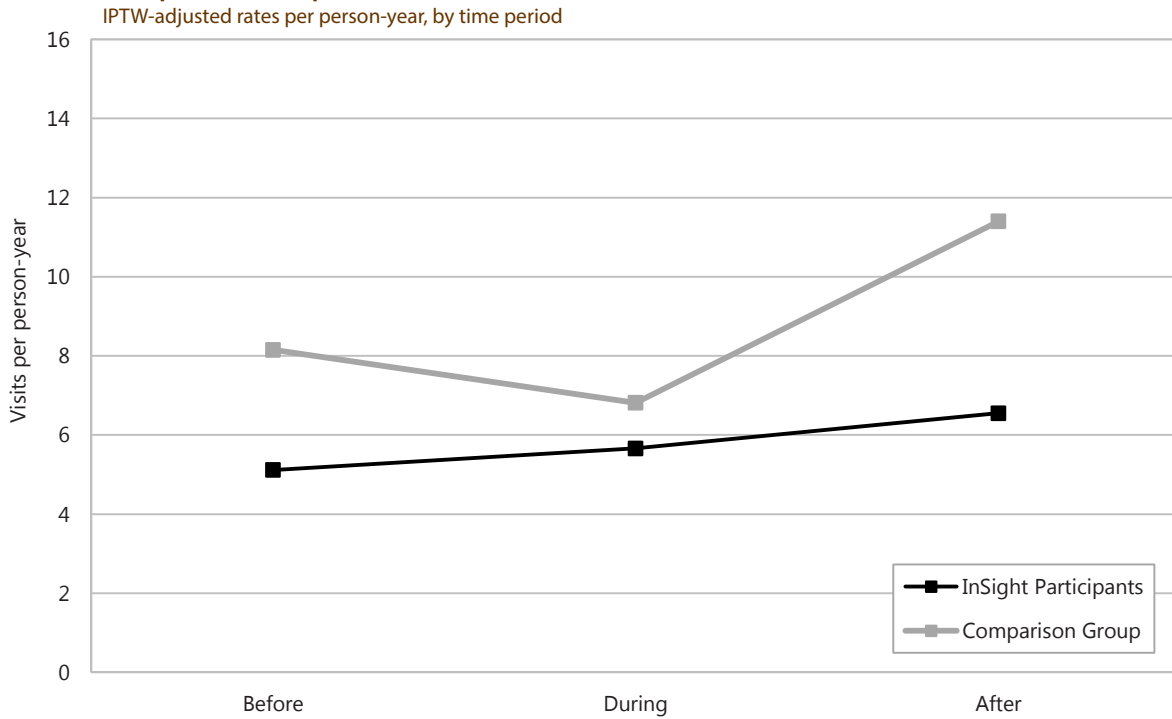
Note: Pregnancy-related visits have been excluded.

When compared as a group to themselves over time the InSight participants demonstrated:

- a significant increase or trend towards an increase during the program for rates of physician visits for all categories with results persisting after program exit;
- significantly increasing rates of physician visits for the “all visits”, “all mental health visits” and “all other visits” categories after program exit; and
- no significantly increased rate of all physician visits related to mental health after the program (compared to during)

3 A person-year is a measurement combining number of persons and the amount of time for which we have data about their risk. For example, if one person has data for three years and was hospitalized once, another has data for one year, and a third has data for two years, we have six person-years of data. Person-years were used in the analyses to allow us to include as many individuals as possible in the calculations and to use individuals who were not part of the evaluation for the entire time period.

Figure 6.4: Adjusted Rates of All Other Physician Visits, InSight Participants and Comparison Group



- No significant difference was observed in the change over time for the subcategory of all other physician visits (p=0.200).

Table 6.3: Adjusted Relative Risks for Physician Visits for InSight Participants: by Time Period

IPTW-adjusted rates per person-year, 95% confidence intervals

	Before	During	After
All Physician Visits	0.63 (0.30-1.32)	0.83 (0.45-1.52)	0.59 (0.31-1.14)
All Mental Health Physician Visits	0.99 (0.40-2.47)	1.09 (0.44-2.72)	0.85 (0.44-1.66)
All Other Physician Visits	0.63 (0.32-1.24)	0.83 (0.50-1.37)	0.57 (0.30-1.09)

Reference: comparison group
Timing in relation to program delivery
Note: Pregnancy-related visits have been excluded.

In the adjusted outcomes, relative to the comparison group, the InSight participants demonstrated (Table 6.3):

- no significant difference in the relative risks of physician visits; and
- a trend towards decreased relative risk of physician visits after the program for all physician visits and all other physician visits.

Hospitalizations

Indicators in this section were taken from the hospital discharge abstracts and subdivided into categories using the ICD-9-CM (prior to April 2004) or ICD-10-CA (after March 2004) codes. Each abstract may include up to 16 ICD-9-CM or 25 ICD-10-CA codes. Results are presented for all hospitalizations (non-pregnancy), all mental health hospitalizations, all injury hospitalizations and all other hospitalizations. Women hospitalized with a diagnosis from both the injury and mental health categories were classified under mental health and counted only once. Results are presented per 1,000 person-years. For the InSight participants the unadjusted rates per 1,000 person-years are 200.87 for all hospitalizations, 51.01 for all mental health hospitalizations, 58.99 for all injury hospitalizations, and 90.87 for all other hospitalizations. The comparison group rates per 1,000 person-years were 107.14 for all hospitalizations, 22.01 for all mental health hospitalizations, 18.15 for all injury hospitalizations and 66.98 for all other hospitalizations. This highlights that even though the comparison group is composed of vulnerable women, they have substantially lower risks than the evaluation cohort.

Table 6.4: Unadjusted Rates of Hospitalizations for InSight Participants

Rates per 1,000 person-years, by time period

	Before	During	After
All Hospitalizations	200.87	208.22	286.03
All Mental Health Hospitalizations	51.01	53.23	64.39
All Injury Hospitalizations	58.99	36.01	37.15
All Other Hospitalizations	90.87	118.98	184.49

Timing in relation to program delivery

Note: Pregnancy-related hospitalizations have been excluded.

Table 6.5: Unadjusted Relative Risks for Hospitalizations for InSight Participants: Time-Period Comparisons

95% confidence intervals

	During vs Before	After vs Before	After vs During
All Hospitalizations	1.04 (0.81-1.32)	1.42 (1.15-1.77)	1.37 (1.11-1.70)
All Mental Health Hospitalizations	1.04 (0.64-1.69)	1.26 (0.81-1.96)	1.21 (0.79-1.86)
All Injury Hospitalizations	0.61 (0.36-1.03)	0.63 (0.39-1.02)	1.03 (0.60-1.78)
All Other Hospitalizations	1.31 (0.93-1.85)	2.03 (1.50-2.76)	1.55 (1.18-2.04)

bold indicates statistical significance for that time period

Timing in relation to program delivery

Note: Pregnancy-related hospitalizations have been excluded.

Key Findings: Unadjusted Outcomes

When compared as a group to themselves over time the InSight participants demonstrated:

- increasing rates over time for all-cause (non-pregnancy), and all other hospitalizations;
- a trend towards decreased rates of hospitalization during the program for all injury hospitalizations, a trend that persisted after program exit; and
- no differences over time for all mental health hospitalizations.

Table 6.6: Adjusted Relative Risks for Hospitalizations for InSight Participants: by Time Period

IPTW-adjusted rates per 1,000 person-years, 95% confidence intervals

	Before	During	After
All Hospitalizations	1.10 (0.66-1.84)	1.10 (0.77-1.57)	1.78 (1.17-2.70)
All Mental Health Hospitalizations	1.15 (0.31-4.31)	1.81 (0.85-3.83)	4.48 (1.86-10.81)
All Injury Hospitalizations	1.45 (0.77-2.73)	1.83 (0.82-4.12)	3.70 (2.06-6.64)
All Other Hospitalizations	0.95 (0.62-1.47)	0.85 (0.54-1.34)	1.26 (0.80-1.97)

bold indicates statistical significance for that time period (InSight vs. comparison group)

Reference: comparison group

Timing in relation to program delivery

Note: Pregnancy-related hospitalizations have been excluded.

As shown in Table 6.6, in the adjusted outcomes, relative to the comparison group, the InSight participants demonstrated:

- a trend towards an increased relative risk for mental health and injury hospitalizations during the program with a significantly increased risk after the program; and
- a trend towards higher relative risk before the program for all-cause hospitalizations with significantly increased relative risks after the program.

What these Findings Mean

Increasing physician-visit rates are a good outcome as they reflect connection to services, which may reduce the need for hospitalization. An overall pattern of increasing physician visits during and after the program parallels the comparison group results; however, the patterns are significantly different, providing strong evidence of a program effect. We observed that after program exit the relative rate of increase for InSight participants was lower than for the comparison group. This could suggest that without the support of the InSight program the participants are unable to achieve or maintain the same level of connection to primary healthcare services as during the program. If this hypothesis is true, perhaps the lower rates of physician visits are partially responsible for the increased relative risk of hospitalizations observed after the program.

The InSight participants trend towards or remain significantly at increased risk relative to the comparison group for hospitalization; this is despite stable rates of hospitalization for mental health and decreasing rates for injury. This result is most obvious after program exit. It is due to decreases over time for the comparison group that are not experienced by the InSight participants, which results in increasing relative risks over time (the gap widens particularly after program exit). The smaller differences observed during the program, together with larger magnitudes of difference after the program may suggest some protection of the health status of the InSight participants that did not persist after the program ended. The exception is for “all other” hospitalizations, of which both groups demonstrated the same increase over time. This result was expected because of increasing age.

InSight participants do not sustain the same increase of physician visits over time as the comparison group. InSight participants have higher relative risks of hospitalization during and after program exit, and the gap widening over time. These outcomes could be attributable to lack of mentor support after program exit, or other unaccounted for influences on InSight participants’ health and wellbeing.

6.2: Pregnancy Outcomes and Prenatal Care

This section evaluates pregnancy rates and uptake of prenatal care for InSight participants and the comparison group. Mentors in the InSight program help women to identify goals related to family planning and pregnancy to reduce FASD through contraception use to delay or avoid pregnancy, and support healthy choices during pregnancy. Use of contraception is not consistently captured in the Repository. However, pregnancy rates in a sexually active population ultimately reflect a combination of its use and efficacy.

Pregnancy-Related Indicators

Live births were measured from the Repository and are reported per 100 person-years. The births were assigned to a time period based on the pregnancy start date, not the birth date. Before the program the unadjusted live birth rate for the InSight participants was 39.22 versus 33.60 per 100 person-years for the comparison group

Non-live births were measured from the Repository and are reported per 100 person-years. The births were assigned to a time period based on the pregnancy start date. Non-live births include stillbirths, therapeutic and spontaneous abortions, and non-viable pregnancies (such as molar pregnancies). Before the program the unadjusted non-live birth rate was 3.83 versus 1.64 per 100 person-years for InSight participants and the comparison group, respectively.

At least one live birth: this indicator measures whether a participant had at least one live birth during each time period, by pregnancy start date. Due to the enrolment criteria, all InSight participants had a pregnancy that started before the program, as did the comparison group.

Key Findings: Unadjusted Outcomes

Table 6.7: Unadjusted Rates of Pregnancy Outcomes for InSight Participants
Rates per 100 person-years, by time period

	Before	During	After
Live Births	39.22	22.54	11.83
Non-Live Births	3.83	3.91	2.81

Timing in relation to program delivery

Table 6.8: Unadjusted Relative Risks for Pregnancy Outcomes for InSight Participants: Time-Period Comparisons
95% confidence intervals

	During vs Before	After vs Before	After vs During
Live Births	0.57 (0.47-0.71)	0.30 (0.24-0.38)	0.52 (0.41-0.68)
Non-Live Births	1.02 (0.58-1.79)	0.73 (0.41-1.30)	0.72 (0.41-1.26)

bold indicates statistical significance for that time period

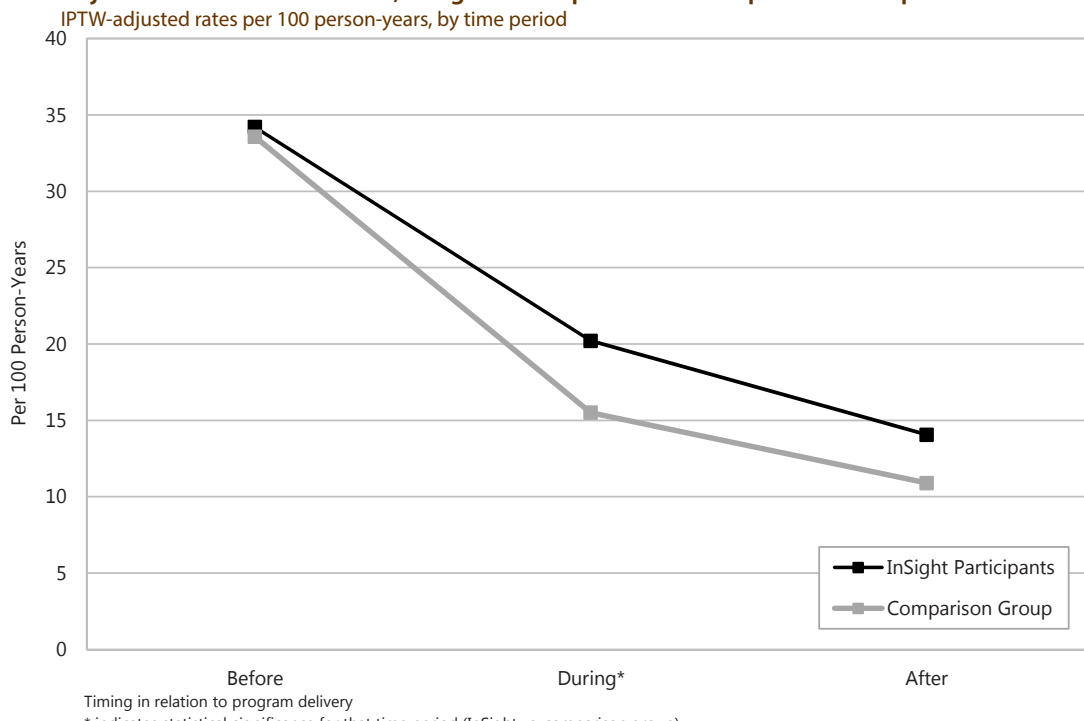
Timing in relation to program delivery

When compared as a group to themselves over time the InSight participants demonstrated:

- a significant reduction in live-birth rates during the program, and a further reduction after program exit;
- an unchanged rate of non-live births over time; and
- a decrease in the proportion having at least one live birth, with 55.6% having one during the program and 33.2% having one after the program (RR 0.60, 95% confidence interval: 0.44–0.80).

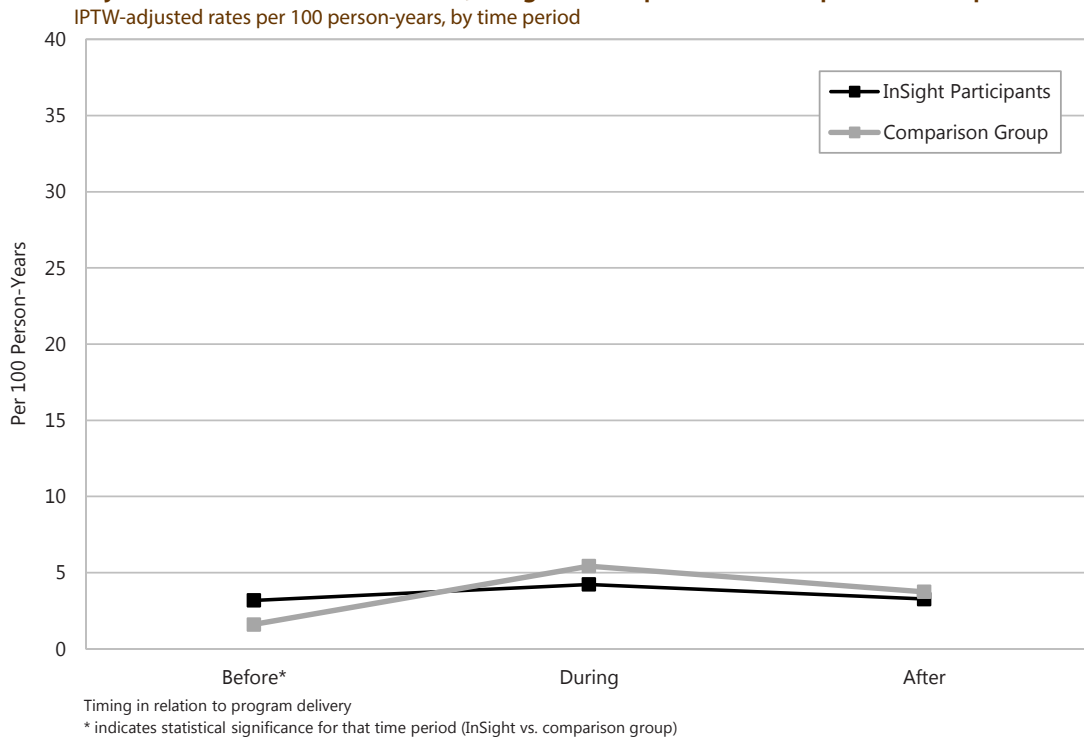
Key Findings: Adjusted Outcomes

Figure 6.9: Adjusted Rates of Live Births, InSight Participants and Comparison Group



- A significant difference in the change over time for live births (**p=0.131**).

Figure 6.10: Adjusted Rates of Non-Live Births, InSight Participants and Comparison Group



- No significant difference in the change over time for non-live births (**p=0.203**)

Table 6.9: Adjusted Relative Risks for Pregnancy Outcomes for InSight Participants: by Time Period

IPTW-adjusted rates per 100 person-years, 95% confidence intervals

	Before	During	After
Live Births	1.02 (0.89-1.16)	1.30 (1.03-1.65)	1.29 (0.94-1.76)
Non-Live Births	1.99 (1.05-3.78)	0.78 (0.39-1.55)	0.87 (0.45-1.68)

bold indicates statistical significance for that time period (InSight vs. comparison group)

Reference: comparison group

Timing in relation to program delivery

In the adjusted outcomes, relative to the comparison group, InSight participants demonstrated:

- a significantly higher rate of live births during the program, and a trend towards higher rates after program exit;
- a higher relative risk of having at least one live birth during the program, but not after program exit; and
- a significantly higher relative risk before the program for non-live births, with no significant difference during or after the program.

What these Findings Mean

Despite decreasing rates of live births over time, rates remain higher for InSight participants relative to the comparison group; they appear close to equal after program exit due to a slower rate of decrease in the InSight participants. It is unclear what their pattern would have been without the program, as the InSight participants are expected to differ from the comparison group on other variables such as family-planning practices and uptake of prenatal care. The patterns of non-live births are difficult to interpret because rates are very low and include a variety of different outcomes. The persistently high rate of non-live births may reflect more frequent pregnancy termination and higher rates of stillbirth in this vulnerable population; however, we do not have the sample size to examine this further.

Pregnancy patterns and outcomes reflect decisions and practices related to contraception, which was an area of support targeted by the InSight program. Personal goals of the participants may have included either embarking upon a healthy pregnancy or avoiding pregnancy; however, data for our sample is unable to discriminate between these. Information about the use of contraception is not complete within the Repository because of the many options available, prescription and non-prescription, including many prescription options not captured in the Repository's dispensation data. Nevertheless, patterns of pregnancy and birth ultimately reflect access to, and use of, contraception in a sexually active cohort. Historically, women from vulnerable populations, such as the InSight participants, have high birth rates (May & Gossage, 2011) throughout their reproductive years, yet rates in the InSight participants fell over time, less steeply than our comparison group. It would be necessary to confirm that the decrease over time in our participants is due to the InSight program with use of a more similar control group.

Prenatal Care

Prenatal care is a widely accepted public health intervention that is available to all women in Manitoba via the publicly funded healthcare system. Despite this, not all women receive adequate prenatal care. Suggested patterns of prenatal visits, services offered, and program-delivery structures vary, but a term pregnancy usually involves 10–15 visits. Inadequate or no prenatal care is associated with many detrimental outcomes such as prematurity, low birth weight, neonatal and maternal morbidity, and mortality (Partridge, Balayla, Holcroft, & Abenhaim, 2012). Factors associated with inadequate prenatal care include many of the risk factors seen in InSight participants: young maternal age, drug and alcohol use, single parenthood, living in low socioeconomic neighborhoods, and high parity. In studies that examine why women in publicly funded systems do not obtain adequate prenatal care, answers given include a lack of understanding of its importance, difficulties with transportation and childcare arrangements, requirements for appointments, and time management (Heaman et al., 2014).

Prenatal care was chosen as an area of focus because one of InSight’s primary goals is to connect women with appropriate services. Prenatal care affords an opportunity to connect women with more healthcare services, and also social and other supportive services. The indicators used to measure prenatal care were drawn from physician billing records and provincial laboratory data. Gestational age and the infant’s birthdate were used to establish timing of prenatal visits. The first trimester is defined as ending the 13th week. Individual participants may have multiple pregnancies reported within each time period, and the pregnancy is assigned to a time period using the pregnancy start date.

Indicators of Prenatal Care

Prenatal care in first trimester: Early initiation of prenatal care reflects knowledge of the pregnancy and of the possibility of accessing preventative services, including those that support healthy nutrition and reducing alcohol use in pregnancy. This indicator identifies the percentage of pregnancies in which the first prenatal visit occurred in the first trimester. Prior to program entry, 48% of the InSight participants initiated prenatal care in the first trimester of their pregnancies, compared to 53% of the comparison group.

Hepatitis B serology testing in first trimester: All women are offered a bundle of laboratory testing in pregnancy that directs interventions during pregnancy and delivery. We report the percentage of pregnancies with results for hepatitis B serology in the first trimester. This reflects attendance at a healthcare provider and receipt of testing, a two-step process. Prior to program entry, 44% of the InSight participants had screening results reported from their first trimester, compared to 54% of the comparison group.

Adequate prenatal care: For research purposes there are multiple ways to define adequate prenatal care. We used the Revised Graduated Index of Prenatal Care Utilization (R-GINDEX), which considers when care was initiated, total number of visits, and gestational age at birth (Alexander & Kotelchuck, 1996). Crude rates varied widely: 50% of the evaluation cohort received adequate prenatal care before program entry, compared to 71% of the comparison group.

Key Findings: Unadjusted Outcomes

Table 6.10: Unadjusted Rates of Prenatal Care for InSight Participants

Percentages, by pregnancy start date

	Before	During	After
First Trimester Initiation of Prenatal Care	47.56	59.03	40.21
Hepatitis B Serology Testing in First Trimester	43.50	54.62	30.44
Adequate Prenatal Care by R-GINDEX	50.41	49.31	44.33

Timing in relation to program delivery

Table 6.11: Unadjusted Relative Risks for Prenatal Care for InSight Participants: Time-Period Comparisons

95% confidence intervals

	During vs Before	After vs Before	After vs During
First Trimester Initiation of Prenatal Care	1.24 (0.94-1.64)	0.85 (0.59-1.21)	0.68 (0.47-1.00)
Hepatitis B Serology Testing in First Trimester	1.26 (1.01-1.56)	0.70 (0.44-1.11)	0.56 (0.35-0.89)
Adequate Prenatal Care by R-GINDEX	0.98 (0.79-1.21)	0.88 (0.68-1.14)	0.90 (0.68-1.19)

bold indicates statistical significance for that time period (InSight vs. comparison group)

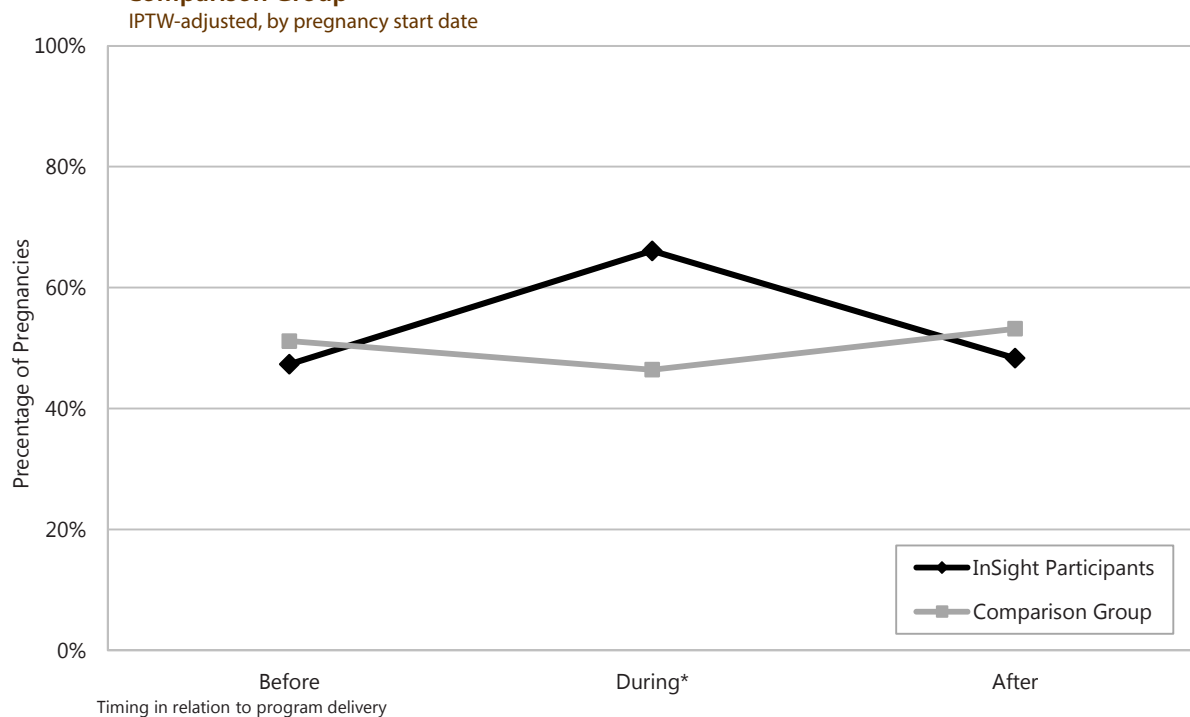
Timing in relation to program delivery

When compared as a group to themselves over time, InSight participants demonstrated:

- significantly higher rates of first trimester hepatitis B screening and a trend towards higher rates of first-trimester initiation of care during the program compared to before;
- a significantly decreased rate of both first-trimester initiation and first-trimester hepatitis B serology after the program compared to during the program;
- no difference for both first-trimester initiation and hepatitis B screening in the first trimester after the program compared to before the program (i.e. a return to pre-program levels); and
- no differences between any time periods in the percentage of pregnancies with adequate prenatal care as measured by the R-GINDEX.

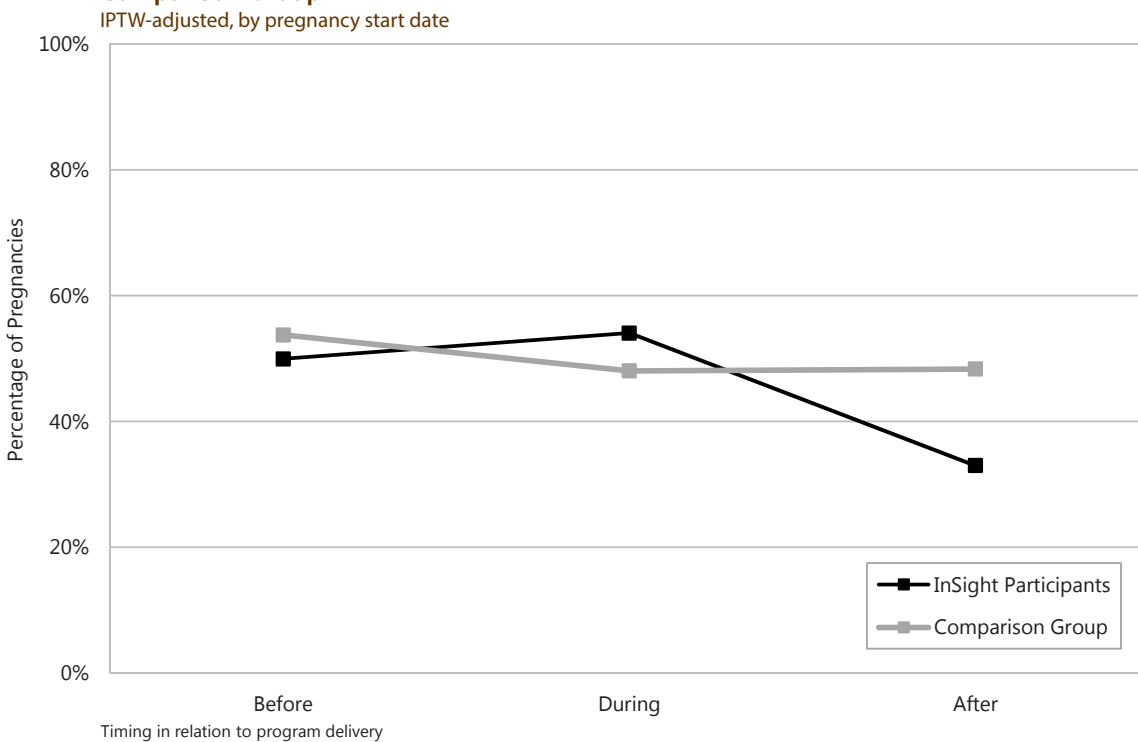
Key Findings: Adjusted Outcomes

Figure 6.11: Adjusted Rates of First-Trimester Initiation of Prenatal Care, InSight Participants and Comparison Group



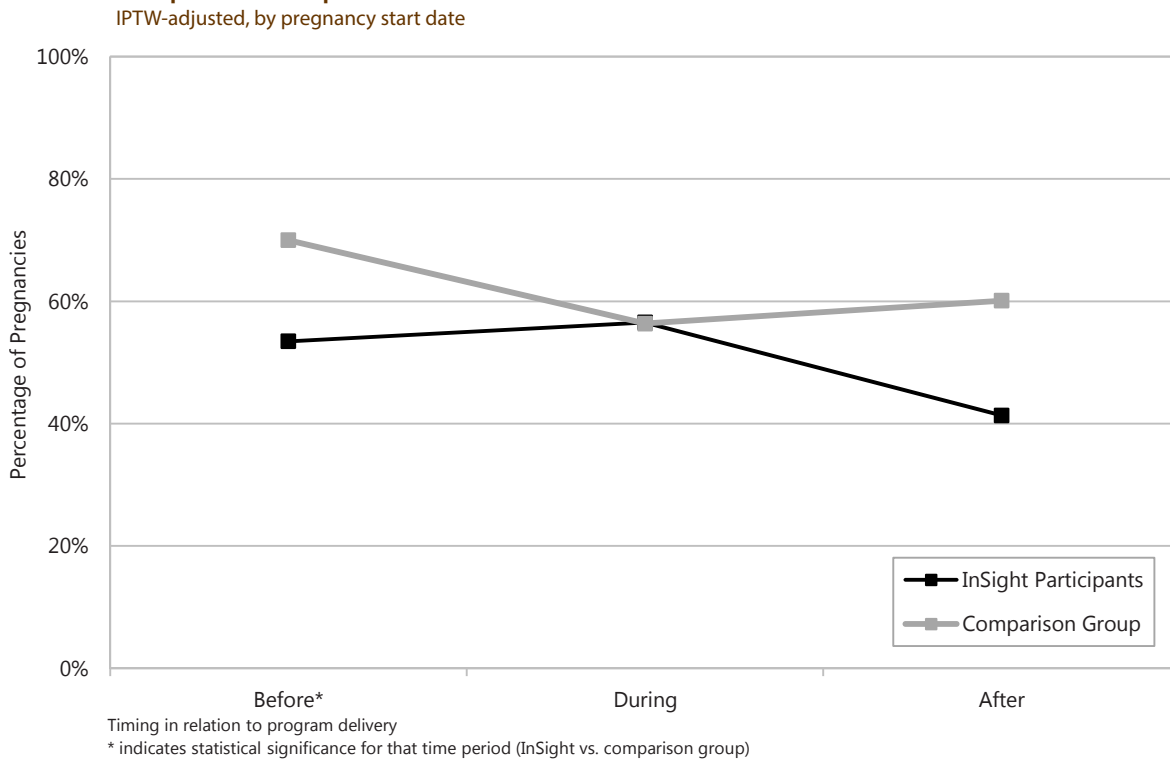
- A significantly different change over time for first trimester initiation ($p=0.013$) of prenatal care

Figure 6.12: Adjusted Rates of Hepatitis B Serology Testing in First Trimester, InSight Participants and Comparison Group



- No significantly different change over time for Hepatitis B serology testing in the first trimester ($p=0.407$)

Figure 6.13: Adjusted Rates of Adequate Prenatal Care From R-GINDEX Rates, InSight Participants and Comparison Group



- A significantly different change over time for adequate prenatal care ($p=0.138$).

Substance-Use Indicators

Results for all indicators are given as the percentage of pregnancies in each time period, determined by the pregnancy start date. For indicators drawn only from the FFS database, pregnancies that could not be linked to an FFS were removed from the analysis (30.8% of pregnancies in the InSight participants and 13.6% of pregnancies in the comparison group).

Smoking in Pregnancy: Smoking during pregnancy is associated with lower birth weights and prematurity (Abbott & Winzer-Serhan, 2012). We report on the percentage of pregnancies in which women reported (on the FFS) any smoking. InSight participants reported that, before program entry, smoking took place in 70.2% of pregnancies, versus 62.2% for the comparison group.

Any Alcohol Use in Pregnancy: This indicator identifies whether any alcohol use was reported in either the FFS or the maternal delivery record. It includes pregnancies to which no FFS could be linked. Alcohol use in pregnancy before program entry was reported by 50.4% of InSight participants. We know from the delivery of the InSight program that this most likely is a falsely low rate. A percentage is not applicable in the comparison group as each woman must have reported alcohol use in pregnancy in order to be included in the group.

No Alcohol Use in Pregnancy: This indicator reports the percentage of pregnancies with an FFS in which no alcohol use was reported after the women knew she was pregnant. Prior to program entry no alcohol use during pregnancy was reported for 28.5% of InSight pregnancies. A percentage is not applicable in the comparison group as each woman must have reported alcohol use in pregnancy in order to be included in the group.

Low-Risk or No Alcohol Use in Pregnancy: This composite indicator is drawn from the FFS data collected from 2006 onwards only, due to a change in data collection. It reports the percentage of pregnancies with an FFS in which either no alcohol use or low-risk alcohol use was reported in pregnancy; this was defined using the frequency and amount reported (see Appendix Table 1.2 for details on high- and low-risk calculations). The InSight participants met these criteria in 54.6% of pregnancies before program entry, versus 63.2% in the comparison group. Data for this indicator was only available for 25 pregnancies among the InSight participants in the period after program exit.

High-Risk Alcohol Use prior to Pregnancy: A composite indicator, only available from 2006 onwards, for women with a FFS form who disclosed some alcohol use in pregnancy. If women disclosed alcohol use in pregnancy, they were also asked about frequency and amount prior to pregnancy. We used this to classify their pre-pregnancy use as high-risk or not. The rate of high-risk alcohol use before pregnancy for InSight participants was 83.3%, versus 46.3% for the comparison group. Data for this indicator was only available for 10 pregnancies among the InSight participants in the period after program exit.

Key Findings: Unadjusted Outcomes

Table 6.13: Unadjusted Rates of Substance Abuse for InSight Participants

Percentages, by time period

	Before	During	After
Smoking in Pregnancy	70.20	75.28	76.92
Any Alcohol Use in Pregnancy	50.35	40.68	35.29
No Alcohol Use in Pregnancy	28.48	34.83	38.46
Low-Risk or No Alcohol Use in Pregnancy	54.55	75.76	72.00
High-Risk Alcohol Use prior to Pregnancy	83.33	61.54	70.00

Timing in relation to program delivery

Table 6.14: Unadjusted Relative Risks for Substance Abuse for InSight Participants: Time-Period Comparisons

95% confidence intervals

	During vs Before	After vs Before	After vs During
Smoking in Pregnancy	1.07 (0.92-1.26)	1.10 (0.90-1.34)	1.02 (0.83-1.26)
Any Alcohol Use in Pregnancy	0.81 (0.61-1.07)	0.70 (0.48-1.03)	0.87 (0.58-1.30)
No Alcohol Use in Pregnancy	6.75 (5.74-7.93)	6.64 (5.59-7.88)	0.98 (0.88-1.10)
Low-Risk or No Alcohol Use in Pregnancy	1.39 (0.97-1.99)	1.32 (0.88-1.99)	0.95 (0.68-1.32)
High-Risk Alcohol Use prior to Pregnancy	0.74 (0.44-1.25)	0.84 (0.53-1.32)	1.14 (0.61-2.13)

bold indicates statistical significance for that time period (InSight vs. comparison group)

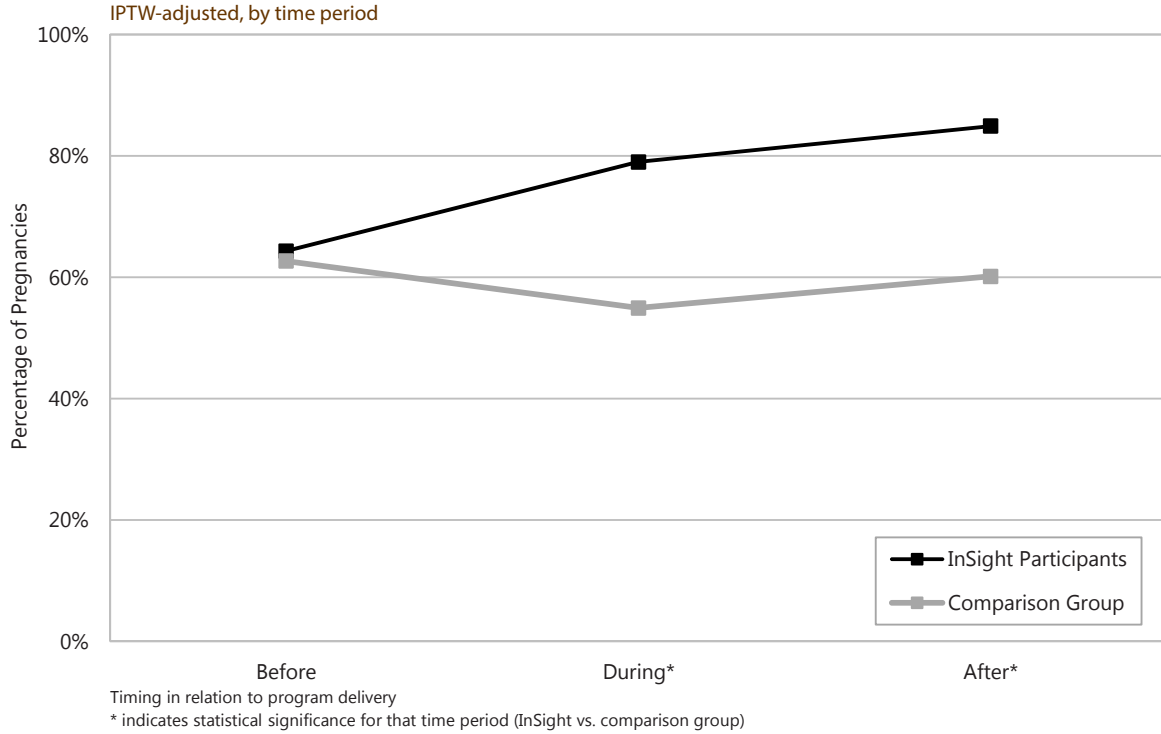
Timing in relation to program delivery

When compared as a group to themselves over time the InSight participants demonstrated:

- a trend towards less alcohol use, as measured by some indicators—low-risk or no alcohol use in pregnancy; and any alcohol use in pregnancy—during the program;
- no changes in alcohol use, as measured by other indicators—no alcohol use in pregnancy and high-risk alcohol use prior to pregnancy—in any time period; and
- no changes in smoking in pregnancy patterns in any time period.

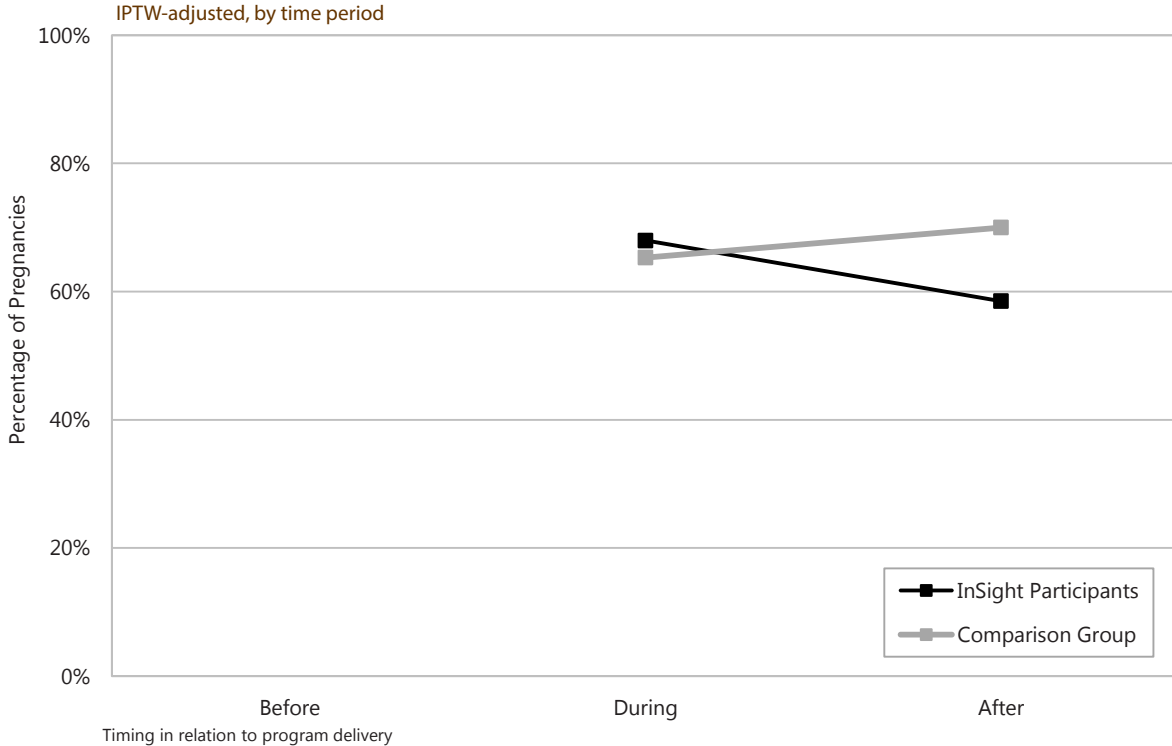
Key Findings: Adjusted Outcomes

Figure 6.14: Adjusted Rates of Smoking in Pregnancy, InSight Participants and Comparison Group



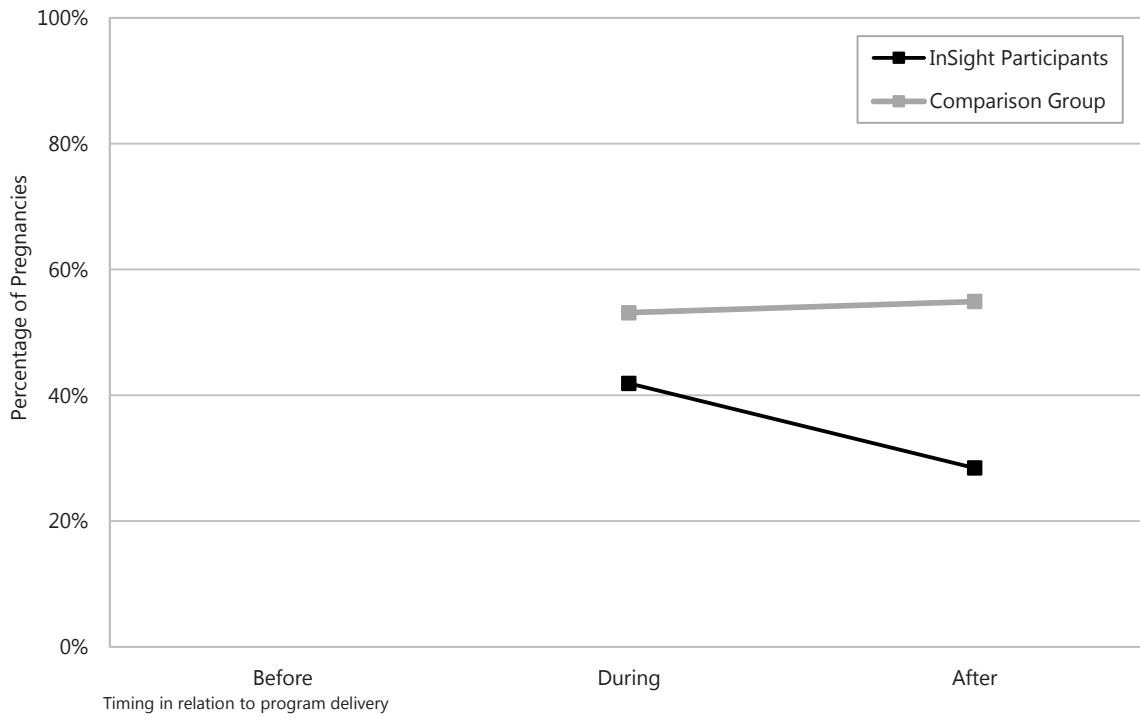
- A significantly different change over time for smoking in pregnancy ($p=0.024$).

Figure 6.15: Adjusted Rates of Any Alcohol Use in Pregnancy, InSight Participants and Comparison Group



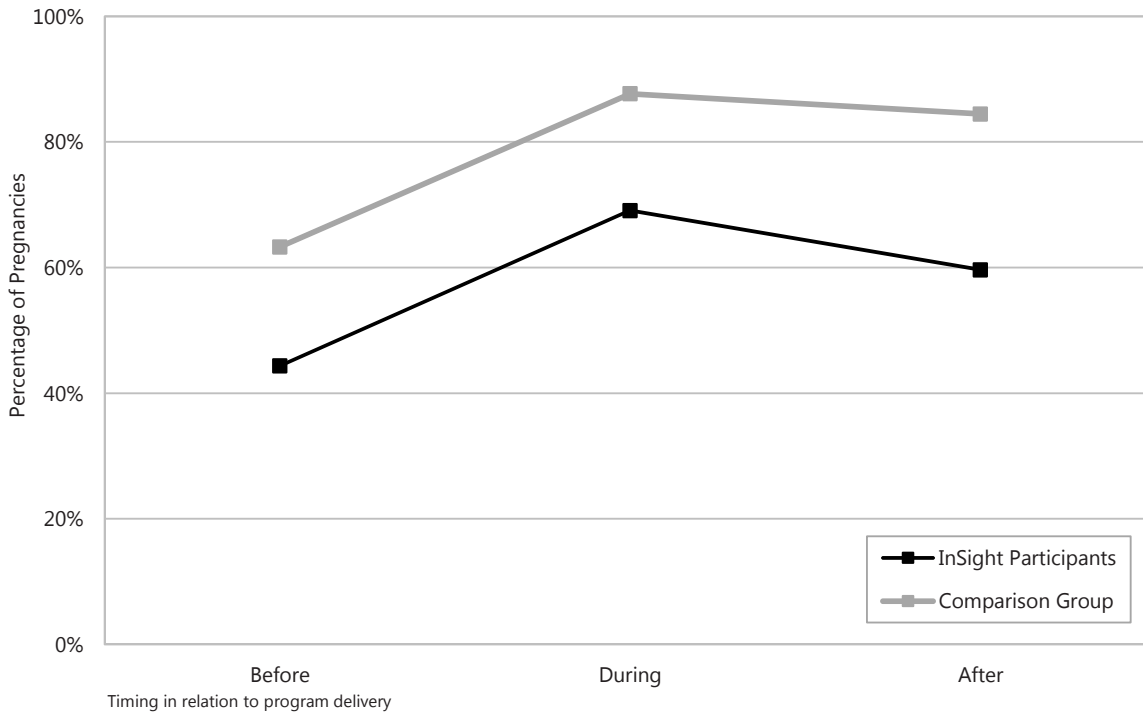
- No statistical difference in the change over time for any alcohol use in pregnancy ($p=0.245$).

Figure 6.16: Adjusted Rates of No Alcohol Use in Pregnancy, InSight Participants and Comparison Group
IPTW-adjusted, by time period



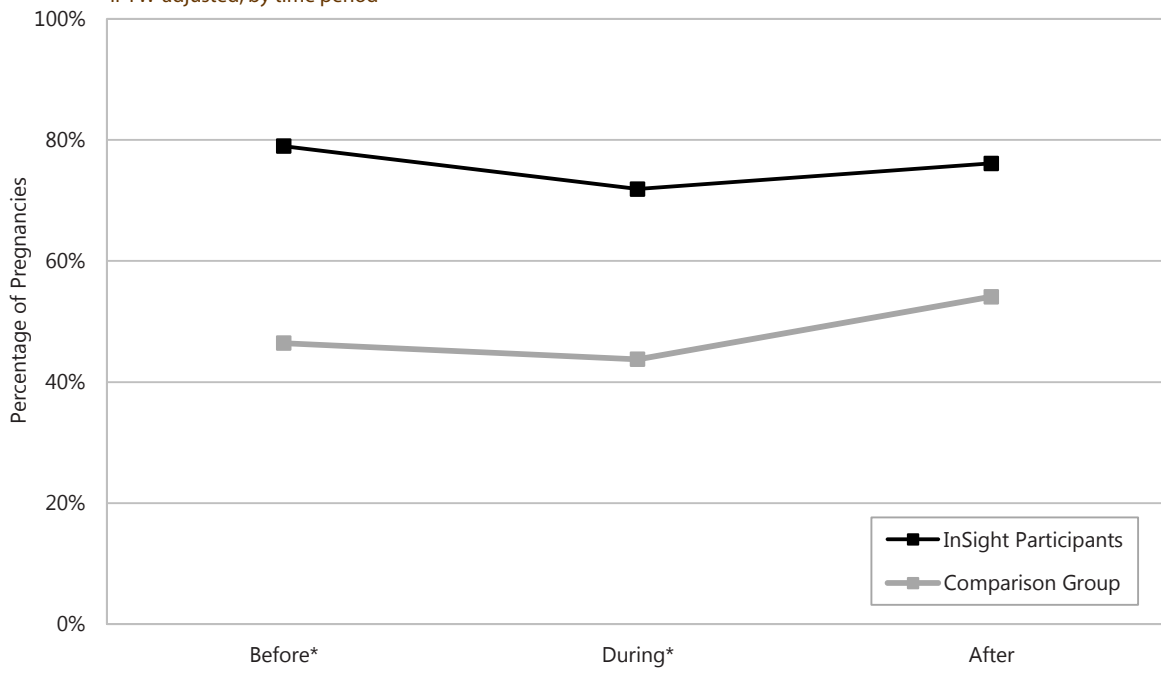
- No statistical difference in the change over time for no alcohol use in pregnancy ($p=0.275$).

Figure 6.17: Adjusted Rates of Low-Risk or No Alcohol Use in Pregnancy, InSight Participants and Comparison Group
IPTW-adjusted, by time period



- No statistical difference in the change over time for low-risk or no alcohol use in pregnancy ($p=0.891$).

Figure 6.18: Adjusted Rates of High-Risk Alcohol Use prior to Pregnancy, InSight Participants and Comparison Group
IPTW-adjusted, by time period



- No statistical difference in the change over time for high-risk alcohol use prior to pregnancy ($p=0.796$).

Table 6.15: Adjusted Relative Risks for Substance Abuse for InSight Participants: by Time Period
IPTW-adjusted percentages, 95% confidence intervals

	Before	During	After
Smoking in Pregnancy	1.03 (0.84-1.26)	1.44 (1.19-1.74)	1.41 (1.20-1.67)
Any Alcohol Use in Pregnancy	n/a	1.04 (0.86-1.26)	0.84 (0.60-1.17)
No Alcohol Use in Pregnancy	n/a	0.79 (0.51-1.22)	0.52 (0.27-1.00)
Low-Risk or No Alcohol Use in Pregnancy	0.70 (0.42-1.18)	0.79 (0.58-1.07)	0.71 (0.42-1.17)
High-Risk Alcohol Use prior to Pregnancy	1.70 (1.23-2.35)	1.64 (1.08-2.50)	1.41 (0.87-2.27)

bold indicates statistical significance for that time period (InSight vs. comparison group)

n/a - not available as alcohol use in this time period was required in the comparison group

Timing in relation to program delivery

In the adjusted outcomes, relative to the comparison group InSight participants demonstrated:

- increased rates of smoking during and after the program;
- significantly higher rates of high-risk alcohol use prior to pregnancy, before and during the program, but no relative difference after program exit (i.e., rates were similar to the comparison group);
- higher use of alcohol during pregnancy across all indicators and time periods (however, results show a trend downward over time for InSight participants); and
- a trend towards equivalent rates in during the program for low-risk or no alcohol use in pregnancy, and in the period after program exit for no alcohol use in pregnancy.

What these Findings Mean

These findings are difficult to interpret. The small number of pregnancies increases the risk of missing a true change that has occurred, and changes in reported use may reflect changes in either actual use or in reporting. Despite this there are suggestions of changes in the expected direction for all outcomes; during the program there were increasing percentages of pregnancies with low or no alcohol use among InSight participants. A lack of a decrease may also represent a falsely low baseline frequency of use if alcohol use is not disclosed. Under-reporting alcohol use in pregnancy for the period before program entry is apparent in the low rates for InSight participants, despite their meeting of the enrolment criteria. There are mixed patterns after program exit, so the persistence of the change is uncertain. The downward trends towards equivalent rates with the comparison group suggests the program had an impact on alcohol use in pregnancy, which is consistent with the program outcomes described in Chapter 5. There is a suggestion that these trends continue after program exit.

InSight participants remain at a higher risk of alcohol use relative to the comparison group. Due to the use of alcohol in pregnancy as an inclusion criterion for the comparison group we were unable to assess the adequacy of the model in adjusting baseline risks. As the rates of high-risk use were higher for the InSight participants at baseline, we suspect that the statistical adjustment was not sufficient to equalize the two groups for these outcomes.

Smoking patterns did not change over time for the InSight participants, which resulted in an increased relative risk over time due to dropping rates in the comparison group. While smoking in pregnancy has detrimental effects, from a harm-reduction standpoint it is lower in priority than alcohol use and some other drugs.

6.4: Outcomes Related to Mental Health

Research, both qualitative and quantitative, examining the impacts of mentoring programs for women with alcohol use problems reveals many gains outside of reducing alcohol use. Gains in areas such as self-confidence, reduction in mental health distress and a growing capacity for self-sufficiency have been reported (Burnside et al., 2012); all changes important for sustained harm reduction. Additionally, connection to social services and to peer and family support are important. Unfortunately these types of outcomes are hardest to glean from administrative data and require a large sample to demonstrate changes due to program participation.

Mental Health Indicators

Receipt of the Families First Screen (FFS): The percentage of pregnancies in each time period that can be linked to a FFS. Pregnancies were assigned to a time period by start date. Many of the indicators in this and other sections are taken from the FFS form. This form is not administered to women living on reserve. Before entry, 68% of the InSight participants' pregnancies were linkable to a form, compared to the population norm of 80% (Heaman et al., 2012). Rates of linkage were artificially high for the comparison group before program entry because this form was used to identify alcohol use in pregnancy.

Peripartum Social Isolation: A question on the FFS asks whether the respondent experiences social isolation due to lack of social support, culture, language, or geographical issues. We examined this indicator because it is a potentially modifiable risk factor that has been linked to maternal mood disorders and difficulties with functioning (Eastwood et al., 2013). For women who have an FFS, we report the percentage of pregnancies where this question was answered with "yes" or was coded as "missing," because previous research has linked poorer outcomes to women with these codes. Before program entry, 10.6% of InSight participants answered "yes" to social isolation; a response to this question was missing for 29.8% of participants. Only 6.2% of the comparison group answered "yes," and only 10.7% were coded as missing. Out of the total population of Manitoba women who gave birth and had an FFS, 4.6% reported experiencing social isolation. The results for the InSight participants should be interpreted with caution, however, because they represent only 89 InSight participants during the program and 39 participants after the program.

Diagnosis of a Mood or Anxiety Disorder: We report the percentage of women in each time period meeting established criteria for identifying a mood disorder in administrative data using data on physician visits, hospitalizations, and prescription medication. Depression is a potentially modifiable risk factor associated with significant mortality and morbidity (Hanley & Oberlander, 2014) for women and their families. Before program entry 26.9% of InSight participants met the criteria for a mood disorder at least once, versus 15% of the comparison group. Previous research has reported a prevalence of 23.3% for all Manitobans over the age of 10 (Fransoo et al, 2013).

Key findings: Unadjusted Outcomes

Table 6.16: Unadjusted Rates of Mental Health Indicators for InSight Participants

Percentages, by time period

	Before	During	After
Receipt of FFS	68.02	70.63	70.91
Peripartum Social Isolation	10.60	8.99	15.38
Mood and Anxiety Disorders	26.86	34.32	35.26

FFS refers to the Families First Screen
Timing in relation to program delivery

Table 6.17: Unadjusted Relative Risks for Mental Health Indicators for InSight Participants: Time-Period Comparisons

95% confidence intervals

	During vs Before	After vs Before	After vs During
Receipt of FFS	1.04 (0.90-1.19)	1.04 (0.87-1.25)	1.00 (0.82-1.23)
Peripartum Social Isolation	0.85 (0.39-1.86)	1.45 (0.62-3.40)	1.71 (0.73-3.99)
Mood and Anxiety Disorders	1.28 (0.93-1.76)	1.31 (0.96-1.80)	1.03 (0.77-1.37)

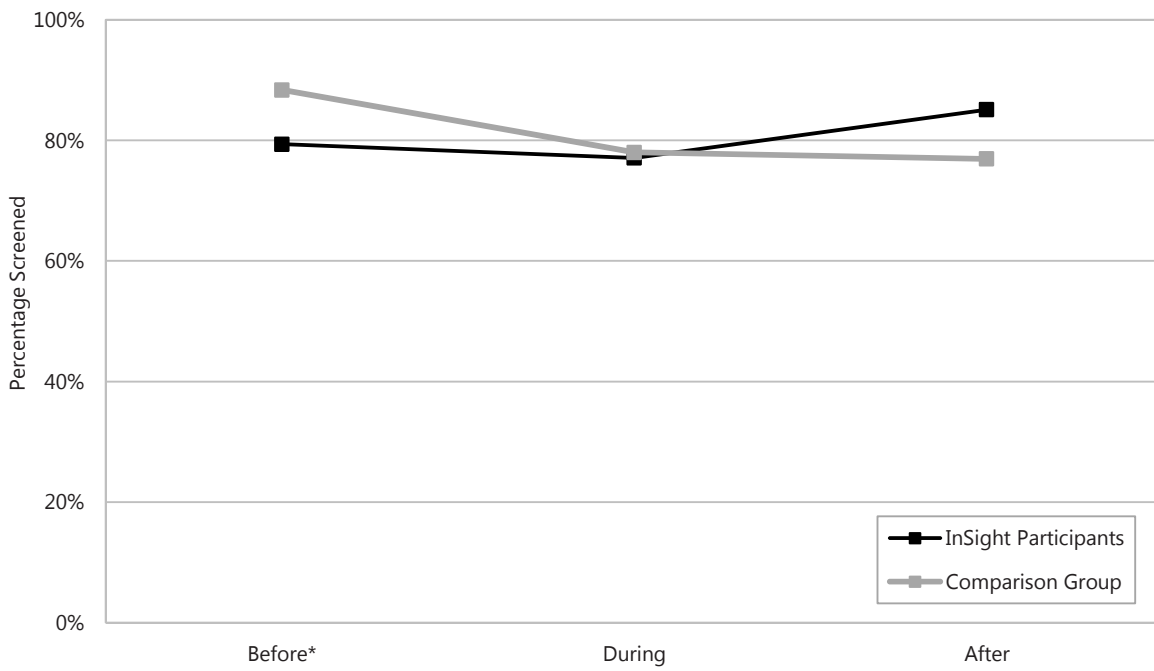
bold indicates statistical significance for that time period
FFS refers to the Families First Screen
Timing in relation to program delivery

When compared as a group to themselves over time the InSight participants demonstrated:

- a trend towards increased diagnosis of mood and anxiety disorders during and after the program;
- no change during the program for those who responded “yes” or whose answer was missing for the social isolation variable—however there is a suggestion of increasing social isolation when the period after is compared to during and before the program; and
- no changes between the time periods for receipt of the FFS.

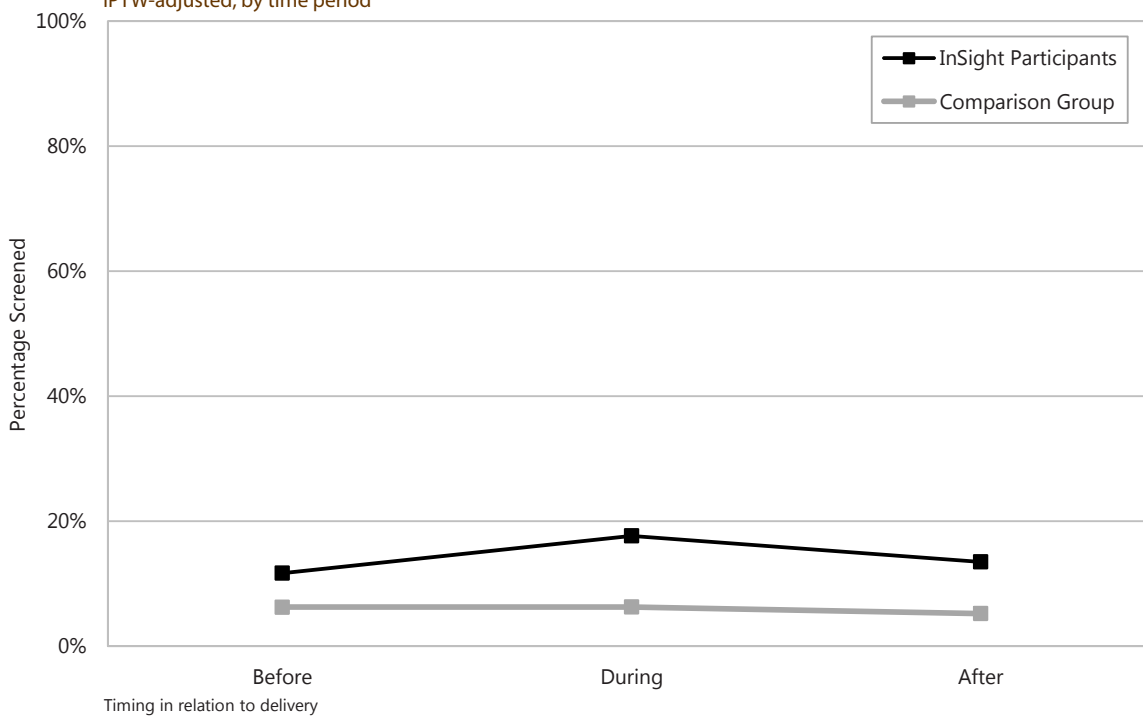
Key Findings: Adjusted Outcomes

Figure 6.19: Adjusted Rates of Receipt of Families First Screen, InSight Participants and Comparison Group
IPTW-adjusted, by time period



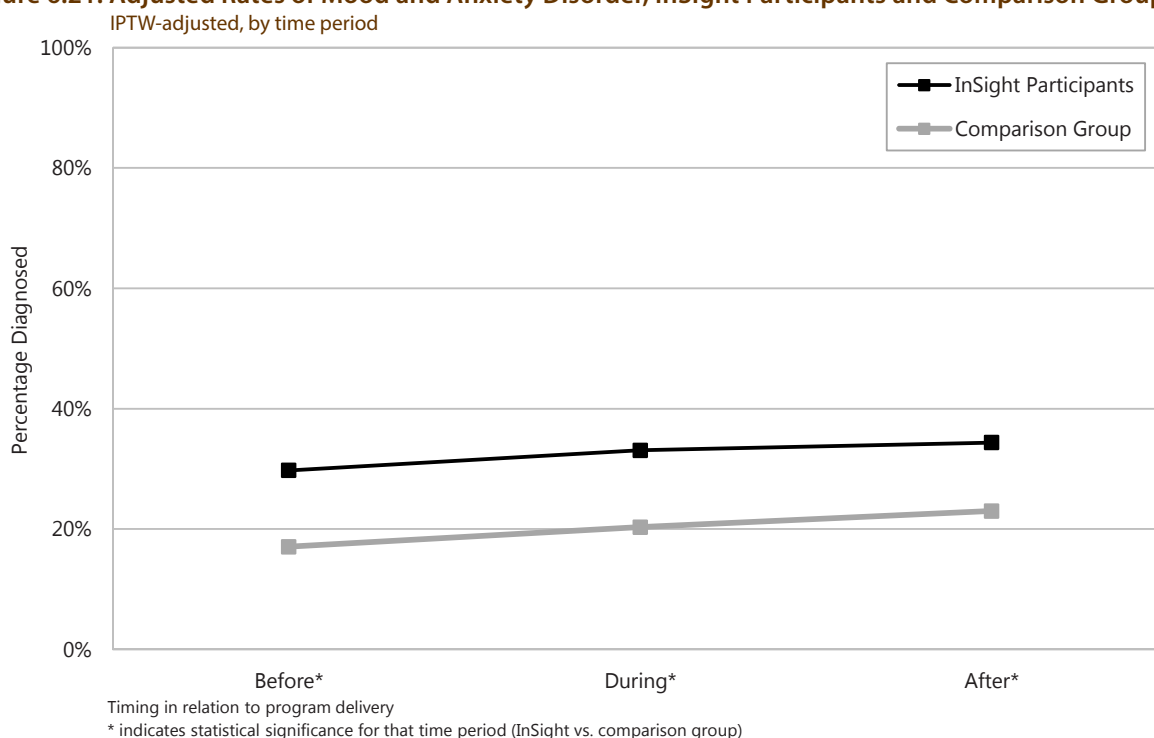
- No significant differences in the change over time for receipt of the Families First Screen ($p=0.065$).

Figure 6.20: Adjusted Rates of Peripartum Social Isolation, InSight Participants and Comparison Group
IPTW-adjusted, by time period



- No significant differences in the change over time for peripartum social isolation ($p=0.799$).

Figure 6.21: Adjusted Rates of Mood and Anxiety Disorder, InSight Participants and Comparison Group



- No significant differences in the change over time for diagnosis of a mood or anxiety disorder ($p=0.845$).

Table 6.18: Adjusted Relative Risks for Mental Health Indicators for InSight Participants: by Time Period

IPTW-adjusted percentages, 95% confidence intervals

	Before	During	After
Receipt of FFS	0.90 (0.81-0.99)	0.99 (0.84-1.16)	1.11 (0.97-1.26)
Paripartum Social Isolation	1.87 (0.89-3.92)	2.82 (0.92-8.65)	2.58 (0.93-7.21)
Mood and Anxiety Disorders	1.74 (1.09-2.79)	1.63 (1.07-2.47)	1.50 (1.03-2.16)

bold indicates statistical significance for that time period (InSight vs. comparison group)

FFS refers to Families First Screen

Timing in relation to program delivery

In the adjusted results, relative to the comparison group, the InSight participants demonstrated:

- a trend towards or significantly higher rates of social isolation in all time period comparisons (respondents answering “yes,” or a “missing” variable);
- higher rates of mood and anxiety disorders in all time periods; and
- a trend towards higher rate of receipt of the FFS after program exit.

What these Findings Mean

Interpretation of these findings is limited by the small sample size. Receipt of the FFS is lower for the InSight participants than for the Manitoba population at large. However, it is not relatively different than that of the comparison group, a group more vulnerable than the general population but likely less vulnerable than the InSight participants. The suggestion of increasing social isolation, and the persistently higher rate relative to the comparison group, despite adjustment, is intriguing. Persistent harm reduction for our InSight participants often requires them to distance themselves from their current peer and social networks. These networks encourage substance use, but they also provide social support. Participants who break these ties require explicit attention to help them establish alternative supportive networks to avoid social and cultural isolation.

Key Findings: Unadjusted Outcomes

Table 6.19: Unadjusted Rates of Social Services Use for InSight Participants

Percentages, by time period

	Before	During	After
Income Assistance*	60.80	66.85	59.85
Resident in MB Housing	25.23	36.45	N/A
Prenatal Benefit**	79.25	78.83	75.31
Community Support Groups**	40.15	36.67	33.33

N/A: valid data was unavailable at this time period

*Percentage of months receiving

**Percentage of pregnancies

Timing in relation to program delivery

**Table 6.20: Unadjusted Relative Risks for Social Services Use for InSight Participants:
Time-Period Comparisons**

95% confidence intervals

	During vs Before	After vs Before	After vs During
Income Assistance*	1.10 (0.83-1.46)	0.98 (0.74-1.31)	0.90 (0.67-1.19)
Resident in MB Housing	1.44 (1.08-1.93)	N/A	N/A
Prenatal Benefit**	0.99 (0.89-1.11)	0.95 (0.82-1.10)	0.96 (0.82-1.11)
Community Support Groups**	0.91 (0.61-1.36)	0.83 (0.52-1.32)	0.91 (0.56-1.47)

Bold indicates statistical significance for that time period

N/A: valid data was unavailable at this time period

*Percentage of months receiving

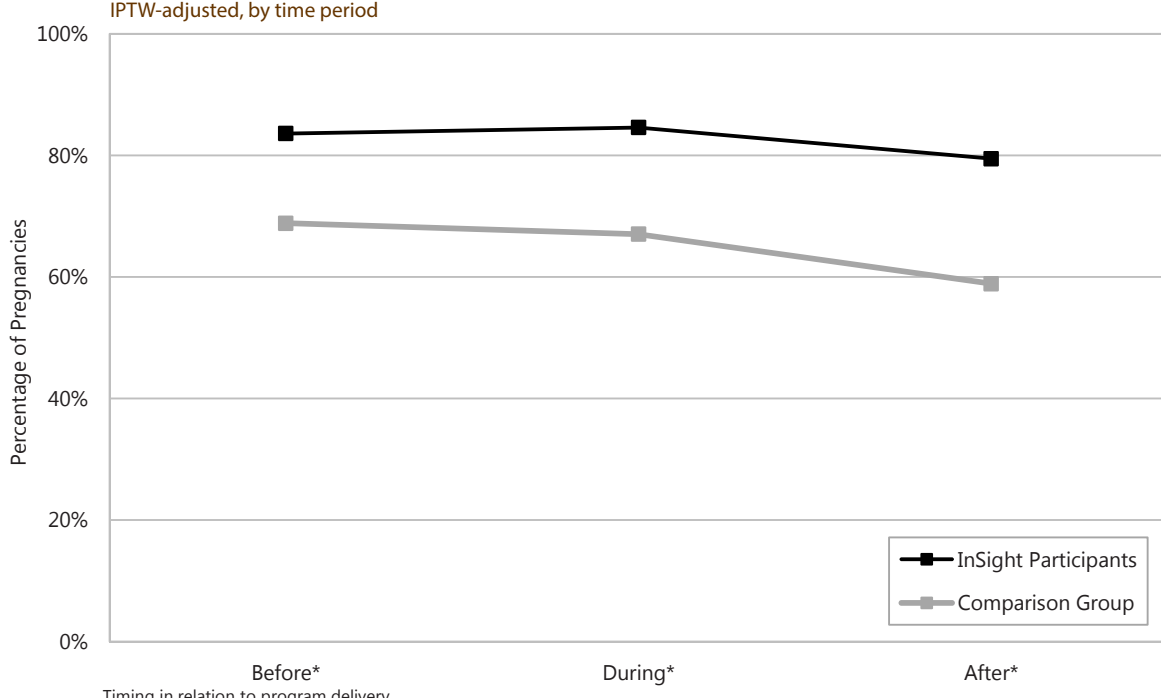
**Percentage of pregnancies

Timing in relation to program delivery

When compared as a group to themselves over time, the InSight participants demonstrated:

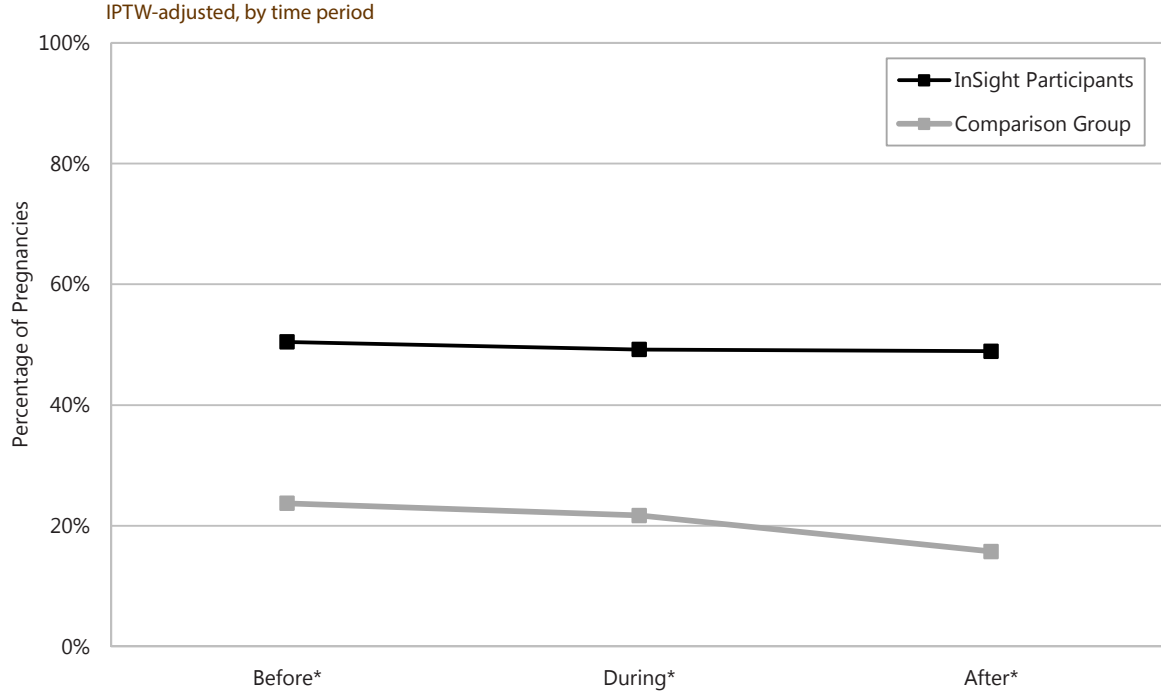
- a significant increase in the percentage living in social housing during the program (results could not be interpreted after program exit due to lack of data); and
- no significant differences in the percentage of months on IA, receipt of the prenatal benefit, or Healthy Baby community-support-group participation between any time periods.

Figure 6.24: Adjusted Participation Rates for the Healthy Baby Program (Prenatal Benefits), InSight Participants and Comparison Group



- No significant difference in the change over time ($p=0.517$).

Figure 6.25: Adjusted Participation Rates for the Healthy Baby Program (Community Support Groups), InSight Participants and Comparison Group



- No significant difference in the change over time ($p=0.380$).

Table 6.21: Adjusted Relative Risks for Social Services Use for InSight Participants: by Time Period

IPTW-adjusted percentages, 95% confidence intervals

	Before	During	After
Income Assistance*	0.87 (0.55-1.37)	1.12 (0.77-1.63)	1.46 (0.98-2.17)
Resident in MB Housing	1.54 (1.04-2.30)	1.80 (1.43-2.26)	N/A
Prenatal Benefit**	1.21 (1.11-1.33)	1.26 (1.12-1.43)	1.35 (1.13-1.61)
Community Support Groups**	2.13 (1.60-2.82)	2.27 (1.52-3.37)	3.11 (1.98-4.89)

Bold indicates statistical significance for that time period (InSight vs. comparison group)

Reference: comparison group

N/A: valid data was unavailable at this time period

*Percentage of months receiving

**Percentage of pregnancies

Timing in relation to program delivery

In the adjusted outcomes, relative to the comparison group, the InSight participants demonstrated:

- a higher relative rate of social-housing use before the program, with a further relative increase during the program;
- no differences before or during the program for the proportion of months on IA, but a trend towards an increased relative percentage after program exit; and
- an increased use of the Healthy Baby prenatal benefit and participation in community-support programs across all time periods.

What these Findings Mean

Our findings show an increase in the use of social housing during the program in both groups, with a trend towards an increasing relative difference over time. The difference in the change over time was not significant, possibly due to our small sample size. These findings suggest that the InSight program may have helped women access social housing at greater rates than women who were not in the program. Further analysis with a greater number of participants would be helpful. Moreover, incomplete data meant that we were unable to look at how patterns change once the program ends.

For IA we see different patterns over time. InSight participants received IA in a greater proportion of months over time while the comparison group remained relatively constant in their receipt of IA. InSight participants are more vulnerable than the women in the comparison group; goals of the program include consistent receipt of IA, with long-term transition to other income sources.

For Healthy Baby support programs, the important findings are a very high rate of both receipt of the prenatal benefit and of participation in the community support programs prior to program entry. This represents good uptake in this target population, especially for the prenatal benefit.

6.6: Neonatal Outcomes

Studying the outcomes of children born to women in the InSight program is complicated by the different trajectories of these children's lives. Many children are involved with the child welfare system or, while remaining legally within the custody of their mothers, are primarily parented by family members, partners, or the extended community. Due to the relatively small number of children available for study during and after the program, as well as the difficulty in identifying the many other variables affecting outcomes, we could not assess the impact of these different situations. We have chosen instead to focus on neonatal outcomes, as these are affected by the maternal environment during pregnancy. Our InSight participants were at very high risk for poor pregnancy and neonatal outcomes due to risks associated with alcohol use, low socioeconomic status, and inadequate prenatal care.

Neonatal Indicators

Preterm Births: Preterm births, even as they approach term, are associated with higher morbidity and mortality, and care of these infants requires significant healthcare resources. Preterm births are defined as infants born at less than 37 weeks gestation. This information is taken from the maternal delivery record. Manitoba's preterm delivery rate is 7.8%. It is higher in lower-SES groups (Heaman et al., 2012). At baseline the InSight participants' preterm delivery rate was 10.4%, versus 8.0% in our comparison group.

Size for Gestational Age: Infants are small for gestational age (SGA) for multiple reasons, including poverty and poor maternal nutrition. These infants experience higher morbidity and mortality, including long-term neurodevelopmental deficits. Infants can be born large for gestational age (LGA) for multiple reasons, of which maternal diabetes and obesity are common. These infants are at higher risk for difficulties at delivery and in the neonatal period. Size for gestational age was defined using birth weight, gestational age, and sex assigned at birth, set at the 10th and 90th percentiles (Kramer et al., 2001). In Manitoba SGA rates are 7.3% and LGA rates are 15% (Heaman et al., 2012). Rates of SGA were 12.1% for InSight participants and 11.4% for the comparison group at baseline. Rates of LGA were 15.2% for the InSight participants and 12.4% for the comparison group at baseline.

Breastfeeding Initiation: Breast milk has been demonstrated to be the best form of nutrition for almost all infants; public-health and hospital-based efforts are underway to improve breastfeeding initiation (Manitoba Health, 2015). Breastfeeding and skin-to-skin care around the time of delivery has other benefits, including improved temperature regulation, neonatal transition, and blood-sugar regulation. Breastfeeding initiation is also strongly associated with SES; lower-SES groups have lower rates. Breastfeeding-initiation rates at the population level in Manitoba are approximately 80% (Heaman et al., 2012). Breastfeeding initiation is taken from the neonatal delivery record and includes both exclusive breastfeeding and mixed feeding practices. The InSight participants initiated breastfeeding in 56.5% of births at baseline, versus 62.2% in the comparison group.

Admission to the Neonatal Intensive Care Unit: Infants requiring a higher level of care at birth than can be provided in current mother-baby units are admitted to a neonatal intensive care unit (NICU). Common reasons include preterm birth, respiratory disorders, and in this population, drug or alcohol exposure in utero, as some infants require monitoring for neonatal abstinence syndrome. In Manitoba the rate of NICU admission is 9.1% and there remains a small effect of low SES once other associations are controlled for (Ruth, Roos, Hildes-Ripstein, & Brownell, 2012). At baseline, babies born to InSight participants were admitted to an NICU 20.8% of the time, versus 11.7% in the comparison group. Results are only available from 2004/05 onwards due to differences in how the data were collected in earlier years.

Key Findings: Unadjusted Outcomes

Table 6.22: Unadjusted Rates of Neonatal Outcomes for InSight Participants

Percentages, by time period

	Before	During	After
Preterm Births	10.39	11.59	16.42
Small for Gestational Age	12.05	10.22	14.93
Large for Gestational Age	15.18	18.98	17.91
Breastfeeding Initiation	56.53	44.74	56.52
Neonatal Intensive Care	20.81	15.00	22.39

Timing in relation to program delivery

**Table 6.23: Unadjusted Relative Risks for Neonatal Outcomes for InSight Participants:
Time-Period Comparisons**
95% confidence intervals

	During vs Before	After vs Before	After vs During
Preterm Births	1.12 (0.65-1.91)	1.58 (0.89-2.82)	1.42 (0.70-2.87)
Small for Gestational Age	0.85 (0.51-1.41)	1.24 (0.72-2.14)	1.46 (0.76-2.80)
Large for Gestational Age	1.25 (0.83-1.87)	1.18 (0.66-2.11)	0.94 (0.51-1.74)
Breastfeeding Initiation	0.79 (0.67-0.93)	1.00 (0.83-1.20)	1.26 (1.03-1.56)
Neonatal Intensive Care	0.72 (0.42-1.23)	1.08 (0.59-1.97)	1.49 (0.78-2.87)

bold indicates statistical significance for that time period

Timing in relation to program delivery

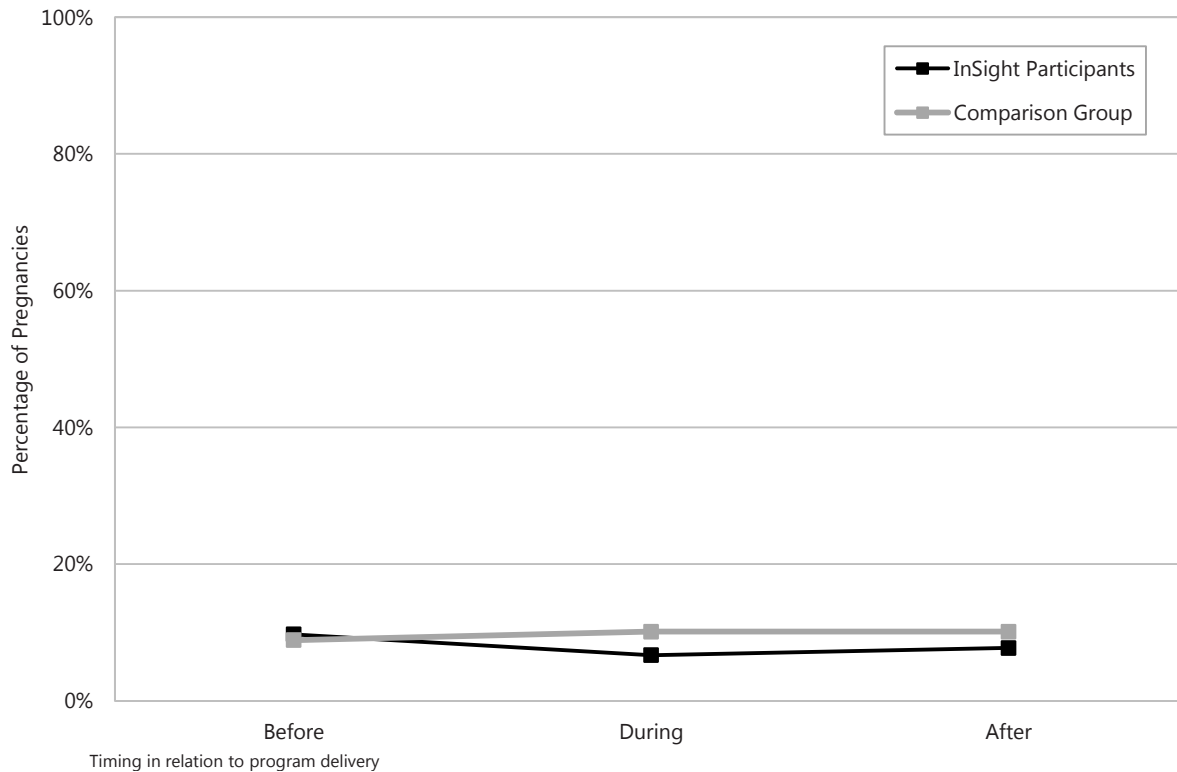
The infant was assigned to a time period using the pregnancy start date; results are presented as the percentage of total live births. Results should be interpreted with caution as the numbers are low; at most there were 138 infants in the during program period and 67 infants in the after program period for the InSight participants.

When compared as a group to themselves over time the InSight participants demonstrated:

- a significant decrease in breastfeeding initiation during the program compared to the period before the program, and a return to baseline after the program;
- a trend towards a higher preterm-birth rate after the program compared to before; but
- no significant differences when any time periods were compared for preterm-birth rates, LGA or SGA, or NICU admissions.

Key Findings: Adjusted Outcomes

Figure 6.26: Adjusted Rates of Preterm Births, InSight Participants and Comparison Group
IPTW-adjusted, by pregnancy start date



- No significant difference in the change over time for preterm births (p=0.355)

Table 6.24: Adjusted Relative Risks for Neonatal Outcomes for InSight Participants: by Time Period
IPTW-adjusted percentages, 95% confidence intervals

	Before	During	After
Preterm Births	1.09 (0.73-1.64)	0.66 (0.32-1.36)	0.77 (0.33-1.75)
Small for Gestational Age	0.95 (0.64-1.40)	0.95 (0.46-1.95)	1.03 (0.44-2.40)
Large for Gestational Age	0.96 (0.68-1.35)	1.12 (0.53-2.35)	1.57 (0.72-3.42)
Breastfeeding Initiation	1.13 (0.90-1.41)	0.76 (0.59-0.97)	1.14 (0.92-1.43)
Neonatal Intensive Care	1.36 (0.84-2.21)	1.41 (0.60-3.28)	1.03 (0.49-2.16)

bold indicates statistical significance for that time period (InSight vs. comparison group)

Reference: comparison group

Timing in relation to program delivery

In the adjusted outcomes, relative to the comparison group, the InSight participants demonstrated:

- a decreased rate of breastfeeding initiation during the program that did not persist after program exit; but
- no difference in relative risk for any other outcomes in this section.

What these Findings Mean

Some of these factors are amenable to the influence of InSight mentoring—for improved uptake of prenatal care and other healthcare services, connection to social programs (see Section 6.5), nutrition habits including diet and control of co-existing medical conditions, and reductions in alcohol and other substance use—others are harder to influence. Because of the small effect of each risk factor, many changes and a larger sample would be required to demonstrate differences.

Interpretation of the results for premature birth and SGA is limited by the small sample size. It is unclear whether gains in these areas could be demonstrated with a larger sample and with greater ability to study and control for other maternal issues such as diabetes and hypertension.

The results for breastfeeding initiation include a decreased rate for InSight participants during the program. The implication of this finding is uncertain without further study. Possible positive reasons for this change may include reducing substance exposure via breast milk in women continuing to consume alcohol or other substances, or to allow bottle feeding, thus simplifying alternative child-care arrangements. It is also possible that during the program women disclosed their substance use more appropriately and were discouraged from breastfeeding (appropriately or inappropriately, depending on the situation). High rates of CFS involvement at birth are also found in this population, and may affect early feeding practices (see Section 6.7).

6.7: Children's Outcomes

As mentioned in the previous section, studying the outcomes of children born to InSight participants is complicated. Social and educational outcomes, which are influenced by the postnatal environment, require accounting for other factors such as custody and placement, as well as other sociodemographic influences. Furthermore, sufficient follow-up time after birth is required to examine many social and educational outcomes. Outcomes resultant from pregnancy conditions, such as diagnosis of FASD, are limited by sample size, and compounded by the need for the children to be of preschool age. Thus we have chosen to focus on services provided to the children and their families, including need for child protective services.

Indicators for Children's Outcomes

To make discussion easier, children born to InSight participants will be referred to as the InSight group and children born to women in the comparison group will be referred to as the comparison group.

Child and Family Services (CFS) involvement

Taken into CFS Care at Birth: When potential risks to child safety and protection are identified before birth, CFS may determine that the infant should be taken into care once delivered. These children are often taken into care during the hospital birth stay. We have defined this as within the first 72 hours of birth. The pregnancy is assigned to a time period based on the pregnancy start date and the indicator is reported as the percentage of live births during that time period. Before the InSight program, 15.3% of infants born to participants were taken into care within the first 72 hours, versus 4.1% of infants born to women in the comparison group.

Ever in CFS Care: Children requiring protective services through CFS have many different patterns of involvement with CFS. Some children have only one episode of care and others have multiple episodes (Brownell M, Chartier M, Au W, MacWilliam L, Schultz J, Guenette W, Valdivia J, 2015). For simplicity, because we do not have the sample size required to examine complex patterns, we report on the percentage of children in each time period who have ever been taken into care. This indicator is calculated by grouping the children into a time period by pregnancy start date and then reporting the percentage of those children ever taken into care (regardless of when the care episode occurred). This indicator is only available from 1992 onwards due to data issues in earlier years. Before the program 81.2% of children born to InSight participants had at least one episode of care, versus 33.9% of the children born to women in the comparison group.

Fetal Alcohol Spectrum Disorder (FASD) Clinic Assessments and Diagnosis

Assessed for FASD: The Manitoba FASD Centre is a clinic affiliated with the Winnipeg Children's Hospital that provides expanded services for assessment, education, training and research in the area of FASD. It provides services to approximately 130–180 Manitobans per year. Their clinic database has been incorporated into the Repository, with data available from 1999 onwards. We report the percentage of children assessed for FASD. This percentage was calculated as the number of children assessed in a time period divided by the total number of children who were not previously assessed. The rate of assessment for the InSight group was 2.1% before the program, versus 1.1% in the comparison group.

Key Findings: Unadjusted Outcomes

Table 6.25: Unadjusted Rates of Children's Outcomes for InSight Participants

Percentages, by time period

	Before	During	After
Taken into CFS Care at Birth	15.26	24.09	25.37
Ever in CFS Care	81.24	71.53	64.18
Ever assessed for FASD	2.13	5.35	4.12

CFS refers to Child and Family Services

FASD refers to Fetal Alcohol Spectrum Disorder

Timing in relation to program delivery

Table 6.26: Unadjusted Relative Risks for Children's Outcomes for InSight Participants: Time-Period Comparisons

95% confidence intervals

	During vs Before	After vs Before	After vs During
Taken into CFS Care at Birth	1.58 (1.13-2.21)	1.66 (0.99-2.78)	1.05 (0.61-1.82)
Ever in CFS Care	0.88 (0.79-0.99)	0.79 (0.66-0.95)	0.90 (0.73-1.10)
Ever assessed for FASD	2.51 (1.32-4.78)	1.94 (1.00-3.76)	0.77 (0.49-1.22)

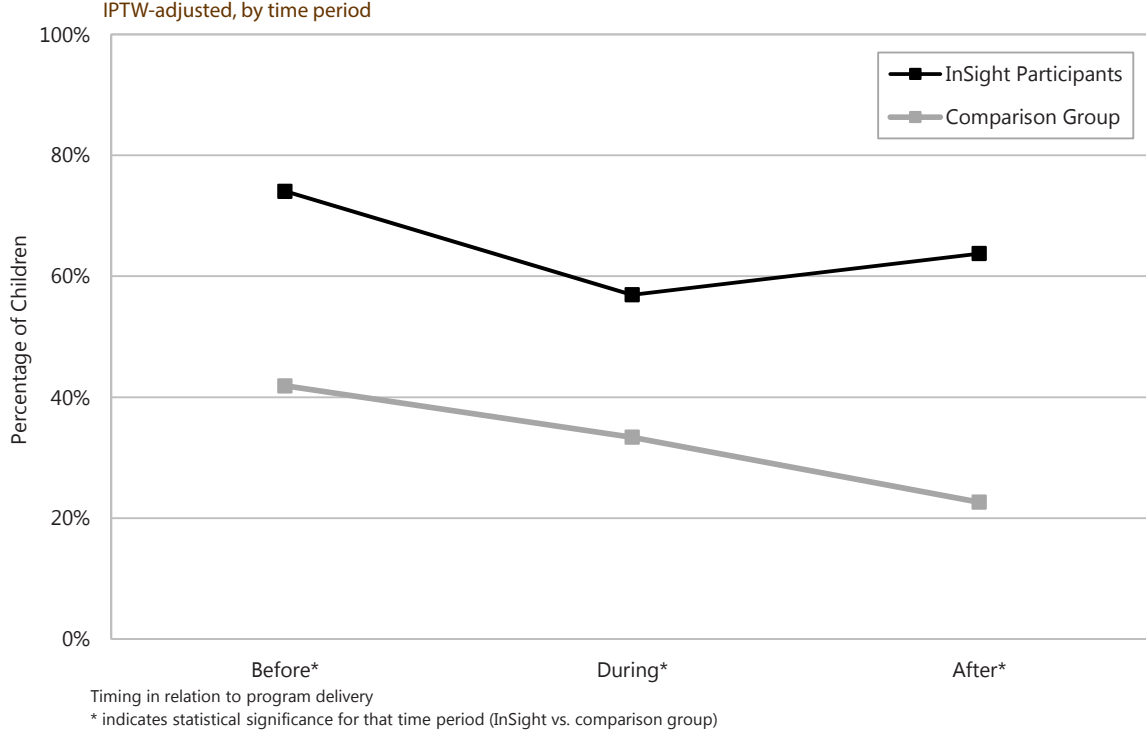
bold indicates statistical significance for that time period

CFS refers to Child and Family Services

FASD refers to Fetal Alcohol Spectrum Disorder

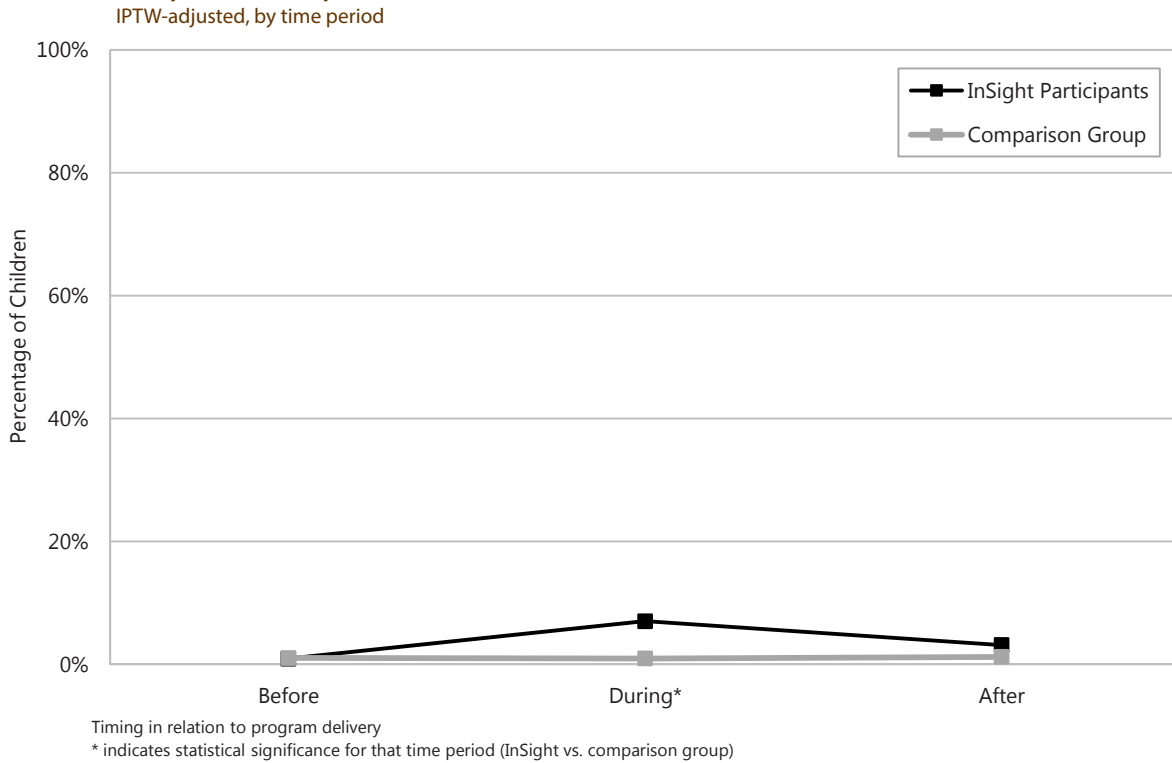
Timing in relation to program delivery

Figure 6.32: Adjusted Rates of Children Ever Taken into CFS Care, InSight Participants and Comparison Group



- No significant difference in the change over time for FASD assessments (p=0.267).

Figure 6.33: Adjusted Rates of Children Ever Assessed for FASD, InSight Participants and Comparison Group



In the adjusted outcomes, relative to the comparison group, the InSight group demonstrated:

Table 6.27: Adjusted Relative Risks for Children’s Outcomes for InSight Participants: by Time Period

IPTW-adjusted percentages, 95% confidence intervals

	Before	During	After
Taken into CFS Care at Birth	2.07 (1.07-4.01)	2.52 (1.12-5.66)	2.57 (1.23-5.36)
Ever in CFS Care	1.77 (1.67-1.87)	1.71 (1.50-1.94)	2.82 (2.32-3.42)
Assessed for FASD	0.88 (0.22-3.42)	7.62 (4.26-13.64)	2.60 (0.90-7.48)

bold indicates statistical significance for that time period

CFS refers to Child and Family Services

FASD refers to Fetal Alcohol Spectrum Disorder

Reference: comparison group

Timing in relation to program delivery

- higher rates of infants taken into care at birth and children ever taken into care, across all time periods (this difference increases over time due to a greater drop in rates in the comparison group); and
- a higher rate of FASD assessments during the program and a trend towards a higher rate after program exit.

What these Findings Mean

The patterns of findings for children taken into care at birth, both over time and relative to the comparison group, suggest an impact of the InSight program despite outcomes remaining quite discrepant in the two groups. Children taken into care at birth represent those deemed to be at highest risk and this only changes during the program for our InSight participants. This suggests that the InSight program increases recognition or disclosure of circumstances at birth that put children at risk. The return to baseline afterwards may represent either a net improvement in the situation or a decreasing recognition of risk—we do not have the sample size or indicators available to discriminate. It is also possible that this change represents unaccounted confounding variables, as the rates were discrepant between program participants and the comparison group even in the period before InSight. The interaction term for pattern difference is not significant; however, this is likely related to sample size.

Both groups show decreases over time in children ever taken into care, but there is a difference in the change over time that is consistent with a program effect. However, the groups were not similar in the period before InSight, despite adjustment, which means the difference could be an effect of confounding variables that were not taken into account. Among the InSight group we see a significant decrease in children ever in care during the program, when connection to services and surveillance bias would be the highest. This suggests that the slower rate of decrease (relative to the comparison group) is not due to increased recognition of child-welfare concerns but due to the program itself. Historically, children born to women similar to the InSight participants tend to continue to have children taken into care throughout their reproductive years (J. Isbister, written communication, December 2014), which makes the hypothesis that this change is evidence of a program effect.

These results suggest that the InSight program is associated with an increased assessment rate for FASD, which reflects connection to services. These are not rates of FASD itself; this indicator describes service provision and is affected by referral bias, especially of children in care of CFS. It does not reflect population rates of FASD (Astley, 2004; Astley, Stachowiak, Clarren, & Clausen, 2002). However, despite decreasing rates of children being taken into care during the program, we see higher rates of assessment, suggesting an impact of the InSight program .

CHAPTER 7: CONCLUSIONS AND RECOMMENDATIONS

This report represents a first look at the InSight data and their utility for examining the health and social outcomes of a vulnerable population of women. For many outcomes, sample sizes were inadequate to draw firm conclusions about the impact of the InSight program. The sample size was limited particularly by the lack of maternal PHINs recorded, and data quality in the InSight database. In this chapter we summarize our findings as they address the objectives outlined in Chapter 1.

Objective 1: What are the Characteristics of the InSight participants?

The vulnerability of the participants in the InSight program was confirmed by findings of multiple unmet needs and risk factors for poor health and social outcomes, including:

- low age at initiation of alcohol use, and alcohol-use patterns both during pregnancy and outside of pregnancy;
- high rates of mental disorders and use of mental health services; and
- poor connection to social services (the exception was the Healthy Baby Prenatal Benefit and community support programs, to which participants were well-connected).

These findings confirm that the InSight program is reaching the vulnerable population it was intended to reach. Because of the missing PHINs, our evaluation did not include the entire population of women who participated in the InSight program. However, as shown in Chapter 4, the sample of participants we studied did not differ from the InSight participants who were not included in the study across most characteristics. Therefore, our findings may be generalized to all InSight participants.

Key Message: InSight participants represent a highly vulnerable population not adequately connected to social services. This program is reaching the population it was intended to reach.

Objective 2: In the InSight Database, What Impact can be Seen on Outcomes Important for FASD Prevention?

Key outcomes important for the prevention of FASD were reported from the InSight database, including the following:

- During the InSight program and at exit, participants had lower alcohol use and higher rates of abstinence.
- The majority of InSight participants achieved at least six months of abstinence during the program.
- Differences in question structure for alcohol use in pregnancy make comparisons difficult, but the findings suggest that the percentage of women reporting low-risk or no alcohol use was higher in subsequent pregnancies during the program compared to the target pregnancy.
- Use of reliable contraception increased during the program.
- Identification of needs for, and connection to social services increased.

Key message: The InSight program had a significant impact on its key focus areas during the program.

Objectives 3 and 4: How do the Long-Term Outcomes of InSight Participants and their Children Compare to those for Women and Children who did not Participate in the Program?

Differences between InSight participants and the comparison group were analyzed in multiple ways over the periods before, during and after the program. Where differences were found, they could represent change secondary to the passage of time, an impact of the program, or differences between the two study groups that could not be accounted for in the current data. Often it was difficult to clarify the reasons for changes due to issues with sample size, and difficulty identifying a comparable comparison group.

We looked for statistical differences in the pattern of change over time between InSight participants and the comparison group over all three periods (before, during, and after). A significant result in these comparisons provides strong evidence of a program effect. We also looked for statistical differences between InSight participants and the comparison group at each time period and, for the InSight participants, between time periods (e.g. during vs before). Significant differences in these comparisons provide moderate evidence of a program effect; they could also be due to confounders—as noted above—or the passage of time itself.

Statistically significant differences were observed in one or more of these comparisons for:

- **Physician Visits and Hospitalizations:** InSight's aim is to increase physician visits and decrease hospitalizations for its high-risk clientele. This effect is seen during the program but is not sustained after program exit.
 - Rates of all hospitalizations (excluding pregnancy), all mental health hospitalizations, and all injury hospitalizations showed a different change over time. Rates decreased during the program then increased after program exit in the InSight participants, while continuing to decrease in the comparison group.
 - Rates of all physician visits (excluding pregnancy) showed a different change over time. Rates were lower and did not increase as quickly over time for the InSight participants.
- **Income Assistance (IA):** In this highly vulnerable population it is not reasonable to expect full transition off of IA. InSight participants demonstrated increased use over time, which can be seen as beneficial in that it increases financial security.
 - The comparison group's use of IA was relatively stable over time.
- **Use of Contraception:** A goal of the program was to empower participants to make informed choices about their contraception use. This goal was achieved as live birth rates approached equivalence in the period after program exit.
- **Prenatal Care:** InSight participants demonstrated the largest gains during the program in uptake of prenatal care, with improved rates relative to the comparison group. However, these gains were lost after program exit. These results strongly suggest a beneficial program impact, though one which does not persist after the program is removed.
 - Receipt of prenatal care, as measured with multiple indicators, increased during the program relative to the comparison group. The relative improvement was not sustained after program exit.
 - The largest improvement was seen for the percentage of InSight participants, relative to the comparison group, initiating prenatal care in the first trimester.
 - A decrease in breastfeeding initiation was observed during the program among InSight participants, which may indicate an appropriate clinical decision for women who continue to use substances, or may indicate inappropriate stigmatization or discouragement of women from breastfeeding. Breastfeeding-initiation rates after program exit were similar to those before.

- CFS Involvement: Patterns of having children taken into care of CFS revealed mixed results, which require further investigation. Higher rates of infant apprehension (in the first 72 hours) may be reflective of greater identification of high-risk situations or surveillance bias. Lower rates of having children taken into care after that period may represent greater ability of the InSight participants to parent safely.
 - InSight participants had higher rates of CFS involvement in all periods, despite adjustment.
 - Participants had higher rates of infant apprehension (in the first 72 hours) during the program compared to before and after.
 - Participants had lower rates of children taken into care during the program.
 - Rates decreased over time in both groups, however the rate of decrease was less for InSight participants.
 - Rates of smoking during pregnancy were higher and remained stable for InSight participants while decreasing for the comparison group.
- Social Isolation: Higher rates of social isolation were observed for InSight participants in all periods, and increased over time in the unadjusted outcomes. This merits attention in planning both program delivery and post-program support.
- Use of Alcohol in Pregnancy: Alcohol use in pregnancy was assessed using multiple indicators. Results suggest decreased use of alcohol during pregnancy for InSight participants, but analysis of this sample could not confirm it. The differences that remain between the groups in the period before the program despite statistical adjustment highlight the difficulty in achieving a fair comparison.
 - Rates were higher for InSight participants relative to the comparison group across all periods and indicators.
 - There were trends towards equivalent rates due to lower use in the InSight participants on some indicators during and after the program.
 - Significantly higher relative differences in high-risk alcohol use before pregnancy were observed for the periods before and during the program, with no relative difference after program exit (i.e., rates became similar to the comparison group).
- FASD Assessment: Increased assessment rates for FASD in the children born to the InSight participants is an important outcome due to the ability to then provide appropriate interventions for these children to optimize their outcomes.
 - The rates for children of the InSight participants increased and thus were higher than those of the comparison group in the during period. The rates decreased again in the after period, but trended towards remaining higher relative to the comparison group. Numbers are low overall due to capacity of the assessment clinic.
- Families First Screening: High rates of FFS in this population is positive because these are opportunities to identify families in need of support.
 - FFS rates for the InSight participants did not change over time; however, there was a trend toward higher rates relative to the comparison group in the period after the program.
- Use of Social Housing: Good connection to social housing was demonstrated.
 - An increase was observed for InSight participants during the program (compared to before), and a relatively higher rate than the comparison group was observed before and during the program. Data issues precluded a comparison of the period after the program.
- Participation in the Healthy Baby Program: InSight participants had higher uptake of the Healthy Baby prenatal benefit and the pre- and post-partum community support groups in all periods relative to the comparison group. No changes were observed between time periods for the InSight participants.
- Diagnosis of a Mood or Anxiety Disorder: Increasing rates of mood or anxiety disorder diagnoses over time may reflect improved connection to services (since this indicator measures treatment prevalence) or a true increasing incidence.
 - Trends toward increasing rates of mood or anxiety disorder diagnoses over time were observed for InSight participants, whose rates remained higher in all periods relative to the comparison group.

Key Messages: Improved or stable connection to many services was observed among the InSight participants; however, for some this did not persist after program exit. Some findings require further interpretation within the context of participants' goals and individual circumstances.

Our ability to interpret results related to the use of alcohol and other substances in pregnancy was limited by sample size.

Despite the employment of sophisticated statistical techniques to ensure the groups appeared similar at baseline, differences between the InSight participants and the comparison group persisted; therefore, observed differences over time and between groups could be due to the program or to confounding variables that were not taken into account.

Recommendations

The authors of this study recommend the following:

1. Extend the program in length, or develop a step-down program for participants exiting InSight to help sustain gains. The lack of continuing effect in the areas below suggests that the participants have not yet developed their own support strategies and remain dependent on their mentor for support. This is supported by:
 - a. gains demonstrated when measured at program exit;
 - b. gains in prenatal care that were lost after program exit;
 - c. the suggestion of increased social isolation after program exit;
 - d. the suggestion of less high-risk alcohol use prior to pregnancy and less use during pregnancy
2. Increase the program's ability to help participants identify and seek treatment for disabilities that require ongoing support, such as FASD. It may be unrealistic to expect all participants to sustain changes without external support. This recommendation arose from a discussion of the study results with our advisory group.
3. Re-evaluate the program in the future to test the hypotheses of improvements in other areas that were seen in this evaluation. Specifically, a repeated evaluation would benefit from:
 - a. a larger sample size due to both program expansion and elapsed time, and more data for longer follow-up, especially for studying the outcomes of children;
 - b. improved collection of participant start and exit dates;
 - c. possible inclusion of women who were eligible for the InSight program, and for whom we have some basic information (such as the PHIN), but who declined to enrol or were only briefly enrolled (these women could serve as a comparison group); and
 - d. use of data forms currently under development which address many of the issues outlined in this report.

This evaluation has used multiple sources of information to show outcomes for InSight participants and their children, covering the periods before, during, and after program participation. It is a first look at previously unrecorded outcomes in a vulnerable population, and has generated several hypotheses for future study. Future evaluation of this program would benefit from a mixed-methods analysis that includes both qualitative and quantitative aspects and incorporates more detailed characteristics of the participants themselves and how they relate to outcomes. Further analysis may include the health status of the participants, particularly whether they have FASD themselves, or evaluation with attention to cultural factors. With the ability to link outcomes to participants' individual goals, or the ability to study the trajectory of individual participants over time, a better understanding of the program's successes could be reached.

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APPENDIX

Appendix Table 1.1: Technical Definitions of Indicators used to Measure Long-Term Outcomes (Chapter 6)

Indicator	Definition	Exclusions
A. Healthcare use		
1. Physician visits		
	For all ambulatory physician visit measures, rates were calculated per person-year: <i>InSight group:</i> Visits within 3 year period before entering InSight and up to 3 years after exiting InSight. <i>Comparison group:</i> Visits from 3 years before the "target" child's birth up to 6 years after the birth.	Pregnancy related visits: prenatal care (tariff codes: 8400, 8401, 8501, 8507, 8509, and 8540), ICD-9-CM codes which suggested a pregnancy: 640-648, 650-669, V22 or V23 (the last two must also have been accompanied with a "prefix" value of '7').
All visits		Pregnancy-related visits
Mental health	Visits with any diagnosis code from chapter 5 of the ICD-9-CM code book.	Pregnancy-related visits
Other		Mental health & pregnancy-related visits
2. Hospitalizations		
	For all hospitalization measures, rates of inpatient hospital episodes were calculated (i.e transfers within the same hospitalization are not counted as separate events) per 1000 person-years: <i>InSight group:</i> Only hospitalizations which occurred within 3 years of entering InSight and up to 3 years after leaving InSight were counted. <i>Comparison group:</i> Hospitalizations from 3 years before the "target" child's birth up to 6 years after the birth were included.	Pregnancy related hospitalizations: ICD-9-CM codes which suggested a pregnancy: 640-648, 650-669, V22 or V23.
All hospitalizations		Pregnancy related hospitalizations
Mental health	All primary diagnoses from chapter 5 of the ICD-9-CM or the ICD-10-CA code book	Pregnancy related hospitalizations
Injury	ICD-9-CM: all diagnoses with an E-code in any of the up to 16 recorded diagnosis fields. ICD-10-CA: all diagnoses in any of the up to 25 recorded diagnosis fields with a value of "V01" - "V89".	Pregnancy-related hospitalizations; E-codes: 1. Misadventures during Surgical or Medical Care (ICD-9-CM: E870-E876 (or eclass=10), ICD-10-CA: Y60-Y69, Y88.1); 2. Reactions or Complications due to Medical Care (ICD-9-CM: E878-E879 (or eclass=11), ICD-10-CA: Y70-Y84, Y88.2, Y88.3); 3. Adverse Effects due to Drugs (ICD-9-CM: E930-E949 (or eclass=18), ICD-10-CA: Y40-Y59, Y88.0).
Other		Mental health, injury, & pregnancy-related hospitalizations.
B. Pregnancy & Prenatal care		
1. Birth rates		
	For all birth measures: births were assigned to a time period based on the pregnancy start date, not the birth date. Only includes births in Manitoba hospitals. Measured per 100 person-years.	
Live birth	All babies born alive	
Non-live birth	Includes stillbirths, therapeutic and spontaneous abortions and nonviable pregnancies (such as molar pregnancies).	
2. Prenatal care		
	Physician tariff codes used in all prenatal measures: 8400, 8401, 8501, 8507, 8509, 8529, 8540, and 8550.	
Prenatal care in first trimester	Percent of pregnancies for which the first prenatal visit occurred during the first 13 weeks of pregnancy.	Women receiving prenatal care from a midwife, cases missing values for either prenatal care or trimester of first prenatal visit.
Adequate prenatal care	Percent of women who were pregnant and who received adequate prenatal care according to the Revised-Graduated Prenatal Care Utilization Index (R-GINDEX; see MCHP concept dictionary for complete details).	
Hepatitis B serology testing in first trimester	Percent of pregnancies for which women had Hepatitis B serology test results during the first trimester. From the CADHAM lab data if variable serologytest = 'HBSAG', 'HPHBS', 'AHBS', 'AHBCT', 'AHBCG', 'HBEG', 'AHBEA', 'AHBCM', 'HBVN', 'HBVL', 'HBVD', 'HBVVL', 'HBVGT', 'HPAHB'.	
C. Substance use in pregnancy		
1. Smoking during pregnancy (FFS)		
	Percent of women with an FFS who had a live birth and who reported smoking during pregnancy (on the FFS).	
2. Alcohol use		
Alcohol use in pregnancy	Percent of women with an FFS who had a live birth and for whom alcohol consumption during pregnancy was reported on either the FFS (self-report) or the hospital discharge abstract.	Cases where the variable was missing in the data set; stillbirths.
Alcohol use in pregnancy, none (FFS)	Percent of women with an FFS who had a live birth and who reported consuming alcohol during pregnancy (on the FFS).	Cases where the variable was missing in the data set; stillbirths.
Alcohol use in pregnancy, none or low risk use (FFS)	Please see Appendix Table 1.2.	
Alcohol use prior to pregnancy, high risk (FFS)	Please see Appendix Table 1.2.	

Appendix Table 1.1: Continued

Indicator	Definition	Exclusions
D. Mental Health		
1. Receipt of the Families First Screen (FFS)	Percent of pregnancies, by pregnancy start date, in each time period that can be linked to an FFS. <i>Note:</i> The FFS started in Manitoba in 2004/05 with changes / additional information being collected starting in 2007/08. FFS not given to women living on reserve. For more details see the FFS entry in the MCHP Concept Dictionary.	
2. Peripartum social isolation (FFS)	Of the women who received an FFS, the percent of pregnancies with a 'yes' response to the FFS question about social isolation due to lack of social support, culture, language or geographical issues.	Cases where the variable was missing in the data set; stillbirths; out of province births.
3. Mood & anxiety disorders	Percent of women in each time period with the following: One hospital diagnosis: mood disorders (ICD-10-CA codes: F36, F33, F38, F38.1), stress and adjustment disorders (ICD-10-CA codes: F43,F43.2,F43.8), mental and behavioural disorders (ICD-10-CA codes: F53), emotional disorders (ICD-10-CA codes: F93) in three years; OR Three ambulatory visit diagnoses: mood disorders (ICD-9-CM codes: 296), reaction to stress and adjustment disorders (ICD-9-CM codes: 309), depressive disorders (ICD-9-CM codes: 311) in three years; OR One hospital diagnosis: anxiety disorders (ICD-10-CA codes: F40, F41, F41.1), depressive disorders (ICD-10-CA code: F32), mood disorders (ICD-10-CA code: F34.1), obsessive-compulsive disorders (ICD-10-CA code: F42), dissociative disorders (ICD-10-CA code: F44), somatoform disorders (ICD-10-CA codes: F45.0, F45.1) in three years AND at least one prescription for antidepressants and mood stabilizers (ATC codes: N03AB02, N03AB52, N03AF01, N06A) in three years; OR Three ambulatory visit diagnoses: anxiety disorders (ICD-9-CM code: 300) in three years AND at least one prescription for antidepressants and mood stabilizers (ATC codes: N03AB02, N03AB52, N03AF01, N06A) in three years.	
E. Connection to Social Services		
1. Receipt of Income Assistance	Percent of women who received IA at some point during each time period.	Federal income assistance to First Nations women living on reserve.
2. Resident in Social Housing	Percent of women who resided in Social Housing (directly managed by Manitoba Housing) at any point during any of the time periods.	
3. Healthy Baby Program participation	Percent of pregnancies, by time period (using pregnancy start date), for which women either received the prenatal benefit or participated in a community support group offered by the Healthy Baby Program.	
F. Neonatal		
1. Preterm births	Percent of pregnancies, by pregnancy start date, that resulted in an infant born at less than 37 weeks.	Stillbirths
2. Size for gestational age		
Large-for-Gestational Age (LGA)	Percent of live births, by pregnancy start date, with birth weight above the standard 90th percentile for their gestational age and sex using a Canadian standard (Kramer et al., 2001).	Stillbirths, multiple births, newborns with a gestation of less than 20 weeks, newborns with missing birth weights
Small-for-Gestational Age (SGA)	Percent of live births, by pregnancy start date, with birth weight less than the 10th percentile for their gestational age and sex using a Canadian standard (Kramer et al., 2001).	Stillbirths, multiple births, newborns with a gestation of less than 20 week, newborns with missing birth weights
3. Breastfeeding initiation	Live born newborns who were exclusively or partially breastfed at hospital discharge. A baby was considered to be breastfed at hospital discharge if the field NBFEEDNG (2001/02–2003/04), was equal to 1 or 3 (0 was excluded and 2 was coded as not breastfeeding at discharge) or if the field nwb_feed (2004/05–2008/09) was equal to 1 or 2 (3 and 4 were coded as not breastfeeding at discharge, 5 was excluded).	Stillbirths, birth records with missing breastfeeding fields
4. Neonatal intensive care unit (NICU) admission	A live born baby was considered to have a NICU admission if there was any admission to a NICU unit during the birth hospitalization (noted by the presence of coding 50 or 98). Limited to 2004/05 onwards due to coding changes that occurred in 2004/05.	Stillbirths
G. Children		
1. Child and Family Services (CFS) involvement		
Taken into CFS care at birth	Percent of live births for which the newborn was taken into care within 72 hours of birth. Reported for each time period (based on pregnancy start date).	
Ever in CFS care	Percent of children in each time period (by pregnancy start date) who were taken into care for at least 1 day at some point in the time period.	
2. Assessed for FASD	Percent of children born to mothers at any time and who were assessed at the Manitoba FASD Centre. It is calculated as the number of children assessed in a time period divided by the total number of children who were not previously assessed. Limited to children born prior to 2010 due to data availability at time of analyses.	

Appendix Table 1.2: Number of Drinks and Frequency of Drinking

Usual Frequency of Drinking	Usual Number of Drinks		
	1 to 2 or less	3 to 4	5 or more
Less than once per month	low risk	low risk	high risk
1 to 4 days per month	low risk	low risk	high risk
2 to 3 days per week	low risk	high risk	high risk
Greater than 3 days per week	high risk	high risk	high risk

Note: 1 drink = 1 beer or 1 wine cooler or 4 ounces of wine or 1 ounce of liquor

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