

Evaluating Manitoba's FASD Strategy

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DATA COLLECTION GUIDE

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Purpose of Guide

This Guide is meant to assist program staff in supporting Healthy Child Manitoba (HCMO)'s evaluation of the Provincial FASD Strategy. This guide provides the reader with an overview of the evaluation process and reasons that we evaluate programs and strategies. Also included is an overview of how privacy of individuals is protected as well as how the data itself is stored and collected.

Step-by-Step instructions about each evaluation form are provided as well as information outlining how and when to submit the forms to HCMO.

Although we have tried to be both as comprehensive, and as clear as possible, we know that there may be gaps in the information provided. Please provide us with your feedback so that we may periodically update this document thereby ensuring it is as useful as intended.

Key Contacts

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The Data Collection Process

Data collection tools will be paper based and program staff will be responsible for submitting the data to HCMO once collected. HCMO has been very careful to minimize the amount and frequency of data collected, focusing only on those indicators that provide the most amount of information with the least amount of intrusiveness.

Data collection will take place at two different times:

1. **At program entry: “Participant Welcome Form”.** To be used with only new program Participants and any program participants whose information was not collected previously. All participants (with support from their family or program staff if requested) fill in once for each program they attend.

HCMO will rely on Service Providers to ensure that the Participant Welcome Form data are collected and submitted on an ongoing basis. Many programs have staff who are already familiar with this form and the process for filling it out, keeping track of participant numbers on the spreadsheet described below, and submitting the data.

Spreadsheet for keeping track of participant numbers:

- Used a spreadsheet to track Participant (Provincial FASD Evaluation) Numbers that will be automatically assigned to the Participant at program entry. This number appears in blue at the bottom of the Participant Welcome Form.
 - An example of the spreadsheet is available in **Appendix A**. It is recommended that you set up something similar in excel to keep track of your Participant Numbers.
 - It is essential that programs keep track of all Participant Numbers as these may be used in the future to connect data to other Forms.
 - The Participant Number will also be used to track which paperwork has been completed and can be useful for scheduling the completion of the Forms.
 - Never send the spreadsheet, or the names of Participants to HCMO.
2. **Every September: “Service Provider Check-In Form”.** This is an annual "Check-In" form for Service Providers. These forms will always be filled out in September as September 9th is FASD Awareness day. The Forms do not have to be filled out on September 9th specifically. They can be filled out and sent into HCMO anytime from September 1st to December 10th each year depending on

what works best for the Service Providers. This form does not relate or refer to a specific program Participant, but is related to the Service Providers experience with the program they offer.

HCMO will remind all Service Providers about the Check-In form each September. HCMO will also mail out the forms to the Service Providers each September, and follow-up with programs as December approaches if data has not been submitted.

3. **Spreadsheet** (sample in **Appendix A**)

- Used to track the Participant Number that will be automatically assigned to the program Participant at program entry.
- It is essential that programs keep track of each client's Participant Number as it may be used in the future to connect data to other Forms.
- The Participant Number will also be used to track which paperwork has been completed and can be useful for scheduling the completion of the Forms.

Consent and Foster Parent Permission

Consent

Data for this Evaluation is being collected under the authority of *The Healthy Child Manitoba Act*. Written consent is not required from caregivers or program participants to use or link their data anonymously for the purposes of program evaluation. See Section 9.4 for further details about *The Healthy Child Manitoba Act*.

Even though there is no consent required, participation in the evaluation is still voluntary and participants should be assured of the privacy and confidentiality acts guiding the information they provide for the evaluation. See Section 9 for more information on collection of PHIN and Privacy Protection.

Foster Parent Permission from Child and Family Services

If you find that foster parents are hesitant in filling out the evaluation forms because they are not legal guardians of their foster children we have provided a letter of permission signed off by the CEOs of all the CFS Authorities. This permission letter has also been circulated to all CFS agencies.

It is not necessary to show every foster parent this letter, but if any foster parent feels he/she does not have legal authority to fill out the forms on behalf of their foster child, service providers can show or provide them with a copy of this foster parent permission letter. See **Appendix B** for the foster parent permission letter.

Key Instructions for All Forms

1. General rules for filling out Teleforms (note: Teleform is the name of the forms that we use at HCMO. A Teleform differs from a regular form in that they are set up to be read into our databases electronically. The little black squares in the corners of the forms let you know that you are working on a Teleform):
 - **Do not make photocopies of the Teleforms when you run out of forms.** Always request for new forms from HCMO. This is essential to good, clean, data collection.
 - **Pen MUST be used** – do not use pencil.
 - **Circles MUST be filled in completely** – do not use an ‘X’ or a ‘√’.
 - When filling in **Numbers** – **please print clearly and stay inside the squares** – the Teleform reader will not recognize anything that is printed outside of the designated circles and squares.
 - **Do not use cursive** (handwriting) on any section of the Teleform. When filling in any text response, **please print** clearly and stay inside the writing space provided.
 - When entering single digit numbers, use the “01”, “02” format.
2. General rules for submitting forms to HCMO data centre:
 - We ask that you **FAX** the Participant Welcome Forms to the HCMO data centre so that the Teleform system can receive them and automatically put them into the database. **Do not add a cover page** to any forms that you fax. **The Teleform reader at HCMO will not recognize a cover page.**
 - We ask that you **MAIL** the Service Provider Check-In Forms to the HCMO data centre where they will be manually scanned into the Teleform system. **When mailing out forms, ensure you make yourself a file copy.** This will help you know how many forms you mailed out and if the form goes missing in the mail you will be able to still provide HCMO with the file copy.
 - Submit all forms to HCMO within a timely manner; it is recommended that this occur within one week of form completion.

Data Collection, Protection and Use

How Information is Submitted

In general, information is provided to Healthy Child Manitoba Office (HCMO) through the use of Teleforms which are faxed (if only one page) or mailed (if more than one page) to the secure data centre. Using Teleforms means that this information is transmitted **electronically**, directly into the computer system at HCMO. There is no printing of the forms. This means that **the only people who see this information are the people who have been given authority by HCMO.**

To protect everyone's privacy, instead of providing any names or addresses to HCMO, **we use special code numbers** to identify both program sites and program Participants.

If a form is more than one page long, programs are encouraged to mail the forms instead of faxing. The forms are mailed directly to a designated secure data centre staff member. This staff member manually feeds the forms through the Teleform reader and then shreds the original paper form.

How We Keep Information Safe

After faxing or mailing copies, you protect the original paper forms (and HCMO shreds all mailed copies). You keep the forms secure at your offices in your own secure personal file. Keep the form at least for the duration that the participant is active in your program. On the other end of the fax line at HCMO, our staff protects the electronic information. Only a few select HCMO staff have access to the computer system which is located in a locked room at HCMO. **All of the information is coded in numbers (no names or addresses),** to provide another level of security for privacy. **At every step of the way, we keep everyone's information and their privacy safe and secure.**

What We Do With Information

Once we receive the electronic information in the HCMO computer system, we combine it all into one large set of information. This information is used for many important statistical purposes, all with one common goal: to learn more about people who need support and information offered through the programs that fall under the FASD Strategy.

What We Do Not Do With Information

We do NOT report information about individuals. We use only information about groups when preparing evaluations. We do NOT report information to anyone who is not supposed to see it.

How to Submit Forms

Check over the forms

It is good practice to do a quick check of the forms before faxing them: Are they filled out **properly, and as completely as possible**? This quick check saves time and work in the long run.

Fax in the Participant Welcome Forms

These "Teleforms," are specially designed for faxing directly into our computer system for data analysis. **You fax these Teleforms as you normally would fax any other document but DO NOT include a cover page.**

Ensure the forms are facing the correct way on the fax machine and send them to our fax number: **(204) 948-3768**

Mail in the Service Provider Check-In Forms

Some forms that are more than one page cannot be faxed to us due to concerns of pages "sticking" together as sometimes happens with fax machines. These forms must be mailed to us so that we can manually feed them through the Teleform scanner at HCMO. Before mailing the form it is good practice to **make a file copy** of the original form you are mailing to HCMO. This way you have a record of the form you mailed in case the original form gets missing in the mail. You can mail the forms in individually or in a batch (if you have more than one staff completing the form).

Mail these forms to:

FASD Strategy Evaluation

Healthy Child Manitoba Office (HCMO)

Attention: DATA CENTRE

3rd Floor- 332 Bannatyne Avenue

Winnipeg, Manitoba R3A 0E2

File the forms

After faxing or photocopying and mailing them off, **ensure the protection of the original paper forms** for the forms you faxed by filing them properly and securely.

You're done! Here's where the Teleform software takes over. It automatically processes the data on the fax you have just sent, verifies its accuracy, and transfers it into our computer database for compilation and statistical analysis. Gone is the need for data entry at every office, a significant savings in time, costs, and workload. Additional benefits include improved data entry accuracy, improved data tracking, improved ease of data storage, automation of forms, reduced paper costs, and reduced workplace stress.

Updating or Correcting Information

Note that forms can always be updated, even after you submit the form. Our Teleform system is set up to keep only the most recent version of a form with the same unique identifier (that is, if you send the form in again, the system will overwrite the previous information).

For example, if you find an error or if you receive new information (such as the PHIN wasn't provided originally), please enter the information onto the form and re-fax.

If you no longer have the form, or cannot update it for some other reason please contact the FASD Evaluation Coordinator at HCMO. We can manually update the Teleform information if needed.

Participant Welcome Form

1. See **Appendix C** for Teleform sample.
2. Start date: **July 2014**.
3. The questions on this form are to be answered in relation to the **Participant** (not in relation to the Caregiver or any other family members). The Participant may require assistance by Service Providers or a Caregiver in filling out the form – use your discretion in helping the participant to make this decision.
4. For **current/existing program Participants**: If feasible given program size and structure, a "Participant Welcome Form" should be completed for all active Participants in your program starting July 2014. This means that even if someone has been attending prior to July 2014, the Participant should complete the form as soon as possible.
5. For **new program Participants** as of July 2014: The Participant Welcome Form is considered an Intake Form and is to be filled out at the earliest possible convenience to the program staff and the participant/family, recognizing that sometimes the first visit does not lend itself to this kind of data collection.
6. This form must be filled out in addition to current processes. Regardless of the similarities that may exist between this form and your own program-specific Intake Forms, these questions must be asked in the way that they are presented on this form to ensure good data for the Provincial FASD Strategy. This form is not meant to replace current program-specific intake data collection, unless your program decides to use this form in replacement of your current process.
7. If Participant decides not to take part in the evaluation, simply complete the following three data points, and fax the form in to HCMO:
 - The circle marked "Decline" in the PROGRAM USE ONLY box at the top of the form (see next section, under Decline Indicator for more detail).
 - The date
 - The program code

Even if no further information is provided, it is essential that one Participant Welcome Form be submitted to HCMO for every Participant in your program. This is our way of tracking the number of participants in each program – regardless of whether or not they are involved in the evaluation. If forms are not submitted for some Participants, then the numbers of Participants in your program will be under-reported in the Provincial Evaluation.

Question by Question Instructions for the Participant Welcome form

Participant Welcome Form, Top Section:

NEW OR EXISTING PARTICIPANT

Moving forward, these forms will be completed by “NEW” Participants only. However, for new programs coming on board with the Provincial Evaluation, it is requested that Participant Welcome Forms are completed for all existing Participants as well (to the extent that your program deems this feasible).

Participant Welcome Form, Bottom Section:

DECLINE INDICATOR

This indicator is in small font in a box at the bottom middle of the form and looks like:

Program Use Only: ☐ D

Fill in the circle ONLY IF a Participant decides not to take part in the evaluation (the D beside the circle on the form stands for “Decline”). Be sure to also fill in the date, and the program code, and then send in the blank form to HCMO.

PARTICIPANT NUMBER

(bottom middle of form) – PRE-PRINTED in RED INK

This number will start with “**FS**” and will look like: **FS01234**

It is very important that you remember to write this number on each of the Participants’ other forms. There is a place on each Check-In and Exit Form to complete this. Without this number on each of the forms submitted, we have no way of knowing which data belongs to which participant.

You may want to start a Participant file with all forms together and write this Participant Number on each right away.

Develop and use an electronic spreadsheet (see Appendix A for an example) to keep track of Participant Numbers.

PROGRAM CODE

(bottom right of form)

Each program requires a unique code to identify both the program and the location of the program (if there is more than one location). The code will have two letters and two numbers. For example, if an Agency called “Healthy Together” offers its program at three different sites, then the Agency would have three different codes:

HT01

HT02

HT03

If you have a new program and/or your program is not included in the Appendix, please contact the FASD Evaluation Coordinator at HCMO for a new code.

Do not fax in forms without a program code as we will not know from which program the form belongs.

PROGRAM CODES as of June 27, 2018

Program/Agency	Program Site	Program Code
Family Support, Education & Counselling	Winnipeg	FS01
FASD Centre-Diagnostic Coordinators	Wellington Crescent, Winnipeg	FC01
	Brandon	FC02
	Brandon Rural	FC03
	Churchill	FC04
	Dauphin	FC05
	Pinawa	FC06
	Portage	FC07
	Selkirk	FC08
	Steinbach	FC09
	The Pas	FC10
	Thompson	FC11
FASD Outreach	Winnipeg	FO01
MKW	Selkirk	KW01
Spectrum Connections	Winnipeg	SC01
Stepping Out on Saturdays (SOS)	Winnipeg	SO01
	The Pas	SO02
	Thompson	SO03
Youth Justice Program	Winnipeg	YJ01
	The Pas	YJ02

PARTICIPANT START DATE

(bottom far right side of form)

This should be the date that the Participant entered your program. For existing Participants, please attempt to use the date of entry, or as closely as can be estimated. It is essential that the date of program entry be used so that duration of contact with programs can be calculated.

Complete clearly in the format of: DAY, MONTH, YEAR (dd|mm|yyyy)

Use all four digits for year. Keep numbers clear and within each box.

Numbered Section (Main Body of Participant Welcome Form):

1. PHIN (Public Health Information Number)

Required to be entered on these forms. This is the nine-digit individual number (NOT the family number which is only six digits).

If the Participant does not have the PHIN at the first visit, ask that it be brought on the next visit so that you can complete the form. Participants may opt to refuse to provide the PHIN, but program staff are required to make a reasonable attempt to obtain this information from the Participant.

If, after 3 months from starting program, the Participant has still not provided the PHIN, please fax in form.

Note that forms can always be updated, even after you submit the form. If you acquire the PHIN at a later date, please enter onto the form and re-fax. If you acquired the PHIN but you no longer have the Participant's Welcome Form, contact HCMO and they can ensure that this information is added to the record in the database.

2. Postal Code

Enter the full six-digit postal code of the Participant's current residence. This includes group homes and incarcerated individuals.

3. Date of Birth

Use DAY, MONTH, YEAR (4 digit year) (dd|mm|yyyy).

Ensure that printing is clear and contained within the boxes.

Age

Enter the Participant's age in years. If the Participant is nine years old write "09" if they are twenty-one write "21".

4. Gender

While HCMO recognizes that there are other valid answers to this question, at this time we ask that you choose either Male or Female. Please use the option with which the Participant identifies. Please note that Participant may also choose not to answer.

5. Years in Canada

To assess ongoing and future programming needs, HCMO is interested in learning how many Participants are newcomers to Canada. We recognize that in many cases, the response will likely be equal to the Participant's age.

6. Waitlist

Please estimate how long the Participant waited on the waitlist before being entered into the program using the categories presented.

7. Ethnicity

Please choose the option(s) from the list. If "other" is chosen, please indicate the ethnicity by writing clearly in the section provided. Please note that Participant may also choose not to answer.

8. Current Living Arrangement

More than one option may be chosen from this list. For example, a Participant may live alone (just one option would be selected) or the Participant may live with a partner, and children, and with parents (three options would be selected).

The EXCEPTION is INCARCERATED. If a Participant is incarcerated, no other option from the list may be chosen.

If "other" is chosen, please indicate the living arrangement by writing clearly in the section provided.

9. Disrupted Living Arrangements

Moving to a group home or becoming incarcerated would be counted as a disruption to living arrangements once. If the Participant became homeless, that would also count as a disrupted living arrangement. If the Participant was in a living with their parents, then was incarcerated, and then moved to a group home, this would count as two disruptions in the past year.

Counting disruptions to living arrangements is not always easy. Please provide the best estimate in cases where the number is not distinctly recalled. It is preferable to have an estimate than have you select “Don’t know”.

This question is meant to track changes to *living arrangements*, therefore, disruptions to school placements should not be counted here.

10. Highest Level of Schooling

Please choose one option only from the list.

If the Participant is still in school indicate the grade that the Participant is currently in, using two digit numbers. This means that for grade 9, you enter “09” for example.

If the Participant enters your program while on summer holidays indicate the most recent grade attained.

If the Participant did not complete high school, please indicate the highest full grade attained.

Please note that if the participant is too young to attend school, the final option is “does not apply” for this reason.

11. Changed schools

Please note that this questions states “more than once” – this means if the Participant has changed schools just one time, you would answer “no”. The reason for this is that within the twelve month period, many students will make a natural transition from a junior school to junior high or junior high to high school settings. These moves do not reflect transiency or instability.

Please choose one option only. If the Participant is not in school, please ONLY choose “does not apply”, do not also answer “no”.

12. Use of other programs, services and supports

Please answer based on Participant's current state of affairs.

There are four response options: "Yes", "No, not needed", "No-but needed", and "Don't know". One response option must be selected for each category listed.

If the family is receiving respite services, please clearly indicate the Agency providing services.

Some of the categories are tricky to define and you will find that caregivers and families have a hard time deciding whether or not they are using some of the services. Please use the definitions below to help sort this out.

Accommodations at school: everything from a teacher who uses specialized strategies, to a rocking chair or dark room, to alternative programming, to funding.

Accommodations at childcare: as above.

Children's disABILITY Services (CDS): supports families who are raising their children with developmental and/or physical disabilities, to meet some of the additional needs they may have. CDS offers a variety of supports (e.g. respite, therapy services, supplies, equipment and home modifications, behavioural services) to parents to assist them to care for their children at home in their own communities.

Community Living disABILITY Services (CLDS): offers a range of services aimed at providing adults with a mental disability the opportunity for independence in a community setting to the extent possible for each individual. CLDS supports include: residential services, supported employment, vocational training and clinical support services.

Cultural programming: this is meant to be a broad catch-all for everything that could be viewed as cultural programming that the participant attends outside of that which is offered through your FASD program itself. All cultures should be considered. This may include things like drumming, sewing, dancing, singing, sharing, teaching/learning, and spiritual care.

Provincial Alternative Support Services (PASS): offers services to adults who meet the following criteria: 1) have a diagnosed mental disorder or disability, 2) Are at high risk of re-involvement in the criminal justice system or pose a high risk to themselves or others, 3) are not eligible for other existing services (ie. CLDS or Community Mental Health). The program helps support individuals to live successfully in the community, while striving to ensure public and personal safety. Services include case management, consultation, funding support (for housing, support staff, counselling, etc.), advocacy and support in criminal justice matters, and connecting clients to community resources.

13. Employment

Please choose all that apply. It is expected that in most cases, only one option would be chosen. However, the Participant can “choose all that apply” if for example, they have both a part time job with one employer and a casual job at the same time with another employer.

For differences in employment categories, please note the following Statistics Canada definitions:

Full-time: employed persons who usually worked 30 hours or more per week, at their main or only job.

Part-time: employed persons who usually worked less than 30 hours per week, at their main or only job.

Casual: This category will be used to cover temporary employment (clear end dates such as completing a project or pilot program or training program), seasonal employment (such as a summer job), term or contract work, as well as casual jobs and other short-term work without clear week to week schedules or guaranteed hours of work.

If the Participant is a child, please ONLY choose “Child participant - does not apply”, do not also answer “no”.

14. Employment and Income Assistance/Age of Majority Funds

Please choose all that apply. For example, if the Participant is currently receiving EIA, but also did in the past, choose BOTH “Yes, currently” and “Yes, in the past”. If the participant has received EIA but does not currently, select “Yes, in the past” and we will understand that this means the Participant does not currently receive EIA. These instructions also apply to a Participant who is receiving Age of Majority Funds.

If the Participant is a child, please ONLY choose “does not apply”, do not also answer “Have never received either”.

Please also note that this question does not refer to Participants’ families. That is, if a child Participant lives in a family that receives EIA, the answer is still “does not apply”.

15. Involvement with Justice

This question includes room for both current and past states of affairs. Please select all that apply. For example, if an adult was involved with youth justice in the past and is also involved with adult justice currently, select both.

Please note that “involved with justice” includes:

- Charges pending but not convicted
- Convicted
- Breeches
- Incarcerated
- On parole

16. Diagnosis of FASD

There are three parts to this question. If the Participant *has not been* diagnosed with FASD, is suspected to have FASD, or the Participant does not know, please select the appropriate response and skip follow up questions A & B by proceeding to Question 18 regarding referral.

If the Participant *has been* diagnosed with FASD, select “Yes” and move to follow up questions.

A: Please indicate the approximate date of diagnosis (month and year only).

B: Please also indicate where the Participant was diagnosed.

Note: We are not asking Service Providers to assign a diagnosis. This diagnosis must have been provided by the Participant or Caregiver or on file.

Further details about diagnosis of FASD can be found at:
http://www.cmaj.ca/content/172/5_suppl/S1.full

17. How Participant Came in Contact with Program

Please indicate whether the Participant was referred to the program (and specify by whom in the space provided) or if the Participant came in contact through “other” means. If “other”, please clearly specify how in the space provided. This could include “self” if the Participant found out about the program themselves or “Caregiver” if the family or Caregiver made the first connection to the program.

NOTE: Sample of this Teleform is in APPENDIX C.

Service Provider Check-In Form

1. See **Appendix D** for Teleform sample.
2. Start date: **September 1, 2014** is the official date of implementation of this form for the purposes of the Provincial Evaluation. All Service Providers are asked to fill out one Check-In Form between September 1st and December 10th each year.
3. This form is to be filled out by **Service Providers**. If there is more than one Service Provider at the organization, each of you is asked to fill out the form individually and submit to HCMO. This is because everyone may have a different opinion and we want to hear from each of you!
4. This form consists of 15 questions and covers issues related to program accessibility, Participant engagement, collaboration with other services and training.
5. Please send completed form by MAIL (not through fax as it is more than one page) by December 10th of each year.

Question by Question Instructions for the Service Provider Check-In Form

Service Provider Form, Top Section:

DATE

This is the date that the form is completed.

Complete clearly in the format of: **DAY, MONTH, YEAR** (dd|mm|yyyy)

Use all four digits for year.

Keep numbers clear and within each box.

PROGRAM CODE

Each program requires a unique code to identify both the program and the location of the program (if there is more than one location). The code will have two letters and two numbers. For example, if an Agency called “Healthy Together” offers its program at three different sites, then the Agency would have three different codes:

HT01

HT02

HT03

If you have a new program and/or your program is not included in the Appendix, please contact the FASD Evaluation Coordinator at HCMO for a new code.

Do not fax in forms without a program code as we will not know which program the form belongs to.

PROGRAM CODES as of June 27, 2018

Program/Agency	Program Site	Program Code
Family Support, Education & Counselling	Winnipeg	FS01
FASD Centre- Diagnostic Coordinators	Wellington Crescent, Winnipeg	FC01
	Brandon	FC02
	Brandon Rural	FC03
	Churchill	FC04
	Dauphin	FC05
	Pinawa	FC06
	Portage	FC07
	Selkirk	FC08
	Steinbach	FC09
	The Pas	FC10
	Thompson	FC11
FASD Outreach	Winnipeg	FO01
MKW	Selkirk	KW01
Spectrum Connections	Winnipeg	SC01
Stepping Out on Saturdays (SOS)	Winnipeg	SO01
	The Pas	SO02
	Thompson	SO03
Youth Justice Program	Winnipeg	YJ01
	The Pas	YJ02
Starfish	Winnipeg	ST01

PROGRAM FREQUENCY

Please choose only one option which best represents the typical frequency of contact between your program and Participants. If contact with your program participants differs greatly from participant to participant and week to week, please select, “Too varied to categorize”.

Numbered Section (Main Body of Service Provider Form):

SECTION A – Introductory Questions and Demographics

1. Your Current Role

We do not need to know your specific position within the organization (such as policy analyst, social worker etc.) but just your broad role such as manager, staff or volunteer for example.

If you choose “Other”, please print your specific role within the space provided.

2. Length of Time with Organization

Please indicate the number of years you have been with this particular organization. Please use whole numbers only and if you have been with the organization for less than one year, please use “00”. Do not use decimals to try to indicate part years. Use “01” format to enter single digit numbers.

SECTION B – Program Accessibility

3. Barriers to Program Accessibility

Please indicate whether or not there are barriers to accessibility in your program by selecting yes or no.

If you have selected yes, please select all barriers that apply. If there are no barriers to accessibility, please select “this program does not experience any barriers” which can be found at the bottom of the options list.

4. Changes in the past year that have resulted in increased accessibility

Please think back to the past year and consider any changes that may have had a positive impact on accessibility, even if accessibility was not the original reason leading to the change (for example, a lease may expire that requires a program to move to a new site and as a result, accessibility may be impacted in a positive way).

Please select all that apply and if no changes have been made (or there were no accessibility issues to be addressed), please select “no changes have occurred that resulted in increased accessibility to this program” which can be found at the bottom of the options list.

SECTION C – PARTICIPANT ENGAGEMENT

5. Barriers to Identifying and Engaging with Your Population of Interest

Your population of interest is the group of people that your organization has identified as meeting the criteria for your organization’s particular objectives, programs and services (for example, “homeless women” or “young offenders”).

Please indicate which of the barriers listed make identifying and engaging with your population of interest a challenge.

For example, some people who are at most high risk of giving birth to a baby with FASD or people affected by FASD can also be the most difficult to find or continue to maintain contact with. This may be because they do not have a telephone, change cell phones (and numbers) frequently, move frequently, live with others so that they have no permanent address or do not wish to engage with programs or services. There are many reasons that make it difficult to engage and these are just a few examples.

If you are experiencing barriers that are not listed, please select “other” and then print the barrier(s) clearly in the section provided.

If there are no barriers, select “No barriers” which can be found at the bottom of the list.

SECTION D – COLLABORATION WITH OTHER SERVICES

6. Program's ability to identify when Participants need programs or services outside of those offered at your program

This is a four-option rating scale ranging from Highly INEFFECTIVE (listed first) to Highly EFFECTIVE (listed last). Please choose only one option.

7. Program's ability to connect Participants with other programs or services when needs are identified

This is a four-option rating scale ranging from Highly INEFFECTIVE (listed first) to Highly EFFECTIVE (listed last). Please choose only one option.

8. Barriers to Connecting

If you have experienced barriers in connecting to other programs and services, please choose as many as apply from the list provided. If there are other barriers, please choose "other" and then identify these barriers in the section provided.

9. Community Partners or Services

This is an open ended question about the community partners and services with whom you work most closely. Please neatly print the names of the partners or services with whom you work most closely.

10. Positive Changes In Past Year

This is an open ended question about changes that have occurred in the past year to positively impact your ability to link with other programs and services. If applicable, please succinctly describe changes that have occurred (please print neatly).

11. Better linkages with Other Services

This is an open ended question. If applicable, please succinctly describe how better linkages with other programs and services might be achieved (please print neatly).

12. Awareness of Manitoba FASD Strategy

Please indicate "Yes" or "No" in response to this question.

SECTION E – TRAINING

13. Training

Please indicate “Yes” or “No” in response to this question.

If you answered “Yes”, please select all that apply to indicate the types of training you have engaged in during the past year.

14. Training that would be most Beneficial

This question relates to training opportunities that would be most beneficial to you in your current role. Please choose your top three priority areas from the list provided and if you have training needs that are not listed, please identify those using the “other” line(s).

SECTION F – FINAL THOUGHTS

15. Additional comments

This is an open ended question to provide an opportunity for you to give further feedback about issues that may have been raised in the form as well as your opportunity to raise any issues of concern that may not have been identified in the form. Please remember to print neatly in the space provided.

NOTE: Sample of this Teleform is in APPENDIX D.

SUPPORTING RESOURCES FOR EVALUATION

Reasons for Evaluation

There is "**value**" in evaluation

Good evaluation does five things: It **validates**, it **assures**, it **learns**, it **understands**, and it **educates**. Each of these adds up to the **value** of evaluation.

Validate experiences

To validate means to show the importance of something. Evaluation **validates experiences**. These include the experiences of children, youth, families, workers, and researchers. Evaluation validates the strengths of families, and shows how they are central to the success of all services for Manitobans. Evaluation validates the experiences of people who work with individuals and families in Manitoba.

Assure quality

We want what is best for Manitobans across the lifespan. We want the best for kids and services for adults, for example. We want the best strategies and the best programs supporting those strategies. We want the best people working towards these goals. Most of all, we want the best possible outcomes (results) for the children, youth and adults who live with FASD in Manitoba. Evaluation **assures quality**. It does this by measuring outcomes to see if the strategy leads to the best possible results. This also helps us make the best use of funds, to support the best available programs to support our provincial strategy.

Learn what works

Evaluation is the best way to **learn what works**. It helps us learn which strategies lead to the best results. It also helps us learn what parts of a strategy might be most important in leading to those results. For example, we have learned that the best strategies children need to have a good start in life is by providing support in the different parts of children's lives: in the family, in school, and in the community.

Understand what is needed

Although we have learned a lot about how to help children become healthy and happy adults and how to support adults in making healthy choices, there's still more to learn. Evaluation helps us **understand what is needed**, including how to **improve strategies** so that they lead to better results. This also includes what kinds of **new strategies** are needed for Manitoban across the lifespan, not just for children and youth.

Educate stakeholders

All the people who are interested in a strategy are known as "stakeholders." These include individuals with FASD and their families served by a program that links to the provincial FASD strategy. Also included are those involved in supporting the strategy by providing the programs as well as the public who have paid for a program through taxes and want the best programs for their investment. Stakeholders can be found everywhere: in families and communities; in schools and agencies; in government and in businesses; and in other places. Evaluation **educates stakeholders** by **sharing effective practices**, showing people the programs and strategies that lead to the best results.

How to Ask Questions

It is expected that for the most part, Participants will require assistance by Service Providers in filling out the evaluation paper work. Service Providers can achieve this through a friendly "interview" approach with the Participant and Caregiver as needed. It will be up to Service Providers to assess the degree to which Participants may need help in filling in the forms and in some cases, the Participant may not require any assistance.

The 3 R's of interviewing

Through your experiences, you have likely already become familiar with the basics of interviewing (for example, just by talking to your Participants you are able to find out more about them), so only a few points will be noted. When gathering information for the provincial evaluation, you must provide the Participant with the 3 R's of interviewing: **relationship**, **respect**, and **rationale**.

Relationship

First and foremost, you must establish trust and rapport with your Participants and Caregivers. Your positive relationship with the Participant and Caregiver provides a **secure base** for them to be open, honest, and direct with you when answering questions for the evaluation. The "Check-In" forms do include questions which ask for the opinions of Participants and Caregivers about the program and how it is meeting their needs. Please assure the Participant that you as the staff know that these questions are not about you personally but about the program overall. It is important to assure the Participant that their honesty can lead to program improvements and better meet their needs and would never lead to yourself or another staff member being angry at the Participant.

Respect

The basic quality of the relationship you provide to the program Participant and Caregiver is one of respect. The Participants should always feel that their experiences—especially the privacy of those experiences—are fundamentally

respected. You must respect their freedom to refuse answering particular questions. You must respect their freedom to withdraw their participation from the evaluation at any time, without any consequences.

Rationale

Before any questions are asked, you must provide **purpose and meaning for answering** those questions. You must share with the Participant the basic reasons for collecting information in the provincial FASD evaluation:

"The purpose of the provincial FASD evaluation is to gather information about:

- How children/youth with FASD are doing over time
- How adults with FASD are doing over time
- How families affected by FASD are doing over time
- How well the provincial FASD strategy is working
- How we could improve the provincial FASD strategy
- What other programs and policy developments may be needed

We cannot achieve this without collecting information from Service Providers, program Participants and their Caregivers. This includes basic information such as your age and whether or not you have a job as well as your needs and your experiences with different programs.

How to Answer Questions

Be yourself

This applies to both Service Providers as well as Participants and their Caregivers! That is, when you talk with your clients, just be yourself and talk about these issues in your normal friendly way. We do not want to get too technical in providing direction or answering questions. We also recommend that you encourage Participants and Caregivers to also "be yourself" and just answer questions in the way they think is best. We want their true feelings and value all feedback.

When you complete the yearly Check-In Forms, please **tell us about your experiences, and, what you really think or feel!** The most important thing to us is learning about your experiences.

There are no right or wrong answers

Although data quality is important and we hope the basic demographic and descriptive information will be answered accurately, keep in mind that there are no right or wrong answers for any of the evaluation questions. Everyone has different experiences, thoughts, and feelings. Our approach is simple: **We respect your answers and this applies to Service Providers, Participants and Caregivers.**

Ask for help if you need it

If a question or instruction is not clear, **ask for help.** Participants and Caregivers should be encouraged to ask Service Providers for help in understanding the forms. Service Providers are encouraged to assist Participants in filling out all aspects of the paperwork as needed. **Service Providers** can ask for help from any of the key contacts at Healthy Child Manitoba Office (HCMO) listed at the front of this guide if further assistance is needed in interpreting any of the forms or processes.

Privacy and Legislation

Collection of PHIN and Privacy Protection

In this section we address the important questions and concerns that Service Providers may have in collecting PHIN from Participants and providing that information to Healthy Child Manitoba Office (HCMO). There may also be questions about how data are sent to HCMO and how and where data are stored. These questions may also be posed by program Participants and Caregivers. Therefore, it is important that Service Providers review and are familiar with the information about privacy, PHIN and the Healthy Child Manitoba Act. If you have further questions, or if Participants or Caregivers have questions that you do not feel you can answer, please feel free to connect with one of the key contacts identified in the front of this guide for further support and information.

Note that PHIN is collected only on the Intake Form and is only collected for the Participant.

Before getting into the specifics of PHIN collection and privacy protection, it is important to note that:

We ask only for information that is necessary for the provincial evaluation.

Many experts from other government departments and community programs have been consulted in developing the data collection tools. The final version of the forms represents a significant amount of collaboration between Healthy Child Manitoba and the FASD Evaluation steering committee members.

Regardless of the reasoning for data collection and the steps in place to protect privacy, **Participants always have a choice**. Participation in the evaluation and provision of PHIN is completely voluntary. At the same time, participation is to be encouraged as it is essential to ensure that the results of the provincial evaluation are accurate. There may be some information that Participants do not feel comfortable providing. **Participants are always free to refuse to answer any questions.**

Reasons for Collecting PHIN

The PHIN (Personal Health Identification Number) is a number that everyone is provided by Manitoba Health and no one has the same number. This allows us keep data organized about individuals in an anonymous way. The PHIN also helps us to connect the information collected in the evaluation to other information collected by government departments (e.g. education, health services, education, family services and housing).

One of the goals of the provincial FASD Strategy is that people of all ages suspected of, or living with, FASD are provided with assessment and diagnosis and, along with their Caregivers, have access to support and other necessary services to meet their needs. The PHIN acts as a link between the different banks of information helping us to tell if the strategy is successful at encouraging people to access services that they need. Using the PHIN as our linking identifier we can ask very specific questions about the way that groups of people access services.

For example we can ask: How many of the children who have been diagnosed with FASD this year have attended programming through Stepping out on Saturdays? Without the PHIN, we cannot link the two data sets. Having the PHIN allows us to link data in ways that help us answer the most pressing questions regarding FASD programming.

With data linkage comes information and knowledge, and that is powerful. As we learn more about how people affected by FASD are experiencing life we can take more steps in helping them reach their potential. **We can improve the programs that we have, and develop new ones that are needed. We can make sure that our programs provide Manitobans who are touched by FASD the results they value and deserve.**

How the PHIN is Used

The PHIN is entered into a secure database at Healthy Child Manitoba Office (HCMO) data centre with the other information you give us for the evaluation. Note that there are **no names, phone numbers or addresses** in this database. To connect the information in the provincial FASD evaluation database with Manitoba Health data, the database with all the PHINs are sent to Manitoba Health. The staff in charge of the health database makes the linkages to their information from our database. If linking data are sent back to us, the numbers are changed around so that we can never connect a Participant PHIN and health

information to a specific Participant. This combined information is then used **for statistical purposes about groups of people and never about individuals.**

Identification of Individuals

We never use the PHIN to gain information about an individual, we do not have access to an individual's personal records, and we are not interested in looking at an individual's outcomes. The Provincial Evaluation is about looking at outcomes at a group level only. In fact, evaluations that are done by Healthy Child Manitoba Office (HCMO) are always done at the group level, meaning that individuals are never at risk of being singled out in any way.

In the FASD strategy evaluation, we do not collect any program Participant's name, address or phone number.

The PHIN might be used to connect one data set to another, but this is done only by HCMO staff in our secure data centre or Manitoba Health in their secure data centre. In both cases, very few people would ever see the PHIN and no one at HCMO has any access to identifying information associated with a PHIN (such as name or address). Identifying information is held securely by Manitoba Health, and even at Manitoba Health, very few people would have permission to access databases to link PHIN to identifying information.

When linkages are complete and data are ready to be analyzed, PHIN is removed and a different unique number is used (such as the number on the Intake Form) by the analyst who works with the data. Data are analyzed and reported at the group level, and no child's data are ever reported on an individual basis.

Healthy Child Manitoba Act

In accordance with ***The Healthy Child Manitoba Act***, Service Providers are permitted to provide the PHIN to the Healthy Child Manitoba (HCMO) Office for program monitoring and evaluation purposes. No additional consents or permissions are required from Participants.

The Act can be viewed at:

<http://web2.gov.mb.ca/laws/statutes/ccsm/h037e.php>

Key sections of the act related to data collection for program evaluation include:

Section 10 (evaluation)

"The Healthy Child Committee of Cabinet may require the Healthy Child Manitoba Office or a partner department to evaluate government policies, programs or services that directly impact children and their families, including process and outcome evaluations."

Sections 18-20 (collecting personal health information) in particular:

Section 19(1)

"The office may require another public body or a community partner to provide personal information or personal health information to, or collect personal information or personal health information on behalf of, the office for the purpose of researching, planning, implementing, evaluating or monitoring the Healthy Child Manitoba strategy as set out in section 3."

Section 20(1)

"For any of the purposes stated in subsection 19(1), the office may disclose personal information or personal health information to

(a) another public body; or

(b) a government or entity that has entered into an agreement under section 26."

FIPPA and PHIA

Manitoba has passed two laws, known as FIPPA and PHIA. Whenever people provide personal information to us about themselves or their children, these laws protect their privacy. The word "FIPPA" is short for the "Freedom of Information and Protection of Privacy Act." The word "PHIA" is short for the "Personal Health Information Act."

All HCMO program evaluations follow FIPPA and PHIA. It is important to note this with Participants and Caregivers. When people know that their privacy is safe and protected, they can be confident to provide accurate information to HCMO.

FIPPA can be viewed at:

<http://www.gov.mb.ca/chc/fippa/index.html>

PHIA can be viewed at:

<http://www.gov.mb.ca/health/phial/>

Frequently Asked Questions

What is the purpose of the FASD Provincial Evaluation?

The purpose of the Provincial Evaluation is **to use outcome results to improve programs, make management decisions, and report outcomes to stakeholders** (families, Service Providers, home visitors, Public Health Nurses, Regional Health Authorities, government, and the general public).

The purpose of the provincial FASD evaluation is to gather information about:

- how children/youth with FASD are doing over time
- how adults with FASD are doing over time
- how families affected by FASD are doing over time
- how well the provincial FASD strategy is working
- how we could improve the provincial FASD strategy
- what other programs and policy developments may be needed

We cannot achieve this without collecting information from Service Providers, program Participants and their Caregivers. This includes basic information such as your age and whether or not you have a job as well as your needs and your experiences with different programs.

What answers will the Provincial Evaluation provide?

The Provincial Evaluation will answer three primary questions:

- (a) Does the provincial FASD Strategy make a difference?
- (b) How does the provincial FASD Strategy make a difference?
- (c) Where are there gaps along the continuum of programs and services for people affected by FASD?

In other words, the evaluation will provide answers regarding **program effectiveness** (or impact) in achieving outcome objectives and the **effective program components** that contribute to outcomes. Because we are including measures related to completion of education as well as involvement with the

justice system, this evaluation will allow us to measure both good outcomes (for example increasing high school completion rates for people diagnosed with FASD) as well as outcomes that we would prefer to avoid (for example, involvement with justice system, frequent changes to living situation or lack of employment).

What are some advantages of the Provincial Evaluation?

There are a wide variety of programs and services providing support and information to a wide age range of people living with FASD as well as their Caregivers. There are also numerous programs and services that focus on FASD prevention and broad public education. These programs and services touch people of all ages and socio-economic groups throughout Manitoba. Many of the programs and services that are considered to be part of the Provincial FASD Strategy may not even themselves realize that they are working together toward common provincial goals. This evaluation allows us to pull together information from the large numbers of programs and services and show how these programs and services together are making a difference for Manitobans.

Programs that fall under the provincial FASD Strategy are in operation throughout Manitoba, serving a large number of people, of all ages, living with FASD (along with their supports). This large number (sample size) permits a high level of **statistical power**. This means that the evaluation is capable of detecting smaller, but still important, program effects. Further, the type of evaluation design allows us to **attribute outcomes to the strategy**. In other words, we will be able to say that outcomes resulted from (i.e., were caused by) participating in programs or services that are considered to be part of the overall provincial strategy. In addition, by looking at a strategy level as opposed to program specific evaluation, we will be able to identify key gaps that may exist along the continuum of need for people living with FASD along with Caregivers. Gaps in prevention and education programs may also be identified throughout the course of the evaluation.

How long will the Provincial Evaluation be conducted?

Although the specific time span has not been identified, the provincial evaluation will be long term. Going forward, programs will be requested, as part of their contract with their funder (HCMO), to collect data about program Participants for the duration of the evaluation.

Our perspective is that **evaluation completes best practice** and, as such, is **an ongoing process** throughout the delivery of a program.

Healthy Child Manitoba Office (HCMO) is also committed to longitudinal evaluation, that is, to measure outcomes in the longer-term, for example, even **after Participants are no longer in a FASD Strategy related program**. We may also compare people who have been diagnosed with FASD and either have or have not participated in particular FASD Strategy programs to see if there are differences in life experiences and key outcomes (such as avoidance of the justice system, employment, completion of high school).

What outcomes are being measured?

A variety of outcomes are being measured. These outcomes are related to the Provincial FASD strategic outcomes which include ensuring that individuals with FASD are better supported and live more stable lives and that families are able to find support for their loved ones with FASD. Some of these outcomes will be measured using the data we collect through the evaluation paperwork and some will be measured by linking to other administrative databases sets such as Manitoba Health data, Education data, Social Services data, Housing data, and Justice data. These linkages will provide us with archival outcome measures. Any linkages to other data sets would be done anonymously and data access and linkages would be strictly controlled.

Who analyzes the Provincial Evaluation data and reports the findings?

Healthy Child Manitoba Office (HCMO) is responsible for evaluation data analysis and reporting of evaluation findings.

When enough data are collected (after several years), it is anticipated that HCMO will work with other agencies such as Manitoba Health and Manitoba Centre for Health Policy for in depth analysis of data which would include anonymous linkages to other data sets. Where possible and appropriate, evaluation results will be reported at Provincial, Regional Health Authority and Community levels.

How often will Provincial Evaluation findings be reported?

Preliminary evaluation findings will be reported on periodically. In the beginning, reports may be limited to "quality assurance" type of reports where we report back to all agencies the numbers of forms we have received and any data quality issues that have been identified (this may include lack of data being provided, inconsistencies or other issues). This will allow for ongoing improvement of data collection, the ability to continue to educate about the data collection process and to ensure that we are receiving the numbers of forms that programs/agencies have sent to us (that is, ensure that all faxes are received!).

It should be noted that the accuracy of the evaluation findings is in part determined by the number of Participants (i.e., sample size) that are included in a given data analysis. This means that it is very important that Service Providers do as much as possible to collect the information required in our forms.

Thank You for Participating in the Evaluation Data Collection

APPENDIX A

SAMPLE SPREADSHEET FOR KEEPING TRACK OF PARTICIPANT NUMBERS

Sample spreadsheet

(Please modify to suit your needs. HCMO absolutely needs you to keep track of: 1. Participant Number and 2. Name. The rest is up to you.)

The two columns are required by HCMO for you to track participants.		These columns are examples of others types of information that you may want to collect to keep track of your Participants. They are optional.						
Participant Number (from Intake Form)	Participant Name	Participant Contact information	Participant completed Participant Welcome Form	Participant Program Exit Date	Participant completed You're Moving on Form	Check-In Reminder sent to Participants and or/Caregiver	Date Check-In Form will be completed	Who completed Check-In
FS12345	Sue Smith	Address, e-mail, phone number	Yes			Yes	September 15, 2014	Participant only
FS33442	Joe Jones	Address, e-mail, phone number	No Note - even though the Participant did not complete the Participant Welcome Form, he was still assigned an FASD number based on the form he would have used.			Yes	September 20, 2014	Caregiver and Participant
F56894	Ann Apple	Address, e-mail, phone number	Yes	June 5, 2014	Yes			

APPENDIX B

FOSTER PARENT PERMISSION LETTER



First Nations of Northern
Manitoba Child and
Family Services Authority



The General Child
and Family Services
Authority



July 1, 2014

Dear Foster Parents,

We understand you have been asked to participate in the evaluation of the Provincial FASD Strategy by completing some forms on a periodic basis. The purpose of this evaluation is to help us improve FASD programs and services in Manitoba, and the evaluation information is being collected under the authority of *The Healthy Child Manitoba Act* <http://web2.gov.mb.ca/laws/statutes/ccsm/h037e.php>

Key sections of the act related to data collection for program evaluation include:

Section 10 (evaluation)

"The Healthy Child Committee of Cabinet may require the Healthy Child Manitoba Office or a partner department to evaluate government policies, programs or services that directly impact children and their families, including process and outcome evaluations."

Section 19(1)

"The office may require another public body or a community partner to provide personal information or personal health information to, or collect personal information or personal health information on behalf of, the office for the purpose of researching, planning, implementing, evaluating or monitoring the Healthy Child Manitoba strategy as set out in section 3."

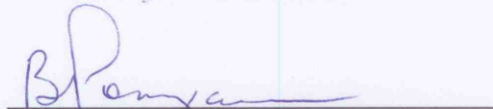
Although you are not required to participate in the evaluation in order to receive services, your participation is valuable and would be greatly appreciated. It is only through collecting information and feedback from program participants and partners, that we can learn how we can improve provincial FASD programs and services. To that end, through this letter, we encourage your participation in this evaluation process. The specific forms you have been invited to complete are the "Welcome Form" when a participant first attends the program, a periodic Check-In Form called "We Want to Hear Your Voice" and the exit form titled "You're Moving On". Thank you again for your consideration.

If you have any questions about the evaluation of the Provincial FASD Strategy please feel free to contact Holly Gammon, Manager, FASD Programs, Healthy Child Manitoba Office (204-945-2215, holly.gammon@gov.mb.ca.)

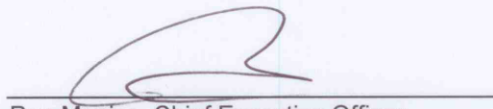
Sincerely,



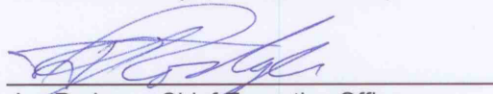
Billie Schibler, Chief Executive Officer
Metis Child and Family Services Authority



Bobbi Pompana, Chief Executive Officer
First Nations of Southern Manitoba
Child and Family Services Authority



Ron Monias, Chief Executive Officer
First Nations of Northern Manitoba
Child and Family Services Authority



Jay Rodgers, Chief Executive Officer
General Child and Family Services Authority



Ben Van Haute, A/Assistant Deputy Minister
Family Services
Province of Manitoba

APPENDIX C

“PARTICIPANT WELCOME FORM”

INTAKE FORM

TELEFORM SAMPLE

PARTICIPANT WELCOME FORM

Please print numbers neatly within squares without touching the lines, and fill in circles completely, using dark blue or black pen.
Once complete, please fax to the HCMO Data Centre at 204-948-3768

☐ New Participant ☐ Existing Participant

<p>01. Participant PHIN (9 digits)</p> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <p>02. Participant Postal Code</p> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <p>03. Participant Date of Birth (DD/MM/YYYY)</p> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <div style="border: 1px solid black; width: 100px; height: 20px; margin-bottom: 2px;"></div> <p>Age: </p> <p>04. Participant gender: <input type="radio"/> Male <input type="radio"/> Female <input type="radio"/> Trans</p> <p>Other: </p> <p>Choose not to answer <input type="radio"/></p> <p>05. How many years has Participant lived in Canada? </p> <p>06. How long was Participant on the wait list for this program? <input type="radio"/> No wait <input type="radio"/> 0-3 mos. <input type="radio"/> 4-6 mos. <input type="radio"/> 7-12 mos. <input type="radio"/> Over 1 year <input type="radio"/> Don't know</p> <p>07. Participant ethnicity: <i>Select all that apply.</i></p> <p><input type="radio"/> Arab <input type="radio"/> Caucasian <input type="radio"/> Inuit</p> <p><input type="radio"/> Asian <input type="radio"/> Filipino <input type="radio"/> Métis</p> <p><input type="radio"/> Black <input type="radio"/> First Nations <input type="radio"/> Choose not to answer</p> <p>Other: </p> <p>08. What is Participant's current living arrangement? <i>Select all that apply.</i></p> <p><input type="radio"/> Alone</p> <p><input type="radio"/> With partner</p> <p><input type="radio"/> With my children</p> <p><input type="radio"/> With parent(s)</p> <p><input type="radio"/> With other family members</p> <p><input type="radio"/> With foster family or guardians</p> <p><input type="radio"/> Staying at a friend's home</p> <p><input type="radio"/> Share home with friends/roommates</p> <p><input type="radio"/> Lives independently with support</p> <p><input type="radio"/> Group home</p> <p><input type="radio"/> Incarcerated</p> <p><input type="radio"/> Homeless, if yes: <input type="radio"/> I live in a short-term shelter</p> <p>Other living arrangement, specify: </p>	<p>09. How many times has Participant's living arrangements been disrupted in the past year? </p> <p>10. What is the highest level of schooling Participant has completed? <i>Select one.</i></p> <p><input type="radio"/> Still in school/home school - Enter grade: </p> <p><input type="radio"/> Currently attending adult or alternative education</p> <p><input type="radio"/> Graduated high school or equivalent</p> <p><input type="radio"/> Completed adult or alternative education</p> <p><input type="radio"/> Completed or currently attending post-secondary training or education</p> <p><input type="radio"/> Did not complete high school - specify highest grade completed: </p> <p><input type="radio"/> Transitioning back to school</p> <p><input type="radio"/> Does not apply - Participant too young to attend school</p> <p>11. Has Participant changed schools more than once in the past year? <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Does not apply (not in school)</p> <p>12. Does Participant use these programs, services or supports: <i>Please respond to each.</i></p> <table border="1"> <thead> <tr> <th></th> <th>Yes</th> <th>No, not needed</th> <th>Don't know</th> </tr> </thead> <tbody> <tr><td>Accommodations at school</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Accommodations at childcare</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Addictions Services</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Child and Family Services</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Children's disability Services (CDS)</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Community Living disability Services (CLDS)</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Cultural programming</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Employment/vocational training program</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Family doctor</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Mental health counselling/therapy, services and/or programming</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Jordan's Principle worker</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Occupational Therapist</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Provincial Alternative Support Services</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Public Health Nurse</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Respite Services</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Specify Agency</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Speech and Language Pathologist</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> <tr><td>Subsidized housing</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr> </tbody> </table>		Yes	No, not needed	Don't know	Accommodations at school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Accommodations at childcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Addictions Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Child and Family Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Children's disability Services (CDS)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Community Living disability Services (CLDS)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Cultural programming	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Employment/vocational training program	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Family doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Mental health counselling/therapy, services and/or programming	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Jordan's Principle worker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Occupational Therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Provincial Alternative Support Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Public Health Nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Respite Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Specify Agency	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Speech and Language Pathologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Subsidized housing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<p>13. Is Participant employed: <i>Select all that apply.</i></p> <p><input type="radio"/> Does not apply - child participant</p> <p><input type="radio"/> Full-time <input type="radio"/> Casual <input type="radio"/> No</p> <p><input type="radio"/> Part-time <input type="radio"/> Volunteer work</p> <p>14. Is Participant receiving: <i>Select all that apply.</i></p> <p><input type="radio"/> Employment and Income Assistance - currently</p> <p><input type="radio"/> Employment and Income Assistance - in the past</p> <p><input type="radio"/> Age of Majority Funds - currently</p> <p><input type="radio"/> Age of Majority Funds - in the past</p> <p><input type="radio"/> Have never received either</p> <p><input type="radio"/> Does not apply - child participant</p> <p>15. Is Participant involved with: <i>Select all that apply.</i></p> <p><input type="radio"/> Does not apply - child under age 12</p> <p>Youth Justice <input type="radio"/> Current <input type="radio"/> Past <input type="radio"/> Never</p> <p>Adult Justice <input type="radio"/> Current <input type="radio"/> Past <input type="radio"/> Never</p> <p>16. Has Participant been diagnosed with FASD?</p> <p><input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> No, but FASD is suspected</p> <p><input type="radio"/> No, but on wait list for diagnosis <input type="radio"/> I don't know</p> <p>If YES:</p> <p>A. Approximate date of diagnosis (MM/YYYY): </p> <p>B. Where was Participant diagnosed?</p> <p><input type="radio"/> Manitoba FASD Centre in Winnipeg</p> <p><input type="radio"/> Other location in Manitoba: </p> <p><input type="radio"/> Outside of Manitoba</p> <p>17. How did Participant come into contact with this program?</p> <p><input type="radio"/> Referral, specify: </p> <p><input type="radio"/> Other, specify: </p>
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revised 08/2018

0406187062

Program Use Only: ☐ D

FS

Participant Number

Program Code

Participant Start Date (dd/mm/yyyy)

APPENDIX D

SERVICE PROVIDER “WE WANT TO HEAR YOUR VOICE” CHECK-IN TELEFORM SAMPLE



SERVICE PROVIDER CHECK-IN WE WANT TO HEAR YOUR VOICE!

Please print numbers neatly within squares without touching the lines, and fill in circles completely, using INK.
Once complete, mail to Healthy Child Manitoba Data Centre.

--	--	--	--	--	--	--	--

Date Completed (dd/mm/yyyy)

--	--	--	--

Program Code

How frequently do program participants attend your program/connect you (include in person, Telehealth, phone, text, email, etc.)

- ☐ Daily ☐ Monthly ☐ Every year
☐ Weekly ☐ Every 3 months ☐ Too varied to categorize
☐ Every two weeks ☐ Every six months ☐ Other, specify: _____

A INTRODUCTORY QUESTIONS AND DEMOGRAPHICS

01. What is your role within your program/organization?

- ☐ Diagnostic Coordinator
☐ Program coordinator
☐ Program manager
☐ Program staff
☐ Volunteer
☐ Other, specify: _____

02. How long have you been in your current FASD-related position in this organization?

Please enter 'oo' if you have been in this position for less than one year.

--	--

 years

B PROGRAM ACCESSIBILITY

03. Are there **barriers to accessibility** in your programs/services? ☐ Yes ☐ No

If **yes**, select all that apply.

- | | |
|---|---|
| <input type="radio"/> Age limits are restrictive | <input type="radio"/> Perceived safety of program location |
| <input type="radio"/> IQ limits are restrictive | <input type="radio"/> Transportation (e.g. the program is not located on a bus route) |
| <input type="radio"/> Confirmation of prenatal alcohol exposure is required | <input type="radio"/> Time of day the program is offered |
| <input type="radio"/> FASD Diagnosis is required | <input type="radio"/> Staff turnover |
| <input type="radio"/> Justice involvement is required | <input type="radio"/> Not enough staff positions to keep up with demand |
| <input type="radio"/> Court order prohibits access to program | <input type="radio"/> Wait lists are lengthy |
| <input type="radio"/> Jurisdictional issues (geography) | <input type="radio"/> Funding considerations, specify: _____ |
| <input type="radio"/> Physical characteristics of the building (e.g. wheelchair access) | <input type="radio"/> Other, specify: _____ |

04. In the last year, what changes have occurred that have resulted in an **increase in accessibility** to your program?

Select all that apply.

- | | |
|---|--|
| <input type="radio"/> Age limits have been made more inclusive | <input type="radio"/> Increase in the number of locations where the program is offered |
| <input type="radio"/> IQ limits have changed or been removed | <input type="radio"/> Use of interpersonal technology is now permitted/available (phone, text, email, telehealth).
Specify: _____ |
| <input type="radio"/> FASD Diagnosis is no longer required | <input type="radio"/> The program is now located on a bus route |
| <input type="radio"/> Justice involvement is no longer required | <input type="radio"/> Transportation is now provided for participants |
| <input type="radio"/> Court order conditions are less restrictive | <input type="radio"/> Time of day the program is offered has expanded or changed |
| <input type="radio"/> Addition of staff who speak relevant language(s) | <input type="radio"/> Staff turnover has been effectively addressed |
| <input type="radio"/> Addition of staff who possess relevant cultural knowledge | <input type="radio"/> New staff members have been hired |
| <input type="radio"/> Staff have undergone training | <input type="radio"/> New funding has been secured |
| <input type="radio"/> Participant comfort issues have been addressed | <input type="radio"/> New resources (other than funding) have been secured |
| <input type="radio"/> Participant safety issues have been addressed | <input type="radio"/> Other, specify: _____ |
| <input type="radio"/> Change in the physical characteristics of the building | |
| <input type="radio"/> Safety enhancements regarding program location | |
| <input type="radio"/> Program moved to a new (more desirable) location | |

☐ No changes have occurred that resulted in increased accessibility to this program

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C PARTICIPANT ENGAGEMENT

05. What are the current or on-going barriers to identifying and/or engaging the population that your program serves?
Select all that apply.

- | | |
|--|--|
| <input type="radio"/> Developing trust with this group | <input type="radio"/> Geography/Location |
| <input type="radio"/> Language barriers | <input type="radio"/> Isolated communities |
| <input type="radio"/> Cultural barriers | <input type="radio"/> Single parent with multiple children |
| <input type="radio"/> Jurisdictional issues (on/off reserve) | <input type="radio"/> Stigma of being associated with a 'disability' program |
| <input type="radio"/> Making contact with this group (hard to identify, etc.) | <input type="radio"/> Current involvement with other systems |
| <input type="radio"/> Caregiver resources are lacking (time, transportation, money, childcare, etc.) Specify: | <input type="radio"/> Specify: |
| <input type="radio"/> Participant readiness/willingness to engage | <input type="radio"/> Multiple moves |
| <input type="radio"/> Participant attendance | <input type="radio"/> Multiple changes to phone number |
| <input type="radio"/> Stigma of being associated with an "FASD" program (felt by individual or birth family) | <input type="radio"/> Addictions |
| <input type="radio"/> Locked files (for example, confirmation of alcohol exposure in mom when participant is not with her anymore - adopted, foster child, etc.) | <input type="radio"/> Homelessness |
| | <input type="radio"/> Children ages 0-6 years |
| | <input type="radio"/> Other, specify: _____ |
| | <input type="radio"/> No barriers |

D COLLABORATION WITH OTHER SERVICES

06. How would you rate your program's ability to **identify when** participants need programs or services outside of those offered at your program?

- ☐ Highly ineffective ☐ Somewhat ineffective ☐ Somewhat effective ☐ Highly effective

07. How would you rate your program's ability to **connect participants with** other programs or services when needs are identified?

- ☐ Highly ineffective ☐ Somewhat ineffective ☐ Somewhat effective ☐ Highly effective

08. What are the barriers for you as a service provider in connecting to other programs/services? *Select all that apply.*

- | | |
|--|--|
| <input type="radio"/> Geography | <input type="radio"/> Participant characteristics (such as meeting eligibility criteria) |
| <input type="radio"/> Knowledge of other services | <input type="radio"/> Participant readiness |
| <input type="radio"/> Knowledge of referral process | <input type="radio"/> Willingness of other programs/services to collaborate/connect |
| <input type="radio"/> Knowledge of other program or service requirements | <input type="radio"/> Readiness of other programs/services to collaborate/connect |
| <input type="radio"/> Jurisdictional issues when someone moves back on reserve | <input type="radio"/> Other, specify: _____ |
| <input type="radio"/> Time | |

09. Which community partners or other service providers do you work most closely with in your current role?

10. What changes have occurred in the past year to enable improved or increased linkages with other services?

11. In what way(s) could your organization better link with other services?

12. Are you aware that Manitoba has a provincial FASD Strategy? ☐ Yes ☐ No

E TRAINING

13. Have you engaged in any training in the past year? ☐ Yes ☐ No
If **yes**, select all that apply.

- | | |
|---|--|
| <input type="radio"/> Two-day Provincial FASD Training | <input type="radio"/> First Aid/CPR |
| <input type="radio"/> Training related to your program/service specifically | <input type="radio"/> Motivational Interviewing |
| <input type="radio"/> Attachment | <input type="radio"/> Cultural training, specify: _____ |
| <input type="radio"/> FASD specific training | <input type="radio"/> Attended a relevant conference, specify: _____ |
| <input type="radio"/> Harm reduction | <input type="radio"/> Attended a relevant workshop specify: _____ |
| <input type="radio"/> Non-violent crisis intervention | <input type="radio"/> Other, specify: _____ |

14. Which of the following training areas would be most beneficial to you in order to help you succeed in your current position?
Select your top three priorities.

FASD, a lifelong disability

- ☐ FASD 101: the person, the challenges, the strengths
- ☐ FASD and behaviour
- ☐ FASD and cognitive capacity
- ☐ FASD and communication skills
- ☐ FASD and cultural sensitivity
- ☐ FASD and participating in the community
- ☐ Other _____

Supports and interventions

- ☐ FASD supports for adults in MB
- ☐ FASD supports for children in MB
- ☐ FASD supports for seniors in MB
- ☐ FASD supports for youth in MB
- ☐ Transitioning to adulthood with FASD
- ☐ Other _____

FASD and Systems

- ☐ FASD and housing
- ☐ FASD and mental health
- ☐ FASD and substance use
- ☐ FASD and the justice system
- ☐ Other _____

Prevention

- ☐ Contraception
- ☐ Coping skills
- ☐ Men's issues - family engagement
- ☐ Parenting skills
- ☐ Problematic substance use
- ☐ Risk factors for FASD
- ☐ Self harm
- ☐ Sexual and reproductive health
- ☐ Understanding intergenerational trauma
- ☐ Understanding trauma
- ☐ Violence to others
- ☐ Vulnerable populations
- ☐ Other _____

Practices

- ☐ Case management
- ☐ Conflict management
- ☐ Educating others about FASD (law enforcement, teachers, caregivers, etc.)
- ☐ Supporting people with FASD who are also parents/caregivers
- ☐ Supporting caregivers who have children/youth with FASD
- ☐ Motivational Interviewing
- ☐ Other: _____

F FINAL THOUGHTS

15. Please provide any additional comments that you would like to share, including aspects that we may have failed to address in this survey.

THANK YOU! PLEASE NOTE THAT ALL RESPONSES REMAIN CONFIDENTIAL AND ARE NEVER LINKED TO YOUR NAME.