Best Practice Guide
for Fetal Alcohol Spectrum Disorder Assessment and Diagnostic Clinics
Disclaimer:

This Best Practices Guide for FASD was revised and updated in August 2018 based on emerging best practices and in response to the feedback provided from FASD diagnostic clinics across Canada and key stakeholders in the field.

All changes and/or additions to competencies have been **bolded** for easy identification.
Acknowledgements

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Introduction

This Best Practices Guide for FASD comprises evidence-informed practices that describe high-priority areas in the diagnostic clinic that are central to quality and safety. Best management practice should be seen as an adaptive learning process rather than a fixed set of rules or guidelines (adapted from H.R. Twinning, 2013).

How do we define “Best Practices”?

The overarching goal of this guide is to offer guidance to clinicians, coordinators, other team members in an effort to provide the most effective and consistent service delivery for clients undergoing assessment for Fetal Alcohol Spectrum Disorder (FASD; i.e., client-needs driven, not agency-needs driven). These Best Practices were developed to assist in planning, implementing, evaluating and adapting clinic services according to a set of standardized recommendations that were described in the recently revised Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan (1). Note that this guide may evolve and change as new evidence and information become available.

What is their purpose?

The intent of this guide is to provide a framework from which diagnostic clinics can measure their strengths and weaknesses in attempt to provide the most effective diagnostic services and based on a set of standards that are important for all clinics. Importantly, by developing a set of standardized “Best Practice” competencies, the end result will lead to increased consistency in diagnostic outcomes amongst clinics, and higher quality services to clients. This guide is not intended to say what clinics must do in a given set of circumstances; rather, it is intended to offer a broad guide to the scope of services that FASD diagnostic clinics may provide and the professional manner in which this can be delivered. Guidelines are not written for every Standard of Practice.

An overarching goal of this guide is to emphasize the importance of adopting the same set of diagnostic recommendations as described in the revised FASD diagnostic guideline (1). In this way, clinic staff can be assured they are using consistent approaches and criteria for FASD diagnoses and collecting accurate data.

How to evaluate the Best Practices

The Best Practices Guide is divided into 15 Core Competencies that outline specific practices, activities, and expectations that that FASD diagnostic clinics should review before becoming operational. Within these competencies, activities/practices are listed as “major” or “minor” depending on the level of
importance assigned to them. *Major Proficiencies* have an immediate impact on safety, legal obligation, effectiveness and quality service delivery, while *Minor Proficiencies* support longer-term safety culture and quality improvement activities and may require additional time to be fully developed and/or evaluated. The competency divisions are intended to help guide the diagnostic clinic in identifying areas of gaps in their service delivery model where further training and support are needed and can form the basis of future strategic planning initiatives.

For new and emerging diagnostic clinics, the concept of *Major and Minor Proficiencies* and how they are differentiated, may be less straightforward at the outset. In broad strokes, *Major Proficiencies* are tasks or activities that should be considered of paramount importance to establishing a diagnostic clinic. These are tasks that could jeopardize an accurate and comprehensive FASD diagnosis or lead to legal-medical implications. For example, Clinics should have some type of referral and intake process to ensure both clients and clinic staff are prepared and know what is expected. The comprehensive neurodevelopmental assessment must be conducted by appropriately trained clinicians that can administer and interpret the results as a requirement for each assessment. Additionally, obtaining the appropriate consents and procedures for storage and information sharing should be implemented before a clinic becomes operational. *Minor Proficiencies* can be regarded as additional services that can improve the efficiency and competency of each diagnostic assessment (such as additional resource staff; access and availability to new assessment tools etc.). *Minor Proficiencies* may also include tasks that require further resources and can be used to inform future professional development.

While the timeline for achieving *Major and Minor Proficiencies* will be dependent on clinic resources, funding, and infrastructure requirements, clinics are encouraged to meet the full complement of *Major Proficiencies* by the time of launching a FASD diagnostic clinic. For some of the *Minor Proficiencies* for compliance, clinics may aim “to achieve” or “to have a plan in place to achieve” within eleven months of clinic opening. These timelines were based on the Required Organizational Practices from Accreditation Canada (2).
Core Values for Diagnostic Clinics

**Growth & Development**
- Evaluate Clinic practices, processes & policies regularly is essential for maintaining high clinical standards
- Review research findings to improve the delivery of assessment & diagnostic services

**Collaboration**
- Multidisciplinary team approach to assessment & diagnosis
- High quality, safe & coordinated diagnostic services
- Accurate & reliable documentation of client files/reports
- Evaluate performance & clinic activities for accountability purposes

**Patient First**
- Maintain confidentiality
- Provide client-centered services & supports
- Ensure cultural sensitivity in all clinic work

**Education & Training**
- Competence within the scope of practice for each team member
- Leader in conducting FASD Diagnostic Assessments
- Professional expertise from evidence-based learning opportunities

**Respect**
- Provide a case-specific approach
- Create personalized management plans
- Appreciate the uniqueness of the FASD population
### Competency #1: Referral Procedures

#### MAJOR

1. Referral procedures have been implemented.
   - □ Met
   - □ In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
   - □ Unmet REASONS:______________________________________________

2. Clinics have developed wait time and triaging policies and procedures to support clients and their families until the assessment has been conducted (including informing the professionals on the diagnostic team and prioritizing the urgency of the wait list clients)
   - □ Met
   - □ In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
   - □ Unmet REASONS:______________________________________________

3. Staff is trained and knowledgeable to review intake forms.
   - □ Met
   - □ In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
   - □ Unmet REASONS:______________________________________________

#### MINOR

4. Referral criteria have been communicated to community health, social service and other relevant agencies and organizations.
   - □ Met
   - □ In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
   - □ Unmet REASONS:______________________________________________

5. Support staff and resources are available for clients who need additional help completing sections of the referral package and to ensure eligibility of client.
   - □ Met
   - □ In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
   - □ Unmet REASONS:______________________________________________

**COMMENTS (including notes on progress and timelines):**
### Competency #2: Consent

**MAJOR**

6. Informed Consent and Assent records should include the following elements (as mandated by governing information authorities such as Health Information Act (HIA) and Freedom of Information and Privacy Act (FOIP)).

- **Informed Consents must include the name and contact information for the Diagnostic Clinic**
- Written permission from the client or legal guardian to release and obtain information, when necessary;
- Compliance with confidentiality and privacy rights and responsibilities; and
- Documentation of the release of client records;
- **No duress, pressure or other conflict of interest on behalf of the individual or agency completing and/or witnessing the informed consent and/or assent records must influence the consent or assent process.**

- [ ] Met
- [ ] In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- [ ] Unmet REASONS: ________________________________

7. Medical information release policy should include clear release instructions for other members of the family system, other service providers or organizations, or other parties; and should only be permitted with written permission from the client (or the individual/agency legally authorized to represent the client).

- [ ] Met
- [ ] In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- [ ] Unmet REASONS: ________________________________

8. Release instructions should detail which information is to be disclosed, to whom, and in what time frame.

- [ ] Met
- [ ] In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- [ ] Unmet REASONS: ________________________________

9. The clinic has ensured the Final Medical Summary Report will have redacted all confidential personal and medical family history, including specifics of the Prenatal Alcohol Exposure information, when this report is released (with proper consent) to government agencies, organizations, schools, etc.

- [ ] Met
- [ ] In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- [ ] Unmet REASONS: ________________________________
COMMENTS (including notes on progress and timelines):

Competency #3: Record Keeping (Paper Flow)

MAJOR

10. All team members are aware of the local, provincial and professional governing body guidelines regarding confidentiality.
   - Met
   - In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
   - Unmet REASONS:______________________________________________

11. All case management activities are recorded in the appropriate client record in a timely manner.
   - All entries must be dated and signed by the appropriate staff
   - Met
   - In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
   - Unmet REASONS:______________________________________________

12. Documentation is recorded on paper or electronically and prepared, completed, secured, maintained, and disclosed in accordance with regulatory, legislative, statutory, and organizational requirements (i.e., all medical data and information collected must be held in confidence).
   - Met
   - In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
   - Unmet REASONS:______________________________________________

13. Clinic staff must follow the requirements for record keeping specified by their organization and licensing jurisdiction. Such requirements may include:
   - Type of data collected;
   - The manner in which information is recorded;
   - With whom and under what circumstances information may be exchanged;
   - Processes for amending client records;
   - The length of time records are retained; and
   - Plans for appropriate disposal of records.
MINOR

14. Case management documentation should reflect the following elements:
   - Client’s identifying information;
   - Dates, times, and descriptions of contact with the client, family system, and other service providers or organizations;
   - Initial and subsequent neurodevelopmental assessments;
   - Service plan and procedures for monitoring;
   - Services provided and other information about plan implementation;
   - Outcomes of service provision;
   - Referrals to or from other providers,
   - Organizations, or resources, including rationale for referrals, and other collaboration on behalf of the client;
   - Supervision or consultation sought or provided to enhance case management services;
   - Rationale for referrals and transfer or termination of services.

MIXED

15. The diagnostic process should include compiling a comprehensive history including:
   - Past and current medical history, including medication history
   - Nutrition
   - Interview with the caregiver
   - Education history
- Birth history and developmental history
- Social history
- Placement history
- Family history must be reviewed, and if possible, a three-generation family tree should be obtained
- Consanguinity in the parents may indicate a risk of certain inherited disorders
- FASD in other siblings

☐ Met  ☐ In progress  IMPLEMENTED IN: ___3 months ___6 months ___1 year
☐ Unmet  REASONS:______________________________________________

16. The medical assessment must include a complete the physical and neurological screening including measurements of growth and the presence of physical anomalies.

☐ Met  ☐ In progress  IMPLEMENTED IN: ___3 months ___6 months ___1 year
☐ Unmet  REASONS:______________________________________________

**MINOR**

17. Implementation of set collection tools such as standardized forms, checklists etc.

☐ Met  ☐ In progress  IMPLEMENTED IN: ___3 months ___6 months ___1 year
☐ Unmet  REASONS:______________________________________________

**COMMENTS (including notes on progress and timelines):**

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**Competency #5: Maternal Alcohol History**

**MAJOR**

18. Maternal alcohol history is collected by trained staff who must document all the evidence used to confirm prenatal alcohol exposure. **Staff should use best practices in respectful, non-judgemental and culturally sensitive interviewing techniques (such as motivational interviewing).**
Specific criteria may include:
- Reliable clinical observation;
- Self-report;
- Reports by a reliable source;
- Medical records documenting positive blood alcohol concentrations;
- Alcohol treatment or other social, legal or medical problems related to drinking during the pregnancy, in addition to pre-pregnancy behaviours.

Other criteria that may be collected:
- Pre-pregnancy alcohol consumption patterns
- Intended versus unintended pregnancy

□ Met
□ In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
□ Unmet REASONS:______________________________________________

MINOR

19. Support and/or counselling services for women who disclose continued problematic alcohol.

□ Met
□ In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
□ Unmet REASONS:______________________________________________

COMMENTS (including notes on progress and timelines):

Competency #6: Assessing Sentinel Facial Features

MAJOR

20. A Clinical team member, who has received specific training, must measure and document the sentinel facial features associated with FASD using the University of Washington lip-philtrum guide (3), and following the revised diagnostic guideline for FASD criteria for palpebral fissure measurements.

□ Met
□ In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
□ Unmet REASONS:______________________________________________
### MINOR

21. Clinicians should measure and document associated features (abnormalities such as mid-face hypoplasia, micrognathia, abnormal position or formation of the ears, high arched or cleft palate, epicanthic folds, limb abnormalities, palmar crease abnormalities, short-upturned nose, cardiac defects etc.)

<table>
<thead>
<tr>
<th>Met</th>
<th>In progress</th>
<th>IMPLEMENTED IN: ___3 months ___6 months ___1 year</th>
<th>Unmet</th>
<th>REASONS:</th>
<th>COMMENTS (including notes on progress and timelines):</th>
</tr>
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### Competency #7: The Neurodevelopmental Assessment

#### MAJOR

22. Diagnostic team must have the clinical expertise to evaluate all 10 neurodevelopmental domains, using the criteria for severe impairment in 3 or more domains as an indication of pervasive brain dysfunction.

- Clinicians should use the most current version of neurodevelopmental testing tools when evaluating the 10 brain domains;
- In situations where it is not possible, or detrimental to the diagnostic process, to assess all 10 neurodevelopmental domains, the client’s neurodevelopmental function must be interpreted by a team member with specific expertise in this area.

<table>
<thead>
<tr>
<th>Met</th>
<th>In progress</th>
<th>IMPLEMENTED IN: ___3 months ___6 months ___1 year</th>
<th>Unmet</th>
<th>REASONS:</th>
<th>COMMENTS (including notes on progress and timelines):</th>
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23. The diagnostic clinic has adopted the criteria for severe impairment as defined by a global score or a major subdomain score on a standardized neurodevelopmental measure that is 2 or more standard deviations (SD) below the mean with appropriate allowance for test error.

<table>
<thead>
<tr>
<th>Met</th>
<th>In progress</th>
<th>IMPLEMENTED IN: ___3 months ___6 months ___1 year</th>
<th>Unmet</th>
<th>REASONS:</th>
<th>COMMENTS (including notes on progress and timelines):</th>
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24. The use of direct standardized measures should be used to assess brain domains whenever possible and is recommended for the majority of evidence for brain dysfunction. **When direct measures are not possible, indirect assessment methods such as informant ratings, clinical interview, or historical assessment through file review may be used.**

[*Note: for indirect methods, multiple sources rather than a single informant rating multiple domains of function is required*]

- [ ] Met
- [ ] In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- [ ] Unmet REASONS: _______________________________________________________________________

25. If historical assessment, clinical interview, or file reviews are used for indirect assessment (e.g., assessing adaptive behaviour) deficits should be considered by the team to be at a severity level equal to the clinical cut-off, which is defined as 2 standard deviations below the mean.

- [ ] Met
- [ ] In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- [ ] Unmet REASONS: _______________________________________________________________________

**COMMENTS (including notes on progress and timelines):**

### Competency #8: Diagnostic Guidelines

**MAJOR**

26. The clinical team has adopted the revised diagnostic criteria as outlined in the CMAJ 2015 publication.

- FASD with sentinel facial features
- FASD without sentinel facial features

- [ ] Met
- [ ] In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- [ ] Unmet REASONS: _______________________________________________________________________

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27. The use of the new designation “At Risk for Neurodevelopmental Disorder and FASD, Associated with Prenatal Alcohol Exposure” has been incorporated into the clinic program such that appropriate resources and referrals are made to support individuals in this category.

☐ Met
☐ In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
☐ Unmet REASONS:________________________________________________________

28. Other associated features (e.g., Sleep Problems; Sensory Sensitivities, Physical Findings/Other Congenital Anomalies; Growth; Attachment; and Proprioception) as detailed in the revised diagnostic guidelines for FASD should be assessed and documented.

☐ Met
☐ In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
☐ Unmet REASONS:________________________________________________________

MINOR

29. Clinic team use the term FASD as a diagnosis in all communications with clients and caregivers. Medical documentation should also use FASD as a diagnostic term when communicating with other clinical colleagues.

☐ Met
☐ In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
☐ Unmet REASONS:________________________________________________________

30. All diagnostic assessments are equally and equitably available; and conducted in a culturally sensitive environment.

☐ Met
☐ In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
☐ Unmet REASONS:________________________________________________________

COMMENTS (including notes on progress and timelines):
### Competency #9: The Diagnostic Team

**MAJOR**

31. The multidisciplinary diagnostic team is composed of the Core Team Members as outlined in the revised diagnostic guidelines for FASD and based on the scope of practice set out for the clinic.

**Infants (<18 months):**
- Clinic Coordinator/Team Manager
- Paediatrician/Physician
- Child development specialist who has the skill set to conduct physical and functional assessments (i.e., Speech-Language Pathologist, Physiotherapist, Occupational Therapist, Clinical Psychologist)

**Preschoolers (18 months - 5 yrs.):**
- Clinic Coordinator/Team Manager
- Paediatrician/Physician
- Registered Psychologist
- Speech-Language Pathologist
- Occupational Therapist

**School–Aged Children (6 yrs. - age of majority):**
- Clinic Coordinator/Team Manager
- Paediatrician/Physician with expertise in FASD and differential diagnosis
- Occupational Therapist
- Speech-Language Pathologist
- Psychologist

**Adults**
- Clinic Coordinator/Team Manager
- Physician
- Registered Psychologist
- Speech-Language Pathologist
- Occupational Therapist (Optional)

- Met
- In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet  REASONS:______________________________________________
32. Multidisciplinary team consists of professionals with appropriate qualifications, training and expertise/experience in their field or scope of practice (i.e., professionals must be knowledgeable in the field of FASD and have received training in FASD assessment and diagnosis). Members of the team should provide services only within the boundaries of their education, training, license/certification, consultation received, supervised experience of other relevant professional experience. The team must include member(s) who have appropriate education and background to administer neurodevelopmental assess and interpret the results.

- Met
- In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet REASONS:______________________________________________

MINOR

33. The clinic team membership has access to additional support personnel such as addiction counsellors, childcare workers, cultural interpreters, mental health professionals, parents or caregivers, advocates, mentors, probation officers, psychiatrists, teachers, vocational counselors, nurses, clinical geneticists or dysmorphologists, neuropsychologists, social workers, nurse practitioners and family therapists, and other professionals if needed.

- Met
- In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet REASONS:______________________________________________

COMMENTS (including notes on progress and timelines):

Competency #10: Management and Follow-up

MAJOR

34. The client with FASD and their caregivers are provided with a discharge package linking them to local resources and support programs that can improve outcomes.

- Met
- In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet REASONS:______________________________________________
35. The clinical team should only recommend services and/or interventions that are evidence-based, and for which they have engaged in the appropriate study, training, consultation, supervision and mentorship to support their recommendations.

- Met
- In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet REASONS:______________________________________________

36. When recognized standards do not exist on emerging areas of practice (such as art therapy, equine therapy and other programs with potential efficacy), Clinic Coordinators should exercise careful judgement and take the necessary steps (including appropriate education, research, training, mentorship and supervision) to protect clients from harm.

- Met
- In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet REASONS:______________________________________________

37. It is recommended that a specific clinic member provide education about the impact of FASD and support to the client and those involved with their care. The clinic member must be capable of interpreting the results of the assessment and communicating the impact of the diagnosis to the client (e.g., children, youth or adults, depending on the capacity of the clinic) and their family.

- Met
- In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet REASONS:______________________________________________

38. The team communicates all documents in a cultural sensitive manner, using appropriate first-person language.

- Met
- In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet REASONS:______________________________________________

MINOR

39. The clinic includes recommendation for a re-assessment process for youth and young adults to assist with transition planning for housing, education, health care, mental health, etc. and access to adult services, to identify any changes in their adaptive function scores and to make any subsequent adjustments to their management plan.

- Met
- In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet REASONS:______________________________________________
40. All client identified with the “At risk” designation must receive a recommendation for reassessment at a later date.

- Met
- In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet REASONS: ______________________________________________________________

41. The clinic provides team de-briefing as part of their process after meeting with the client and their family

- Met
- In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet REASONS: ______________________________________________________________

42. It is recommended that follow-up services are provided by a specific team member within a reasonable length of time to ensure that the recommendations have been addressed and to provide further support, if needed.

- The clinic may have a process for clients who have been assessed, but who did not receive a diagnosis
- Follow-up services must recognize the client’s profile (e.g., abilities; limitations etc.) and any cultural, economic and geographic considerations that may impact the delivery of services.

- Met
- In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet REASONS: ______________________________________________________________

COMMENTS (including notes on progress and timelines):

Competency #11: Full Medical Report

MAJOR

43. The medical diagnosis should be communicated to clients and their families by the clinic physician. This includes explaining any essential medical referrals (e.g., for mental or physical health).
- Clinic physician and/or other supporting team members should assume responsibility for interpreting the report findings and relaying this information to the client.
44. Information is recorded in a clear, accurate and professional manner that is non-judgemental or stigmatizing using the FASD Language Guide: [http://www.fasdcoalition.ca/looking-after-each-other-project/fasd-language-guide/](http://www.fasdcoalition.ca/looking-after-each-other-project/fasd-language-guide/)

**Comments (including notes on progress and timelines):**

### Competency #12: Professional Development, Education and Training

#### Major

45. Sustainability of multidisciplinary team (secured funding; resource allocation; training)

- Met
- In progress  IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet  REASONS:______________________________________________________________________________

46. Appropriate training, resources and support are provided equally to all team members

- Met
- In progress  IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet  REASONS:______________________________________________________________________________

#### Minor

47. Ongoing training opportunities are available to clinic staff members that reflect current research, evidence and expertise.

- Met
- In progress  IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet  REASONS:______________________________________________________________________________

48. Clinic maintains a community presence and professionalism

- Met
- In progress  IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet  REASONS:______________________________________________________________________________
49. Educational and professional opportunities are available to team members based on needs assessment (and opportunities are awarded in an equitable manner).

- Met
- In progress  IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet  REASONS:______________________________________________

**COMMENTS (including notes on progress and timelines):**

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**Competency #13: Competency Accessibility**

**MAJOR**

50. Assessment services must be equally available and accessible to all residents in the service region.

- Different clinic composition models can be used to meet the needs of diverse populations and regionality of the service population (e.g., virtual, satellite sessions etc.)

- Met
- In progress  IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet  REASONS:______________________________________________

**MINOR**

51. Support services such as cultural interpretation, transportation and community members should be made available to clients for ensuring accessibility to all diagnostic services

- Clinics may have regional representatives who work closely with families to provide continuity and support while they undergo assessment

- Met
- In progress  IMPLEMENTED IN: ___3 months ___6 months ___1 year
- Unmet  REASONS:______________________________________________

**COMMENTS (including notes on progress and timelines):**
### Competency #14: Evaluation Process

**MAJOR**

52. Clinic performs regular evaluation at set times during the year (annually; bi-annually) to obtain outcomes measures pertaining to program management; impact and deliverables.

- [ ] Met
- [ ] In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- [ ] Unmet REASONS:__________________________

**MINOR**

53. Qualitative and/or quantitative methods are used to get a clear, descriptive sense of the experiences of the service users.

- [ ] Met
- [ ] In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- [ ] Unmet REASONS:__________________________

**COMMENTS (including notes on progress and timelines):**

### Competency #15: Considerations for Research

**MAJOR**

54. Clinic considerations when approached to be part of a research project.

The following questions should be reviewed carefully:

- Does my organization have a policy for participating in research projects?
- How does the research project benefit the clinic, the clients and the broader system?
- Is our clinic able to manage the work required to meet the research requirements?
- What does it mean if we do NOT participate?
- Are projects discussed with the clinical team for input?
- Who makes the final decision?

- [ ] Met
- [ ] In progress IMPLEMENTED IN: ___3 months ___6 months ___1 year
- [ ] Unmet REASONS:__________________________
**COMMENTS (including notes on progress and timelines):**

*Note: Several additional resources were consulted in preparing this guide (4-6).*
Considerations and Contributions

Canada is a world leader in the field of FASD and promotes increased capacity for prevention, intervention and diagnostic initiatives. Many of the programs, services and resources are directly informed by the outcomes of research projects focused on improving our understanding of FASD and the many factors that influence and contribute to this issue.

Specifically, research programs are critical to improving consistency across diagnostic clinics and the delivery of management strategies. Canadian diagnostic clinics have the unique opportunity to contribute to the evolving research landscape by sharing clinical data through various projects underway (such as the Universal dataform project: https://canfasd.ca/topics/national-database/). Not only can the data benefit individual clinics, but also provide a comprehensive picture of FASD prevalence across the country. These data are critically important for creating change at the policy and practice level and influencing future funding opportunities.

Whenever possible, FASD diagnostic clinics are encouraged to contribute to the growing body of knowledge related to this field. By participating in research and data sharing, clinics can receive direct feedback on their performance and this information can be used to make improvements to their diagnostic assessment model and to provide the best management recommendations based on evidence. These data can also be used to highlight areas where additional training and/or expertise are needed.

While not all clinics have the resources and capacity to participate in research activities, it is important to be aware of the programs underway and where to find current information. A useful resource for obtaining all this information in one location is through the Canada FASD Research Network (CanFASD) website: www.canfasd.ca. CanFASD is a collaborative, interdisciplinary research network, with researchers and partners across the country. Its unique partnership brings together many scientific viewpoints to address complexities of FASD, with a focus of ensuring that research knowledge is translated to community and policy action. CanFASD researchers are currently leading 25 major projects related to FASD prevention, intervention and diagnostics; connecting researchers, graduate students and practitioners from communities and institutions across Canada and internationally.
Reference List


Developing a Community Based FASD Assessment & Diagnostic Clinic

A Model for Success

- Demonstrate local service-delivery knowledge by team members
- Identify/enhance community resources & supports for individuals with FASD & their caregivers
- Meet the complex needs of individuals with FASD by providing intervention recommendations
- Reduce stress & expense in travelling distances for clinic services
- Build local community capacity

Surveying the Route

- Need for FASD diagnostic services in the community
- Examine and identify service needs for the community
- Align/collaborate with stakeholders, partners & community leaders
- Explore funding sources

Building the Team

- Recruit team members based on professional knowledge and skill
- Select members who have the interpersonal & collaborative skills to be an effective team member
- Develop a common vision, philosophy & principles for operation

Paving the Way

- Identify supports that can inform diagnostic service capacity & identify consistent approaches to assessment
- Develop policy & management systems for efficient clinic performance
- Recognize & value team development, training & professional development for clinic members

Laying the Foundation

- Train team members on FASD diagnostic & required assessments
- Deliver education opportunities, supports & resources to meet the needs of the team

Moving Forward

- Evaluate/regularly review clinic processes & practices
- Plan, explore & organize resources for obtaining sustainable funding
- Continue to foster partnerships amongst the diagnostic clinic, community & researchers
- Contribute to identifying & developing appropriate services for the community

Measuring Success